



An Analysis Of The Difficulties Encountered By Caregivers In Providing Support And Assistance To Individuals With Neurological Conditions.

Mr. Aman Kumar M.Phil. (rehabilitation psychology), NIEPVD

Dr. Surender Kumar dhalwal, Head of psychology department, NIEPVD

Mrs. Shrami Negi, Supervisor (MPhil. Rehab) , NIEPVD

Ms. Taniya Singh, Psychology Student

Ms. Purnima Bamel, Counselling Psychologist ,Citizen hospital

Abstract: The care of individuals with neurological disorders poses distinct challenges for caregivers. This study offers a comprehensive analysis of the obstacles faced by caregivers in their provision of care to neurological patients. It delves into the physical, emotional, social, and financial burdens encountered by caregivers, while also exploring their impact on overall well-being. Additionally, this paper examines specific challenges arising from the unpredictable nature of neurological conditions, the intricacy of symptom management, the necessity for specialized care, and the dearth of support systems. Through a thorough understanding of these challenges, appropriate interventions and support systems can be devised to alleviate caregiver burden and enhance the overall quality of care for neurological patients.

Keywords: Mental health , Neurological Disorders , S.E.H.T. ,

INTRODUCTION

Neurological diseases encompass a broad spectrum of disorders that impact the functioning of the nervous system. These conditions include stroke, epilepsy, Alzheimer's disease, Parkinson's disease, multiple sclerosis, and others. Caring for individuals affected by neurological illnesses poses distinctive obstacles for both patients and their caregivers. The symptoms and progression of these disorders are unpredictable and demanding, necessitating constant supervision and support. Caregivers bear emotional, physical, and financial burdens as they navigate the complexities of providing assistance. They must adapt to evolving circumstances, manage medications, aid with daily tasks, and address cognitive and behavioural changes. Dealing with the effects of neurological diseases on patients and caregivers remains an enduring and significant challenge.

Most individuals with neurological conditions living in the community are primarily cared for by informal caregivers. The objective of this study was to create a profile of these caregivers for home care clients with neurological issues. The study also aimed to examine the prevalence of caregiver distress and the correlation between neurological disorders, client characteristics, and caregiver discomfort. Medically, neurological illnesses involve problems that affect both the brain and the nerves throughout the human body, including the spinal cord. Structural, metabolic, or electrical abnormalities in these areas can lead to various symptoms, such as paralysis, muscle weakness, coordination difficulties, loss of sensation, convulsions, confusion, pain, and altered states of awareness. Neurological difficulties may arise from genetic conditions, congenital

anomalies, infections, lifestyle factors, or environmental health issues like malnutrition, brain damage, spinal cord injury, or nerve damage. While there are numerous recognized neurological disorders, some are relatively common, while others are exceedingly rare. On the other hand, mental disorders are psychiatric illnesses that primarily manifest as abnormalities in thinking, feeling, or behaviour, causing discomfort or impairing overall function. The National Library of Medicine in the United States identifies approximately 600 neurological illnesses.

The impact of neurological disorders on both patients and their caregivers is significant and multifaceted. Neurological conditions can be highly unpredictable and demanding, affecting various aspects of daily life for patients and presenting unique challenges for those who care for them. Here, we explore the impact on both patients and caregivers:

The challenges faced by caregivers of neurological patients have a profound impact on their well-being. Here are the specific ways in which caregivers are affected:

- 1. Emotional Stress and Burnout:** Caregiving for individuals with neurological disorders can lead to intense emotional stress and burnout. Witnessing the decline of a loved one's health, dealing with the uncertainty of their condition, and managing the emotional toll of providing care can all contribute to feelings of stress, anxiety, and overwhelm.
- 2. Physical Strain:** Caregiving often involves physically demanding tasks, such as assisting with transfers, mobility support, and personal care. The repetitive nature of these activities, coupled with the weight and mobility challenges of the patient, can lead to physical strain and an increased risk of injuries for caregivers. Without proper support or access to respite care, caregivers may not have sufficient time to rest and recover.
- 3. Disruption of Daily Life:** Caregiving responsibilities can disrupt caregivers' daily routines and personal lives. The demands of providing care, managing appointments, and addressing the needs of the patient may limit their ability to work, pursue personal interests, or spend time with other family members. This can lead to feelings of frustration, loss of personal identity, and a sense of being overwhelmed by caregiving responsibilities.
- 4. Social Isolation:** Caregiving often results in social isolation for caregivers. The time and energy required to care for a neurological patient may leave little room for social activities and maintaining relationships. Caregivers may experience a sense of loneliness and a loss of social connections, which can further contribute to feelings of isolation and emotional distress.
- 5. Financial Burden:** Caring for a neurological patient can lead to increased financial expenses. The cost of medical treatments, medications, specialized equipment, home modifications, and transportation can place a significant strain on caregivers' financial resources. These financial burdens can create additional stress and anxiety, especially if caregivers face limited income or lack access to financial assistance programs.
- 6. Lack of Support:** Many caregivers of neurological patients do not have access to adequate support services or resources. This lack of support can intensify feelings of frustration, helplessness, and isolation. Caregivers may struggle to navigate the complex healthcare system, find appropriate respite care options, or access support groups and educational resources tailored to their specific needs.

Addressing these challenges requires a comprehensive approach that includes recognizing and addressing the emotional well-being of caregivers, providing physical support and respite care, offering financial assistance programs, and enhancing access to support services and resources. By acknowledging and addressing the specific challenges faced by caregivers, we can better support them in their crucial role and ultimately improve the overall care provided to neurological patients.

REVIEW OF LITERATURE

1. McCrossin, J., Lach, L., & McGrath, P. (2023). Caring for children with neurodevelopmental disorders, particularly when coupled with behavioural issues, poses significant challenges for parents. These difficulties can impact the well-being and happiness of the caregiver. This study aims to explore the physical and psychological outcomes of caregivers of children with both neurodevelopmental disorders and behavioural difficulties, comparing them to caregivers of children with either condition or no condition.

2. Rouhani, A., & Alamdarloo, G. H. (2022). The experiences of parents caring for children with rare neurodevelopmental diseases that require complex care are often overlooked. Parents struggle to meet their children's medical, behavioural, and social needs across various systems, including healthcare, social services, and family. This study investigates the experiences of parents providing medical and social care for children with rare neurodevelopmental disorders.

3. McDonagh, K., McGuire, B. E., & Durand, H. (2022). Growing up with a sibling who has a neurodevelopmental disorder can have both positive and negative impacts on personal, social, and emotional health. However, there is limited knowledge about the implications for the quality of life of siblings who are not directly affected. This review aims to synthesize research findings on the quality of life of siblings of children with neurodevelopmental disorders who are not themselves impacted.

4. Predebon, M. L., Pizzol, F. L. F. D., Santos, N. O. D., Bierhals, C. C. B. K., Rosset, I., & Paskulin, L. M. G. (2021). Understanding the characteristics, tasks, and challenges faced by informal caregivers of dependent older individuals after a stroke is crucial. This study identified three major themes: "Struggle for Help," "Mothers Know Best," and "Daily Impacts." Common challenges included concerns about child discomfort, communication difficulties, and obstacles in obtaining diagnoses and related healthcare treatments. Connecting with other parents of children with developmental arthritis provided emotional and educational support.

5. Lin, C. Y., Shih, P. Y., & Ku, L. J. E. (2019). Family caregivers of individuals with dementia experience high levels of burden due to the presence of neuropsychiatric behaviours and the decline in activities of daily living (ADLs). This study examines the mediating role of caregiving hours in the relationship between the ability of people with dementia to perform basic ADLs or their neuropsychiatric behaviours and caregiver burden. To alleviate caregiver strain, respite care services for caregivers of people with dementia should focus on supporting the basic ADL function of individuals with dementia.

6. Sheikh, F., Ismail, Z., Mortby, M., Barber, P., Cieslak, A., Fischer, K., Smith, E. (2018). The challenges faced by caregivers of individuals with neurodevelopmental disorders are significant, particularly when accompanied by behavioural difficulties. This study aims to examine the physical and psychological outcomes of caregivers of children with "Neuro" and behavioral issues compared to caregivers of children with only one of these conditions or no condition at all.

