

TO STUDY THE EFFECT OF PARTICIPATION IN LEISURE AND RECREATIONAL ACTIVITIES ON QUALITY OF LIFE AMONG PARENTS OF CHILDREN WITH AUTISM SPECTRUM DISORDERS.

ABSTRACT

Leisure and recreation are crucial to maintaining a healthy, active lifestyle. Participation in regular physical activity is part of the solution to addressing chronic illness and improving mental health. Parents of children with Autism face a variety of risk and problems that can decrease their spirit and motivation, leading to poor performance which make them sometimes neglect their own health in the cause of rendering care services for their children.

Thus, this study therefore will assess the role of leisure and recreation activities in improving the quality of life of these parents in Jaipur.

There are only a few studies carried out on the quality of life among parents of children with Autistic Spectrum Disorder in India. To my Knowledge, this study is the first study in Jaipur to gain a better understanding of the QOL of parents with children having ASD in Jaipur. Therefore, it is important to consider the mental health of the parents in the interventions proposed for children with neuro developmental Disorders. Leisure and recreation are crucial to maintaining a healthy, active lifestyle. Participation in regular physical activity is part of the solution to addressing chronic illness and improving mental health.

KEY WORDS:-

Leisure activities, Recreational Activities, Quality of life

1. INTRODUCTION –

Autistic Spectrum Disorder (ASD) is considered as one of the most complex childhood disabilities (APA, 2000). Children with ASD facing a wide range of symptoms that markedly presented as impairment in communication, imagination, social interaction, and restricted in activity, interest and behaviour (APA, 2013). Indeed, raring children having ASD is a challenge for both parents; ASD not only affects the diagnosed children throw their life but also their parents' life (Lareau, 2000; Karst & Van Hecke, 2012).

By the end, it will disturb parents Quality of Life (QOL) (Dardas and Ahmad 2014a). Further understanding on how caregiver quality of life will be affected will help to

improve the quality of care in term of services and resources (Halterman J, Yoos H, Conn K, et al. 2004). Moreover, operationalizing parental QOL allows care providers to quantify the degree of burden that parents experience (Halterman et al., 2004). So that more effective disorder related programs can be developed.

Quality of life (QOL) can be highly influenced negatively by the disease situation, however there are many factors that affect the way how they perceive. In this sense, it is important to assess the quality of life of those parents and to identify the factors that influence them perception which ultimately affects the care provided to these children with ASD. Because of the important role that parents play in their children's psychosocial condition, especially during an illness, we chose to focus the current study on the parents' quality of life (QOL).

There are only a few studies carried out on the quality of life among parents of children with Autistic Spectrum Disorder in India. To my Knowledge, this study is the first study in Jaipur to gain a better understanding of the QOL of parents with children having ASD in Jaipur. Therefore, it is important to consider the mental health of the parents in the interventions proposed for children with neuro developmental Disorders.

There are three fundamental aspects to one's life, that when taken together encompass the staples of our existence. From the Western perspective, work, family, and leisure and recreation represent these three pillars of life. All of which demand a balanced portion of our time. Nonetheless, these three dimensions of life do not act independently; rather, each and every one reciprocally affects the other in creating self, community and culture. Leisure activities has been consistently associated with enhanced quality of life which is conceptualized as representing physical, mental, psychosocial health related qualities of life (Stewart and King, 1991). With reference to older adults, a number of physical and psychosocial factors might represent mental and physical health status outcomes; strength power, functional limitation, agility, balance and co-ordination (Siobhan et al, 2009).

The time allocated for work or school, family, and leisure and recreation correlate and complement each other, attempting to create synergy, which is a cooperative action of all three elements (Kelly and Freysinger, 2009). Leisure offers individuals an opportunity to relax and refresh after day to day work.

The dynamics of modern society, caring for children with Autism require special skills from individuals, both psychological (mental and emotional) and biological (functional and motor potential). In the above context, lifelong education becomes imperative.

Leisure and recreation are crucial to maintaining a healthy, active lifestyle. Participation in regular physical activity is part of the solution to addressing chronic

illness and improving mental health. Community facilities provided by government, like leisure and recreational centres are key settings for improving general health and quality of life and enhancing social support through connecting communities (Wang, Wu and Wu, 2013).

Participation in leisure and active recreation can improve educational outcomes and help divert young people from anti-social behaviour through building resilience and providing positive avenues for them to let off steam (Pailard-Borg, Wang, Winblad and Fratiglioni, 2009).

Leisure activities are simply defined as preferred and enjoyable activities participated in during one's free time (Kleiber and Nimrod, 2009), and characterized as representing freedom and providing intrinsic satisfaction. Leisure has often been defined as a quality of experience or as free time (Kelly, 2006). Free time is time spent away from business, work, job hunting, domestic chores, and education, as well as necessary activities such as eating and sleeping.

