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Caregiver Burden and Subjective Well-Being of Caregiver of Person with Dementia: A Comprehensive Review

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Abstract: ***Dementia is a form of cognitive impairment which impacts a person's thinking, reasoning, understanding skills and interferes with their daily activities and thus, this syndrome requires high level of care, which are provided by family members in most cases. It is recollected that the person having dementia shows various types of neuropsychiatric symptoms like, agitation, depression, delusions, hallucinations, sleep impairment etc. This leads to the caregiver's burden, stress, anxiety and depression. The main objective of this review is to recognize the necessities of the caregiver living in the same home as the person with dementia and the factors leading to the caregiver burden, factors responsible for poor subjective well-being and also to investigate the measures to improve their quality of life. After reviewing the local and international literature, use of World Health Organization (WHO) official publications, the common factors observed are: (1) deterioration of the relationship between the caregiver and the person with dementia; (2) adequate information and support required for the caregiver and; (3) realizing the burdens the caregiver faces and the need for their subjective well-being. It is also noted that the ratio of caregivers who felt burdened for looking after a person with dementia and the caregivers who did not is 37:13. When caregivers gradually lose their relationship with the person with dementia, they start craving social contact outside the family especially with persons in an identical situation. This review shows the importance of the caregiver to seek supportive psychotherapy and professional help which minimizes their burden and improve their quality of life.***

Keywords: Neuropsychiatric symptoms, Caregiver burden, Depression, Subjective well-being, Supportive psychotherapy, Quality of life

1.Introduction

Dementia is a syndrome, usually of a chronic or progressive nature, caused by a variety of brain illnesses that affect memory, thinking, behavior and ability to perform everyday activities. The number of people living with dementia worldwide is currently estimated at over 50 million and will almost triple by 2050 as per World Health Organization, 2023 (henceforth WHO). Currently, dementia is the seventh most common cause of death among all diseases and a major contributor to disability and dependency among the older people, every year, there are about 10 million new cases (Centers for Disease Control and Prevention, 2023; World Health Organization, 2023). It is estimated that Mild Cognitive Impairment (MCI) that globally leads to mild dementia among community dwellers is over 17% and is affected by age, gender and education level. (Bai et al, 2022). As per one study conducted in 2007–2008, the overall YLL (Years of Life Lost) was 47.13 per 100,000 and YLD ranged from 1.87 to 16.95 per 100,000 depending on the clinical severity of dementia. At the same time, the overall DALY lost per 100,000 as a consequence of dementia for the year 2007–2008 was around 74.19 (Banerjee et al, 2016). The physical, socio-economic, and psychological health of People Living with Dementia (PLWD) is severely affected due to the close proximity with person with dementia. In most cases, the older people with chronic illnesses are cared for by their close relatives and it entails a higher level of care, sometimes five hours every day; high medical costs; psychological stress; worsening health conditions; social isolation and financial difficulty. Reduced execution of daily living tasks by the care recipients is a sign that the caregivers of PLWD are under more stress than before. The caregivers of PLWD bear a heavier strain than other caregivers (Martis et al, 2024). Caregiver burden or stress is a completely unnoticed, neglected and untreated area which significantly affects their personal and social life. Most caregivers (PLWD) are elderly women and the high rates of mortality and increasing illness of persons with dementia impacts their physical and mental health. (Mondal et al., 2021, Huang et al. 2022). Caregivers are more likely to cut back on their free time and interests, spend less time with their loved ones, and even quit their jobs, refraining from social interaction and thus feel lonely most of the time (Steenfeldt et al.2021).

