



A STUDY ON THE STRESS AMONG CAREGIVER'S OF SPECIAL CHILDREN

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ABSTRACT:

This study is part of an investigation into the stress faced by caregivers of special needs children. Caregivers of Special Children have the task of taking care of the physical, mental and psychological needs of the Special Children. The added requirements of the caregiving puts physical and emotional stress on the caregivers and strains their relationships with others in the family. The caregiving also requires acquiring new skills to take care of the Special Child. This research is focusing on understanding the stress levels among the caregivers of the special Children.

There has been a lot of effort by various researches in understanding the needs associated with caregiving to Special Children and the understanding from these studies have helped the caregivers. This research is attempting to measure the stress among the caregivers of the Special Children in various aspects of caregiving, familial and financial issues.

KEYWORDS: Caregiver stress, Autism Spectrum Disorder

INTRODUCTION:

Parenting a special needs child, whether it's due to physical disability, a learning disability, an emotional challenge, or a developmental disorder, can necessitate the acquisition of specific skills, such as care giving or advocacy, as well as time and energy commitment that can jeopardize careers, marriages, and relationships with other children. Over the years parenting has been studied far and wide by researchers. However, in recent years, we have seen this parenting research has put more focus on positive approaches. It has evolved into outcome-based rather than risk-based. While each child's needs are unique, the experts' advice to parents is the same: do not let your own physical and emotional health deteriorate.

Providing care for a child with different needs is a profoundly rewarding yet inherently demanding role. Caregivers of special children, whether parents, family members, or professional caregivers, are confronted with a unique set of challenges that can significantly impact their physical, emotional, and psychological well-being. At the heart of these challenges lies the omnipresent phenomenon of stress.

The stress experienced by caregivers of special children is multifaceted and can stem from various sources. Financial strain, social isolation, uncertainty about the future, and the constant demands of caregiving responsibilities contribute to heightened stress levels. Moreover, the emotional toll of witnessing a loved one's struggles and the challenges of advocating for their needs within healthcare and educational systems can further exacerbate caregiver stress.

Comprehending the intricacies of caregiver stress in individuals caring for special children is essential for devising impactful support systems and interventions. By acknowledging the unique experiences and challenges faced by these caregivers, we can work towards fostering resilience, providing resources, and promoting strategies for self-care.

KEY THEORETICAL FOUNDATION:

Caregiving can be defined as the provision of physical, emotional, and/or instrumental aid to individuals who are not able to care for themselves due to old age, sickness, disability, or other limitations (Mangrum & Stranahan, 2015). This support often involves supporting with everyday tasks, managing medical needs, providing company, and offering psychological assistance to enhance the well-being of the care recipient (National Alliance for Caregiving, 2020). Caregiving encompasses a wide range of tasks and responsibilities undertaken by family members, friends, or formal caregivers, with the primary goal of ensuring the safety, comfort, and dignity of the care recipient (National Institute on Aging, 2020).

Caregiving stress, also named caregiver burden, refers to the physical and mental strain undergone by individuals who take care of relatives, friends, or others with chronic sickness, disabilities, or frailty. This stress arises from the demands of caregiving responsibilities and can have significant impacts on the caregiver's well-being.

Symptoms of caregiving stress may include:

1. Physical signs such as exhaustion, sleep disturbances, headaches, and digestive problems.

2. Emotional indications such as nervousness, depression, petulance, and mood variations.
3. Cognitive signs such as lack of concentration, memory issues, and indecisiveness.
4. Behavioural symptoms such as isolation from social activities, neglecting one's own needs, and increased use of substances like alcohol or tobacco.

REVIEW OF LITERATURE:

Hayes, S. A., & Watson, S. L. (2013). The article by Hayes and Watson (2013) explores caregiver stress and coping strategies in families of children with Autism Spectrum Disorder (ASD). Through a comprehensive analysis, the researchers investigate the unique stressors experienced by caregivers of children with autism and examine the coping mechanisms employed to manage these difficulties. The study highlights the significant impact of caregiving responsibilities on caregivers' emotional well-being and overall quality of life. Moreover, it sheds light on various coping strategies utilized by caregivers, including seeking social support, utilizing problem-solving skills, and engaging in self-care practices. By providing insights into the complex dynamics of caregiving for children with ASD, the article contributes valuable information for professionals and support networks aiming to assist families in navigating the difficulties faced while raising a child with ASD.