Leisure is not the opposite of work as some people may think, but the end result of work. It is not the antithesis of work, but a key driver to it (Marchildon, 2013). Leisure is the right balance between work and rest. It can therefore be achieved both in work as well as in rest (Steindi, 2009). Ruskin (1988) asserted that life is a harmonious network of activities, in which the distinction between 'work' and 'leisure' is as arbitrary as that between 'body' and 'mind'. Leisure and work are so closely related that the two cannot be separated (Edginton, Jordan, DeGraaf and Edginton, 2012), because elements of leisure are also found in work. According to Brajsazganec, Merkas and Sverko (2011), leisure provides opportunities to meet life values and needs.

Recreation is an organized activity that one engages in during free time. It is voluntarily chosen by an individual because of satisfaction, pleasure or enrichment in their lives. Some recreational activities - such as gambling, recreational drug use, or delinquent activities - may violate societal norms and laws (Breslow, Ballard-Barbash, Munoz, and Graubard, 2001). There is some consensus on the definition of recreation. Recreation is an activity that people engage in during their free time, that people enjoy, and that people recognize as having socially redeeming values (Parent, Rousseau, El-Zein, Latreille, Désy and Siemiatycki, 2010). Unlike leisure, recreation has a connotation of being morally acceptable not just to the individual but also to society as a whole, and thus we program for those activities within that context. While recreation activities can take many forms, they must contribute to society in a way that society deems acceptable.

Quality of Life (QoL) refers to the description and evaluation of nature, and maintaining life conditions for different citizen categories. The necessity of creating and especially improving QoL was noticed since the 60's as a consequence of "The

movement for social indicators; following certain government programs such as educational, social and environmental programmes, there are needs for utilizing indicators that measure the effectiveness of these programs in respect to the QoL. Engaging in leisure activities may affect different aspects of well-being (Gautam, Saito, & Kai, 2007), the specific type of leisure activity may be particularly salient, with some types of activities providing more benefit than others. Paillard-Borg, Wang, Winblad, and Fratiglioni (2009) examined five types of leisure activities in older adults—mental, social, physical, productive, and recreational—to assess how participation affects health status. They found that mental activities (e.g., writing, reading) were not only the most popular type of leisure activities, but also enhanced well-being the most.

During the literature work it is been observed that some work in the field of rehabilitation “to study the effect of participation in leisure and recreational activities on quality of life among parents of children with autism spectrum disorders” are seen in related to websites like google scholar, PubMed, etc not much work seen in the field of occupational therapy. Therefore, to observe the quality of life of parents of children with autism spectrum disorder, that’s why we are conducting the study.

2. METHODS–

Observation studies were included in the review best on the objectives of the current review inclusion and exclusion criteria were prepared and based on that various data base was used in the selection of the study. The collected studies were checked for clarity and content and then used for the review.

Criteria for the sample collection –

2-criterias, via inclusion and exclusion criteria were used for the collection of sample.

INCLUSION CRITERIA

- Participants must be a parent or caregiver of an autistic kid.
- Age : 3 - 8 years
- Both males & females
- Subjects who have IQ above 70

EXCLUSION CRITERIA

- Parents of children with other developmental disabilities
- Participants with any physical deformity
- Participants with seizure

ELECTRONIC DATABASE SEARCHING

The data base searched;

PubMed, online journal, access open, google scholar.

DATA EXTRACTION AND QUALITY ASSESSMENT –

PRISMA flow diagram was used to select the articles eligibility criteria were assessed for extracted data included studies were evaluated on the basis of relevance appropriateness clarity and methodology.

Those studies that were not meeting the criteria were included. Articles selected for review were assessed by two independence reviewer, the data extracted included participant, year of publication, study method, type of intervention and outcome.

ANALYSIS

Steps in the analysis –

Step 1 :- Obtain data were tabulated and classified as author, study design, year of publication, setting, method, sample, size, type of intervention, components of intervention and outcome.

Step 2 :- Identifying the findings of the studies. The studies were identifying with their setting, method and sample size, type of intervention and component of intervention.

Step 3 :- Categorising the findings, finding were categorised under the headings of the effect of enhanced occupational therapy intervention on the study the effect of participation in leisure and recreational activities on quality of life among parents of children with autism spectrum disorders.

RESULTS & DISCUSSION

The reviewed study included 250 potentially relevant articles out of which 200 studies were included as duplicate, 25 articles were excluded as they did not meet inclusion and exclusion criteria. 15 articles did not mention the category of the participants and 10 studies were included for the review.

CHARACTERISTICS OF THE ARTICLES –

Out of the 10 studies included in the review, all the reviews was qualitative study. Majority of the study were conducted in the hospital settings. These studies were published between 2010 to 2020.