2.Findings

Caregiver burden:

The personal lives of caregivers of persons with dementia gets affected due to the continuous effort and care throughout the day for substantial hours which at times becomes quite burdensome. Torrisi et al 2016 conducted a study titled "Neuropsychiatric symptoms in dementia may predict caregiver burden: a silicon exploratory study" among 27 patients and their caregivers using the scale Neuropsychiatric Inventory and Mini-Mental State Examination and Caregiver Burden Inventory. This study revealed that dementia patients' behavioral problems were related to the level of caregiver burden and distress. The researcher detected strong correlations between patient neuropsychiatric symptoms, (i.e. irritability, hallucinations, depression, and agitation) and Caregiver Burden Inventory scores. Multiple regression analysis found hallucinations, irritability, and depression to be significant predictors of caregiver burden. Jennings et al (2016) also conducted a cross-sectional observational cohort study on unmet needs of caregivers of persons with dementia, referred to a dementia care program in urban Academic

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Medical Centre, using the tool Patient Health Questionnaire (PHQ-9), Modified Caregiver Strain Index, Neuropsychiatric Questionnaire and 9-item Caregiver Self Efficacy scale. In both the studies, the majority of caregivers reported stress and low confidence in caregiving management. Anantharamu et al (2016) conducted a study on 'Burden among caregivers of persons with dementia' and identified that financial burden was a mild burden compared to the burden related to disruption of family activities of the caregivers. Similarly, a comparative study was conducted between caregiver burden in Alzheimer-type dementia (AD) and psychosis, in India and found that the mean burden score in dementia caregivers was high at 47.7 whereas the mean burden score for elderly psychosis caregivers was lesser at 33.6. (Sinha et al, 2017). They also highlighted that the presence of psychological distress in caregivers was also an indicator for greater caregiver burden in dementia.

Stress, Depression and anxiety of caregiver:

It is often found that the caregivers of persons with dementia experience bouts of anger, stress, depression and eventually suffer from low self-esteem. To highlight this aspect, a comparative survey was conducted by (Goren et al, 2016)to assess how family caregivers for patients with Alzheimer's Disease (AD) or dementia in Japan differentiated from non-caregivers in characteristics and health outcomes (i.e co-morbidities, health related quality of life, productivity and resource use), They concluded their findings by stating that caregivers providing cares to AD patient's experienced poor quality of life and greater co-morbid risk, productivity impairment and resource use. Fazio et al (2015) investigated by conducting a research study on "Depressive symptoms in caregivers of patients with dementia: demographic variables and burden" in order to analyze the presence of subjective burden among caregivers of patients with dementia. The researcher identified association between burden and depression. Depression may be especially challenging for caregivers to handle because it causes difficulty in dealing with the patients, and also negative impact on the patient's quality of life. The findings also suggested that patient's depressive symptoms may result in caregivers' depression. A cross sectional survey research was conducted to assess the role of resilient coping in dementia carers' wellbeing who are at risk of psychological distress. However, some carers experience positive outcome and resilient coping may account for this variance in carers' wellbeing. The resilient coping was a partial mediator in the relationships between wellbeing and depression, anxiety, stress and burden (Roche et al, 2015). An exploratory study on burden among family caregivers of patients with dementia and concluded that caregivers of patients with dementia had higher role strain, and personal strain (Win KK et al, 2017). Alquahtani et al (2018) investigated the prevalence and risk factors for depression among caregivers of patients with Alzheimer's disease in Saudi Arabia reported that prevalence of depression among caregivers was 70%. Caregivers were mainly sons/daughters (30%) or spouse 11.8%. A total of 30% had mild depression while 44% has moderate depression. Caregiver's scores of depressions positively correlated with the duration of caregivers stay with AD patients but do not correlate significantly with caregiver's age or patient's age. Orla C et al (2021) conducted a comparative research study with the population of caregivers of persons with dementia and nondementia and reported depressive symptoms prevalent among caregivers of persons with dementia. Xian., et al (2022) argued that Caregiver burden is a well-recognized global phenomenon. The objective of the review was to summarise the prevalence of caregiver burden and its measurement scales, predictive factors and impact in Singapore and they concluded that a significant proportion of caregivers in Singapore experienced caregiver burden. It was found that cultural, behavioural and socioeconomic factors affected caregiving experiences and outcomes. They observed that caregivers' burden is associated with poorer self-rated health and reduced quality of life.