Gray (2006) examines the impact of caring for a child with ASD in the article "The impact of caring for a child with autism spectrum disorder: Opportunities for resilience and growth." The study delves into the experiences of caregivers, emphasizing both the challenges and opportunities for resilience and personal growth that arise from the caregiving role. Through qualitative analysis, Gray highlights the diverse range of stressors experienced by caregivers of wards with autism, including emotional, financial, and social challenges. However, the research also identifies moments of resilience and personal growth among caregivers, illustrating their capacity to adapt and find meaning in their caregiving experiences. By shedding light on both the struggles and strengths of caregivers, the study provides valuable insights into the complex dynamics of caregiving for children with ASD, ultimately contributing to a better insights to the needs and struggles of families in this context.

In "Caregiving for Children with Developmental Disabilities: A Comparison between Asian Americans and Non-Hispanic Whites" by **Chan et al. (2011)**, the authors explore the experiences of caregivers belonging to different ethnic backgrounds. The study compares Asian American caregivers with non-Hispanic White caregivers in terms of their caregiving practices and experiences related to children with developmental disabilities. Through quantitative analysis, the research examines various aspects of caregiving, including the level of stress, coping strategies, and social support networks. The findings suggest that Asian American caregivers may experience unique challenges and employ different coping mechanisms compared to their non-Hispanic White counterparts. Despite facing similar stressors related to caregiving, Asian American caregivers may rely more on internal coping strategies and have different perceptions of social support. The research underscores the significance of incorporating cultural considerations when examining caregivers' experiences and customizing support services to accommodate their unique requirements. In essence, the study offers valuable perspectives into the varied experiences of caregivers from diverse ethnic backgrounds, enriching our comprehension of caregiving dynamics within multicultural communities.

In "The Experience of Caregiving for Children with Cerebral Palsy in Bangladesh" by **Jahan, Tofail, and Haque (2017)**, the authors explore the unique challenges faced by caregivers of children with cerebral palsy in Bangladesh. Through qualitative research methods, including interviews and observations, the study aims to understand the lived experiences of caregivers and the impact of caregiving on their daily lives.

The findings reveal that caregiving for children with cerebral palsy in Bangladesh is characterized by various physical, emotional, and social challenges. Caregivers often face significant financial burdens due to the high costs of treatment and rehabilitation services. Additionally, they experience emotional distress and social isolation, as societal attitudes towards disability can be stigmatizing. Despite these challenges, caregivers demonstrate resilience and commitment to providing the best possible care for their children. The study underscores the need for comprehensive support services for caregivers of children with cerebral palsy in Bangladesh. This includes access to affordable healthcare, financial assistance, psychosocial support, and community-based rehabilitation programs. By addressing the multifaceted needs of caregivers, policymakers and healthcare providers can improve the standard of life for both caregivers and children with cerebral palsy in Bangladesh.

Dyson et al. (1997) delineate different facets of caregiving, encompassing emotional, physical, and financial challenges encountered by caregivers. The review examines how caregiving affects family dynamics, stress levels, and the overall well-being of caregivers. Furthermore, the article discusses the significance of social support systems and resource accessibility for caregivers of children with disabilities. By analysing existing literature, Dyson stresses the necessity for customized support services and interventions to cater to the unique needs of caregivers within this demographic. This includes strategies to alleviate caregiver burden, promote resilience, and enhance coping mechanisms. Overall, the article provides valuable insights into the complex and multifaceted nature of caregiving for children with disabilities, highlighting areas for future research and intervention.

The findings of the study by **Giallo et. al (2015)** reveal several key themes. Firstly, parents describe the challenges of accessing appropriate healthcare services, including limited availability of specialists and long travel distances to access support. Additionally, the study highlights the isolation experienced by parents in rural areas, both socially and geographically, which can exacerbate feelings of stress and loneliness.

Furthermore, the study elucidates the impact of caregiving on family dynamics and relationships, with parents often feeling overwhelmed by the responsibilities involved in supporting a child with autism. Despite these challenges, parents also express a deep sense of love and commitment to their children, and resilience in navigating the difficulties of looking after a child with autism in a rural setting.

In summary, the research offers valuable perspectives on the distinct difficulties faced by parents who look after children with autism in rural Australia, highlighting the necessity for customized support services and interventions to meet the particular needs of families in these regions.

Kim and Greenberg (2013) investigated the association between caregiving stress and support among mothers of children with autism. Through a preliminary study, the researchers aim to explore the levels of caregiving stress experienced by these mothers and the extent to which social support mitigates this stress. They employ quantitative research methods, including self-report measures and questionnaires, to assess caregiving stress and social support among participants. The study findings reveal that mothers of children with autism encounter heightened grades of stress associated with caregiving, leading to emotional distress and physical exhaustion. However, the research also demonstrates the significant role of social support in

mitigating the impact of caregiving stress on these mothers. Specifically, greater levels of social support correlate with reduced caregiving stress, suggesting that a robust support system can aid mothers in effectively managing the complications of raising a child with ASD. This underscores the importance of interventions focused on enhancing social support for mothers in this demographic, as it can positively impact their overall well-being and quality of life. Overall, the study emphasizes the intricate relationship between caregiving stress and support among mothers of children with autism, offering valuable insights into potential avenues for intervention and support services in this population.