UNDER PEER REVIEW

TABLE 1 . Literature survey results

| S.N. | STUDY AUTHOR | YAER OF PUBLICATION | RESEARCH DESIGN | NO. OF PARTICIPATION | SAMPLE CHARACTERICS | THEME | SUB THEME |
|------|--------------------------------------|---------------------|--|----------------------|--------------------------|---|---|
| 1. | D'Mello Laveena & Menezes Ida Sylvia | June 2021 | Systematic literature review-based analysis. | 120 | Autism spectrum disorder | Leisure and Quality of Life among Parents of Children with Autism Spectrum Disorder – A Review Based Analysis | <p>The objectives of this review paper are:</p> <p>(1) Review of literature on intervention of Parents of Children with Autism Spectrum Disorder.</p> <p>(2) Identifying research gap on Leisure and Quality of Life among Parents of Children with Autism Spectrum Disorder based on literature review.</p> <p>(3) Identifying various research agendas related to Leisure and Quality of Life among Parents of Children with Autism Spectrum Disorder using</p> |

| | | | | | | | |
|----|--|---------------|--------------------|-----------------------------------|---|---|--|
| 2. | Lauren Bishop, Leann Smith DaWalt, Jan S. Greenberg | February 2017 | Longitudinal study | 60 Age : 24-55 | Autism spectrum disorder | Participation in recreational activities buffers the impact of perceived stress on quality of life in adults with ASD. | (1) perceived stress would be negatively associated with QoL; and (2) higher frequency of participation in social activities and recreational activities would moderate the relationship between perceived stress and QoL. |
| 3. | Roxana SIPOS, Elena PREDESCU, Gabriela MURESAN | March, 2012 | Systemic control | 65-ASd 49-ADHD (2-14 years) | Autism spectrum disorder & Attention Deficit Hyperactive Disorder | The Evaluation of Family Quality of Life of Children with Autism Spectrum Disorder and Attention Deficit Hyperactive Disorder | To evaluate the QoL of families with Autism Spectrum Disorder (ASD) children as compared |

| | | | | | | | |
|----|--|---------------|--------------------------|-----|--------------------------|--|--|
| | | | | | | | with that of families with Attention Deficit Hyperactive Disorder (ADHD) children. |
| 4. | Karen Kuhlthau, Jennifer Delahaye, Jill Hurson | October, 2014 | Qualitative study design | 224 | Autism disorder spectrum | Quality of life for parents of children with autism spectrum disorders | To quantify the influence of ASDs and to assess the effect of interventions for children with ASDs may consider measuring the effects on family members as well. |

| | | | | | | | |
|----|---|---------------|------------------------|---|---|---|--|
| 5. | Yoko Kamio, Naoko Inada, Tomonori Koyama | March 7, 2012 | Observational study | 154 (18 years above) | Higher Functioning Autism Spectrum Disorder (HFASD) | A nationwide survey on quality of life and associated factors of adults with high- functioning autism spectrum disorders. | To identify predictive variables that are potentially ameliorable by therapeutic intervention, this study investigated self-reported psychosocial quality of life and associated factors for adults with HFASD. |
| 6. | D. A. Garcia, Villamisar, J. Dattilo | 25 May, 2010 | Control group study | 37 (22 males, 15 females) Age – 17-39 years | Autism spectrum disorder | Effects of a leisure programme on quality of life and stress of | To demonstrating a positive relationship between leisure participation and the two constructs of |

| | | | | | | | |
|----|--|--------------|-----------------|----------------|--------------------------|--|---|
| | | | | | | individuals with ASD | quality of life and stress reduction. |
| 7. | Alessandro Musetti, Tommaso Manari, Barbara Dioni, Linzia Raffin | 8 sept, 2021 | Systemic review | 96 | Autism spectrum disorder | Parental Quality of Life and Involvement in Intervention for Children or Adolescents with Autism Spectrum Disorders: A Systematic Review | To examined several parental, child-related, and contextual factors associated with parental quality of life (QoL) among parents with a child or an adolescent with autism spectrum disorders (ASD) |
| 8. | Hsu-Min Chiang, Immanuel | August 2014 | Systemic review | Not Applicable | Autism spectrum disorder | Factors associated with quality of life in | to synthesize the existing research on |

| | | | | | | | |
|----|--------------------------------|------------|-----------------|---------------|--------------------------|---|---|
| | Wineman | | | | | individuals with autism spectrum disorders: A review of literature | the level of quality of life (QoL) in individuals with autism spectrum disorders (ASD) and the factors associated with their QoL. |
| 9. | Eleni Vasilopoulou, Joy Nisbet | March 2016 | Systemic review | Less 18 yrsrs | Autism spectrum disorder | The quality of life of parents of children with autism spectrum disorder: A systematic review | This review aimed to systematically examine studies measuring the QoL among parents of children with ASD (<18 years) and to investigate its parental, child-related |

| | | | | | | | |
|-----|---|---------------|------------------------------|--|--------------------------|---|--|
| | | | | | | | and contextual associated factors. |
| 10. | Rebecca L. McStay, David Trembath, Cheryl Dissanayakl | 06 July, 2014 | Cross sectional study design | 196 parents of ASD (3-16 years of ASD) | Autism spectrum disorder | Stress and Family Quality of Life in Parents of Children with Autism Spectrum Disorder: Parent Gender and the Double ABCX Model | To Findings provide further evidence of the negative impact of child externalising behaviours and highlight the importance of family sense of coherence on positive parental outcomes. |