7. Cheng, S. T. (2017). Caregiver burden and depression are influenced by various factors, including the demands of care and specific neuropsychiatric symptoms. This article provides an updated review on these determinants, focusing on the differential effects of different neuropsychiatric symptoms or clusters. Additionally, it refers to studies on caregivers of frontotemporal and Lewy body dementias to identify similarities and differences compared to Alzheimer's caregivers.

8. Liu, S., Li, C., Shi, Z., Wang, X., Zhou, Y., Liu, S., Liu, J., Yu, T., & Ji, Y. (2017). This study investigates the caregiver burden and associated variables among Alzheimer's disease caregivers and patients in China. Female spouses and older individuals play a crucial role in providing dementia care within the household. The majority of caregivers were single and full-time, with limited personal time. Caregivers commonly experienced sleep problems, as well as mild to severe levels of sadness and anxiety. Higher caregiver burden was associated with worse physical health, decreased life satisfaction, and increased levels of sadness and anxiety. The primary difficulties reported by family caregivers included depression, anxiety, and sleep issues.

Caregiver burden was influenced by caregivers' functional status, reduced life satisfaction, sadness, and anxiety. It was also correlated with the severity of the patient's dementia and the characteristics of the caregiver.

9. Kellermair, L., Fuchs, A., Eggers, C., Schwingenschuh, P., Kögl, M., Fellner, F., Forstner, T., Mangesius, S., Guger, M., & Ransmayr, G. (2009). Caring for individuals with progressive supranuclear palsy (PSP) and corticobasal syndrome (CBS) can be challenging and burdensome. This study examines the progression of caregiver burden in PSP and CBS patients over time. The study includes longitudinal data from 68 newly diagnosed patients with suspected PSP and CBS, evaluating various factors such as demographics, motor functions, neuropsychological performance, behavioral and neuropsychiatric impairments, activities of daily living, and caregiver burden. The results show that caregivers reported mild to moderate burden at baseline, which increased over a period of two years. The burden was significantly higher in PSP compared to CBS. Risk for mental health problems, particularly depression, increased over time, especially among female caregivers. Important factors contributing to caregiver burden included apathy, depression, behavioral symptoms, impaired activities of daily living, and a close family relationship.

10. Zarit, S. H., Todd, P. A., & Zarit, J. M. (June 1986). This study examines the evolution of dementia patient caregivers, with a focus on factors associated with nursing home placement. The study includes married couples who were initially providing care at home. The results indicate that subjective characteristics, particularly perceived strain on caregivers, were more closely associated with nursing home placement than objective measures of dementia severity. Although wives initially reported a higher burden than husbands, no significant differences were found during follow-up.

CONCLUSION

Caregivers who look after individuals with neurological conditions encounter significant physical hurdles in their caregiving role. These obstacles can originate from the characteristics of the neurological condition itself, as well as the physical tasks and obligations involved in providing care. Below are some common physical challenges experienced by caregivers:

- 1. Assisting with Activities of Daily Living (ADLs):** Neurological conditions often impose restrictions on performing basic ADLs like bathing, dressing, grooming, and feeding. Caregivers may need to offer hands-on aid or supervision to ensure the individual's safety and well-being. This necessitates physical effort and proper body mechanics to prevent strain or harm.
- 2. Mobility and Transfers:** Many neurological conditions affect mobility, resulting in difficulties with walking, balance, or coordination. Caregivers may need to assist with transfers, such as moving the individual from the bed to a chair or aiding them in getting in and out of vehicles. These tasks demand physical strength and may involve the use of assistive devices like transfer belts or wheelchairs.
- 3. Managing Personal Care:** Caregivers may be responsible for managing personal care tasks such as toileting, hygiene, and incontinence care. This may involve physically demanding activities such as lifting or repositioning the individual, assisting with personal hygiene routines, and handling specialized equipment like catheters or ostomy bags.
- 4. Administering Medications:** Neurological conditions often necessitate complex medication regimens, including multiple medications, specific dosages, and timing requirements. Caregivers may need to assist with medication administration, which can involve physically handling medications, preparing doses, and ensuring adherence to the prescribed schedule.
- 5. Managing Challenging Behaviour's:** Some neurological conditions may present behavioral challenges like aggression, restlessness, or wandering. Caregivers may need to intervene physically or redirect the individual during episodes of challenging behavior, demanding physical strength, endurance, and patience.
- 6. Home Safety and Adaptations:** Caregivers may need to make physical adaptations to the home environment to ensure the individual's safety and accessibility. This may involve tasks such as installing grab bars, ramps,