Tong et al. (2021) identify that the caregiving responsibilities associated with raising a child with special needs often place significant strain on the marital relationship. Couples report experiencing heightened levels of stress, conflict, and emotional strain as they navigate the challenges of caregiving together.

Additionally, the study highlights the role of communication and support within the marital relationship in mitigating the impact of caregiving stress. Couples who are able to effectively communicate with each other and provide mutual support tend to experience greater resilience and cohesion in their relationship despite the challenges they face.

Furthermore, the study underscores the importance of societal and cultural factors in shaping the experiences of couples raising a child with special needs in China. Cultural norms and societal expectations regarding family roles and responsibilities can influence how couples perceive and navigate the challenges of caregiving, as well as access support resources.

Johnson et al. (2018) explores the various difficulties experienced by parents of children with autism and the coping strategies they employ to navigate these difficulties. This study aims to shed light on the multifaceted experiences of these parents and provide insights into effective coping mechanisms. The research outlines several significant challenges encountered by parents of children with ASD, including emotional distress, financial strain, social isolation, and difficulties accessing appropriate services and support. These challenges can have profound impacts on parental well-being and family functioning, exacerbating stress levels and affecting overall quality of life.

To address these difficulties, the research identifies various coping mechanisms utilized by parents to navigate stress and bolster resilience. These approaches encompass seeking assistance from family, friends, and support networks, participating in self-care practices like physical activity and relaxation methods, advocating for their child's requirements within educational and healthcare frameworks, and shifting their mind set to highlight the positive aspects of caregiving. The research highlights the importance of individual differences in coping styles and preferences among parents. While some parents may benefit from seeking professional counselling or therapy, others may prefer more practical forms of support, such as informational resources or respite care services.

Vohra, Madhavan, and Sambamoorthi (2014) investigate the caregiving experiences of mothers of children with autism. The study aims to provide insight into the challenges faced by these mothers and the impact of caregiving on their well-being. The research involves interviews with mothers of children with ASD to explore their experiences and perspectives. The research illuminates the intricate and challenging aspects of caregiving for children with ASD and its influence on maternal welfare. By delving into the perspectives of these mothers, the study enhances comprehension of the support requirements of families impacted by ASD and underscores the significance of offering comprehensive support services to tackle their distinct obstacles.

Zaidman-Zait et al. (2017) undertake a thorough examination of existing literature to explore the factors influencing parental stress among individuals raising children with autism spectrum disorders (ASD). The research aims to offer insights into the distinctive hurdles encountered by these parents and the repercussions of caregiving duties on their overall welfare. The review of literature reveals several noteworthy discoveries concerning parental stress in caregivers of children with ASD. Primarily, the authors ascertain that caregivers of children with ASD endure notably elevated levels of stress compared to caregivers of typically developing children or those with other developmental disabilities. The intricate nature of ASD, marked by variability in symptom manifestation and severity, alongside associated behavioral complexities, contributes significantly to heightened stress levels among these caregivers.

The review emphasizes the role of individual and contextual factors in shaping parenting stress. Factors such as parental coping strategies, social support networks, access to resources and services, and the child's level of functioning and behavior all influence the level of stress experienced by parents. For example, parents who report higher levels of coping self-efficacy and social support tend to experience lower levels of parenting stress.

RESEARCH METHODOLOGY OBJECTIVES:

1. To study about the stress among caregivers of Special Children.
2. To study the socio-demographic profile of the caregivers
3. To examine the stress level among the respondents to the various factors of the caregiving, familial and financial issues

UNIVERSE, SAMPLE AND SAMPLING METHOD:

The universe for this research was the caregivers of the special children of age group of 5 to 15 both boys and girls at Urmi School Sama Vadodara Gujarat and Reach Centre for Autism, Gotri Raod Vadodara Gujarat. The sample of the study was 40 respondents from Urmi School and Reach Centre for Autism, so simple random sampling methods were be used for the study. The author collected data from 40 respondents from Urmi School and Reach Centre for autism.

METHODS OF DATA COLLECTION:

The author employed the method of taking surveys primarily and also used methods like books, journals and internet as secondary methods. The author has used Microsoft Excel to analyze the data to make conclusions.