CONCLUSION –

After studying the various articles related to study the effect of participation in leisure and recreational activities on quality of life among parents of children with autism spectrum disorder.

This study was conducted to look into the relationship between parents of ASD children's leisure, recreational activities and their contribution to their physical and mental well-being. Parents experiences challenges in quality of life whether the child with autism spectrum disorder (ASD) had a major health concern. The research's aim and reasoning have been explained in order to gain a better understanding of how parents/caregivers of children with autism perceive their free time and how they use it when given a break from their parental responsibilities. Slow psychological transformations of parents especially mothers and caregivers of autism spectrum disorder children due to prolonged exposure to the company of ASD children and the extent to which it affects have been raised. It is evident from studies from all over the world that caring for an ASD child has a huge effect on the parent's or caregiver's quality of life. Due to the mental, physical, sometimes social, and often financial pressures of taking care of a disabled child, parental QOL is likely to be less high than that with parents of normally growing children. The elemental characteristics of ASD, such as communication inability and disruptive behaviors, as well as genetic or environmental factors, can trigger greater parental distress, resulting in lower QOL.

Future research should continue to explore how access to disability-related services impacts quality of life; and how these associations may be moderated by contextual factors such as socioeconomic status, health of child and family members, access and engagement in recreational and leisure activities, and severity of the child's needs. This review verified previous reports on lower quality of life among parents of children with ASD.

From the above study article findings suggested that there is a need of doing more researches in relation to study the effect of participation in leisure and recreational activities on quality of life among parents of children with autism spectrum disorders, rather so it will help for construction in better treatment protocol with inclusion and comparison of recreational and leisure activities of parents of children with autism spectrum disorder. To explore the quality of life, condition of parents for the future research. As a result, it's important to enrol, a family-centered approach, as well as schedules for QOL intervention for parents in conjunction with child care, is essential.

References

Lareau A. Social class and the daily lives of children: A study from the United States. *Childhood*. 2000 May;7(2):155-71.

Karst JS, Van Hecke AV. Parent and family impact of autism spectrum disorders: A review and proposed model for intervention evaluation. *Clinical child and family psychology review*. 2012 Sep;15:247-77.

Dardas LA, Ahmad MM. Predictors of quality of life for fathers and mothers of children with autistic disorder. *Research in developmental disabilities*. 2014a Jun 1;35(6):1326-33.

Halterman JS, Yoos HL, Conn KM, Callahan PM, Montes G, Neely TL, Szilagyi PG. The impact of childhood asthma on parental quality of life. *Journal of Asthma*. 2004 Jan 1;41(6):645-53.

Halterman JS, Yoos HL, Conn KM, Callahan PM, Montes G, Neely TL, Szilagyi PG. The impact of childhood asthma on parental quality of life. *Journal of Asthma*. 2004 Jan 1;41(6):645-53.

Stewart AL, King AC. Evaluating the efficacy of physical activity for influencing quality-of-life outcomes in older adults. *Annals of behavioral medicine*. 1991 Sep 1;13(3):108-16.

Kleiber DA, Nimrod G. 'I can't be very sad': constraint and adaptation in the leisure of a 'learning in retirement' group. *Leisure studies*. 2009 Jan 1;28(1):67-83.

Brajša-Žganec A, Merkaš M, Šverko I. Quality of life and leisure activities: How do leisure activities contribute to subjective well-being?. *Social indicators research*. 2011 May;102:81-91.

Breslow RA, Ballard-Barbash R, Munoz K, Graubard BI. Long-term recreational physical activity and breast cancer in the National Health and Nutrition Examination Survey I epidemiologic follow-up study. *Cancer Epidemiology Biomarkers & Prevention*. 2001 Jul;10(7):805-8.

Parent MÉ, Rousseau MC, El-Zein M, Latreille B, Désy M, Siemiatycki J. Occupational and recreational physical activity during adult life and the risk of cancer among men. *Cancer epidemiology*. 2011 Apr 1;35(2):151-9.

Paillard-Borg S, Wang HX, Winblad B, Fratiglioni L. Pattern of participation in leisure activities among older people in relation to their health conditions and contextual factors: a survey in a Swedish urban area. *Ageing & Society*. 2009 Jul;29(5):803-21.