or stairlifts, rearranging furniture for better manoeuvrability, or maintaining a clutter-free environment to prevent falls.

7. Managing Assistive Devices: Many individuals with neurological conditions rely on assistive devices like walkers, canes, or prosthetics for mobility or daily activities. Caregivers may need to assist with the proper use, maintenance, and adjustment of these devices, ensuring they are fitted correctly and functioning optimally.

To effectively navigate these physical challenges, caregivers should prioritize their own physical well-being. This includes practicing proper body mechanics, seeking assistance when needed, engaging in regular exercise and stretching, and utilizing assistive equipment or techniques to minimize the risk of strain or injury. Additionally, caregivers should consider accessing respite care services or seeking support from other family members or healthcare professionals to share the physical demands of caregiving.

Caregivers who look after individuals with neurological conditions often encounter various social challenges that can lead to feelings of isolation. These challenges can have an impact on their social interactions, relationships, and overall emotional state. Here are some of the social difficulties faced by caregivers of patients with neurological conditions:

1. **Reduced Social Support:** Caregivers may find it challenging to maintain their social support networks due to the demands of caregiving. They may have less time to connect with friends or seek support from others who may not fully understand their caregiving experiences.
2. **Stigma and Misunderstanding:** Neurological conditions are often complex and misunderstood by others. Caregivers may face social stigma or judgment, which can contribute to feelings of isolation and frustration. Lack of awareness and understanding about the condition may result in insensitive or unsupportive comments from others.
3. **Impact on Relationships:** Caregiving responsibilities can strain relationships with spouses, partners, children, and other family members. The caregiver's focus on the patient's needs may leave them with less time and attention to devote to maintaining relationships, leading to feelings of isolation and strain in personal connections.
4. **Loss of Personal Identity:** Caregiving can consume a significant amount of a caregiver's time and energy, causing them to neglect their own needs and interests. This loss of personal identity and fulfilment can contribute to social isolation and a sense of disconnection from their pre-caregiving social circles.
5. **Lack of Respite Care:** The absence of respite care options can exacerbate social challenges for caregivers. Without access to temporary relief from caregiving duties, caregivers may struggle to take breaks and participate in social activities beyond their caregiving responsibilities.

It is crucial to address the social challenges faced by caregivers of individuals with neurological conditions. Providing support and resources such as respite care, caregiver support groups, and educational programs can help alleviate social isolation and promote social well-being for caregivers. Increasing awareness and understanding of neurological conditions in society can also reduce stigma and create a more supportive and inclusive environment for caregivers and their loved ones.

There are various therapies and interventions available to support caregivers of individuals with neurological conditions. Therapies aim to provide caregivers with tools, strategies, and emotional support to cope with the challenges they face. It is important for caregivers to seek out and explore the therapies and interventions that best suit their needs and circumstances. The support and tools gained through these therapies can help caregivers navigate their caregiving role more effectively, enhance their well-being, and provide the best possible care for their loved ones with neurological conditions. One of the therapy is S.E.H.T. (Sub-conscious energy healing therapy)

Subconscious energy healing therapy (S.E.H.T)

This therapy is very useful in managing many challenging situations with the clients. The therapy uses holistic approach and incorporate various other therapies in terms of energy healings.

The paradigm of this therapy has is as follows.

The tool used is SANTOSH

S - Sensitising self about the problem

A -Adapting to the New Situation

N - Nurturing self

T -Transformational Tools for Self-growth

O - Opting Optimism for Success

S - Self Love

H - Holistic healing for health

This therapy SEHT works very well in the Indian Society.

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