FINDINGS:

73% of caregivers fall into the category of 36 and above age. 65% of caregivers are male, while 35% are female. The majority of caregivers hold a graduate qualification. Most respondents (n=32) come from families with three or more members. Service is the predominant occupational status among caregivers. The majority of caregivers were married (n=38). Most respondents (n=24) come from nuclear families. 69% of caregivers have a monthly income of 7000 or more. 38% of caregivers felt mild stress due to the experience of sensations of being inundated, excessively busy, or weighed down. 40% of caregivers experienced mild stress due to alterations in their connection with your spouse or family member. 30% of caregivers experienced medium stress due to shifts in their social interactions or activities. Medium stress related to clashes with their existing daily obligations was reported by 38% of caregivers. 38% of caregivers felt mild stress due to sensations of being restricted or confined by the responsibilities or demands of caregiving. 38% of caregivers experienced medium stress related to experience of doubts regarding their capability to provide care. 27% of caregivers experienced considerable stress due to apprehensive about the future caregiving requirements of their spouse or relative. 38% of caregivers felt no stress due to disagreements within their family regarding care decisions. 35% of caregivers experienced mild stress due to disagreements within their family regarding the level of support they receive in caregiving. 33% of caregivers experienced medium stress related to financial challenges of caregiving.

CONCLUSION:

The study conducted on caregivers of special children at Urmi School, Sama, Vadodara, and Reach Centre for Autism, Vadodara, Gujarat, included 40 respondents from Vadodara. The findings revealed that a majority of caregivers experienced stress related to caregiving, family issues, and financial concerns.

73% of respondents reported feeling mild to medium stress due to caregiving issues, feeling sensations of being inundated, excessively busy, or weighed down. This stress can potentially impact their physical and emotional well-being if not addressed adequately. Alterations in connections with spouses or relatives due to caregiving issues are noted with 55% of caregivers experiencing mild to medium stress in this regard, potentially affecting their relationships. Shifts in social interactions or activities are observed among caregivers, with 44% experiencing medium to considerable stress due to devoting time to caregiving, leading to a decreased emphasis on social activities. Existing daily obligations are impacted for 65% of caregivers, resulting in mild to medium stress as caregiving responsibilities take precedence over daily routines, work, or self-care. A significant 70% of respondents felt mild to medium stress due to sensations of being restricted or confined by the responsibilities or demands of caregiving, potentially affecting their emotional well-being and outlook on life.

68% of caregivers reported mild to medium stress due to doubts regarding their capability to provide care, which may affect their mental health. Apprehensions about the future caregiving requirements of spouse or relative are significant, with 52% of caregivers experiencing moderate to considerable stress, impacting both their and their spouse's mental and emotional health. Encouragingly, 38% of respondents did not feel any stress due to disagreements within their family regarding care decisions for the special child, indicating a positive aspect of caregiving. However, disagreements within their family regarding the level of support they receive in caregiving to the special child contribute to mild to medium stress for 60% of the caregivers, highlighting an area of concern.

Financial challenges associated with caregiving are a significant stressor, with 51% of caregivers experiencing medium to considerable stress. This along with apprehensions about the future caregiving requirements of spouse or relative, emerges as the most significant stress contributors among caregivers.

SUGGESTIONS:

Improving the situation of overwhelmed caregivers requires open discussion of their issues with family members, psychologists, or social workers. Equipping them with stress-reduction techniques, promoting self-awareness about their health, and encouraging seeking support are essential steps. Caregivers should seek assistance from family and willing society members and make a list of activities where help is needed. Simple activities like taking a walk with a loved one can be beneficial.

Awareness of changes in relationships and social life is crucial for caregivers of special children. Seeking support and explaining their situation to family members can alleviate stress. Counselling sessions with a psychologist for the family can also be beneficial. Conflicts with previous daily commitments are common among caregivers. Allocating time for various activities without neglecting others and maintaining physical health and positivity are key. Self-care practices such as proper nutrition, relaxation, and activities like yoga are essential.

Maintaining a positive outlook and being aware of the positive aspects of caregiving can boost caregivers' confidence. Sharing experiences with other couples facing similar situations can provide helpful insights. Communication with family members is vital to resolve conflicts in caregiving decisions. Expressing emotions and expectations from family members can improve the situation. NGOs can offer assistance, although their availability in rural areas remains a concern. Public awareness about caregiving issues and available support from NGOs is crucial.

Financial difficulties associated with caregiving are significant stressors for many caregivers. Government schemes and initiatives, such as GyanPrabha, aim to support the education and development of special children. Creating awareness about these schemes can help caregivers access the support they need.

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