Prerequisite for subjective well-being:

Subjective well- being of caregivers of persons with dementia is a significant area of study. In this respect, feasibility research was carried out with a one- group before-after design and interviews, using a multiphase mixed method design with 12 caregivers through the program over three months. They adapted Namaste Care program which was judged to be feasible, given that all caregivers used it at least twice a week over the 3-month period. The above-mentioned program was perceived by the caregivers to be practical that enhanced the wellbeing of persons with dementia, and brought them closer in their relationship with persons with dementia. However, there were no statistically significant changes for quality of life, perceptions of caregiving, self-efficacy, or burden outcomes. But the caregivers found the program to be valuable and important to integrate into their caregiving routines (Yous et al 2022). The issue of subjective well- being also involves analyzing the quality of life as envisaged by the caregivers while performing their tasks and thereby, a cross-sectional research was carried on by (Martis et al, 2024) in India to assess the caring burden and Quality Of Life (QOL) among the caregivers of person with dementia, as well as to ascertain the relationship between QOL scores and burden. This is a perpetual problem in developing countries like India where counseling, awareness program, stress-related interventions and education on home health care for people with dementia is not provided to reduce the burden and improve the QOL. It is been observed that depressive symptoms are a common phenomenon among caregivers of patients with dementia. Considering variables such as severity of dementia, sex, age and financial state of the patient by recruiting 222 caregivers of patients with dementia from King Abdullaziz Medical city, Saudi Arabia, a research was carried on by Alfakhri et al (2018) which reported the prevalence of clinical dementia among caregivers as well as lower level of health-related quality of life. It is also extremely difficult for the caregivers to adopt appropriate coping mechanisms to avert depression which affects their overall quality of life. It was found that the caregivers of patients with dementia experience considerable burden as revealed from the research of Hawken et al (2018) to determine the effects of coping strategies on distress of the older adult's caregiver, including guilt as a mediating factor in those maladaptive strategies. The revealed results showed that the strategies which have a better ability to reduce stress are active, positive reframing and acceptance; on the other hand, behavioral disengagement, self-distraction, self-blame and venting positively predicted the feeling of guilt that facilitated the perception of stress. The issue of understanding the impact on carers' fulfilment of needs in the context of providing them a better life while caring for their patients, semi-structured interviews of 48 family caregivers indicated that there was need of feeling in control, time to relax or being spontaneous as well as relational needs for belongingness and love (Pini et al, 2017).

Available support system:

The mental health of caregivers of persons with dementia is a relevant area of study and it entails making adequate provisions for sufficient support system. One such qualitative study examined the barriers and facilitators of service use among family caregivers of people with dementia focusing on the need for ongoing information about available services and support, the existence of some barriers for utilizing the in-home-care services and also highlighted the poor quality or mistrust of the services (Macleod et al, 2017). Killin et al (2018) had also carried on a qualitative study through a semi-structured interview to establish the feasibility of the Digital Support Platform (DSP), an internet-post diagnostic tool designed for families living with a diagnosis of dementia. However, the investigator found that a digital support forum perhaps was beneficial to caregivers experiencing patients with later stages of dementia or with patients who required physical care. The needs and requirements of the existing problems of the caregivers and their families were not taken into consideration. To support everyday life of family caregivers, researchers had suggested the use of assistive technologies in order to facilitate the person with dementia to become independent of the family caregiver, but it was believed that if a device is too difficult to use it may enhance the caregiver burden (Holthe et al, 2018).

Relationship between caregiver burden, stress, anxiety, depression and subjective well-being based on demographic profile:

Mukherjee et al, (2017) conducted a cross-sectional study to evaluate the Behavioral, Psychological Symptoms of Dementia (BPSD), to determine their correlation with types and stages of dementia and patient demographic and to assess the impact on caregiver distress. Total sample size was 107 patients and their caregivers recruited from a cognitive clinic to assess the impact on caregiver distress by using Neuro Psychiatric Inventory scale. Results showed (99.1%) had at least one BPSD; 71% had ≥ 4 symptoms. Most frequent symptoms were apathy and agitation, followed by irritability, sleep and appetite disorders, whereas mood disorders; disinhibition and euphoria were least frequent. BPSD were less prominent with increasing age; males showed more agitation. Similar such researches were undertaken to measure the perceived stress of caregivers of person with dementia. For instance, Anand et al., (2016) conducted a cross sectional study to evaluate the perceived stress in caregivers of persons with Alzheimer's Disease (AD) and Mild Cognitive Impairment (MCI) that leads to dementia by using Perceived Stress Scale (PSS). This study was conducted among caregivers of 31 patients with AD/MCI and it proved that perceived stress of caregivers of AD and MCI is higher than other chronic disorders. Researches were also carried on to understand the issues of family burden and subjective well-being of the carers. In this respect, mention can be made of Behura SS et al (2017) who conducted a comparative study on family burden and subjective well-being between caregiver of schizophrenia and dementia patient. Data was collected among 128 caregivers (64 in each group) by using World Health Organization Quality of life Instrument (WHOQOLBREF scale) to assess the level of family burden. Through this study researcher concluded that caregiver perceived physical and psychological burden. Statistical significant differences ($p < 0.05$) were found in the areas of financial burden, disruptions of family routine activities, family leisure and family interaction between dementia and schizophrenia caregivers. Whereas there was no statistical significant difference ($p > 0.05$) found in different domains of subjective well-being between these two groups of caregivers. A one year follow up study on factors associated with caregiver burden in dementia was done to investigate the dementia-related symptoms, and how the progression of these symptoms, had influenced caregiver burden using the tool, the Zarit Burden Interview. The aim was to assess the burden among caregivers and for assessment of patient's severity, cognitive function, daily function, neuropsychiatric symptoms, the tools used respectively were Clinical Dementia Rating Scale (CDR), Mini Mental State Examination (MMSE), Seoul-Activities of Daily Living(S-ADL), Seoul-Instrumental Activity Daily Living(S-IADL), Korean version of the Neuropsychiatric Inventory (K-NPI). Researcher concluded that there were significant factors for increasing caregiver burden due to increase neuropsychiatric symptoms and memory impairment in daily-living functions (Shim SH et al, 2016). The families of persons with dementia undergo tremendous stress and it is more reflected upon the person of caregiver whose quality of life is under duress. To identify the burden experienced by families giving care to relative with dementia, the consequences of care of the mental health of the primary caregiver and the strategies which the families use to cope with the caregiving stressors, Papastavron et al (2017) conducted a study. The findings suggested that psychopathology and caregiver's sex, income and level of education were important predictors of burden. The issue of maintaining subjective well-being while living with persons with dementia is indeed very crucial and to highlight this aspect, Srivastava et al (2016) conducted a research study on caregiver burden and quality of life of key caregivers of patients with dementia. Data was collected from 24 caregivers of patients with dementia by purposive sampling technique from the in-patient of the Department of Geriatric Mental Health, King George's Medical University, Lucknow, Uttar Pradesh, India. Through this study, researcher concluded that all key caregivers felt mild to moderate level of burden and also found that there was insignificant difference between male and female. Though, female caregiver felt more burden in comparison to male. The mean score on ZBI was found to be of dementia key caregivers that fall in the category of mild to moderate level of burden. The intersectionality of gender, race and ethnic status also affect significantly the amount of stress felt by the caregivers of persons with dementia. Liu, R., et al (2022) have shown how financial, emotional and physical burden varies across gender, racial and ethnic status among the caregivers of persons with dementia. The study examined differential burdens of 1,206 caregivers who provided services to Medicare beneficiaries across gender and racial/ethnic groups and logistic regressions were performed to assess the 3 types of burdens each subgroup was experiencing. Results indicated that within the intersectionality framework, compared to White female caregivers, Black male caregivers were 3.3 times more likely to experience financial burden, and Black female caregivers were 54% less likely to experience physical burden. The findings highlighted that Black male caregivers were experiencing financial burden and White female caregivers were experiencing emotional burden disproportionately. of 1,206 caregivers who provided services to Medicare beneficiaries

Martin et al, (2023) conducted a cross-sectional observational study in caregivers of non-institutionalized dementia patients by using Neuropsychiatric Inventory Caregiver Distress Scale (NPI-D) and burden based on the ZBI, Global Deterioration Scale (GDS). It was revealed from the study that the burden was greater when the caregiver lived in the same home as the patient or if he or she provided more than 8 hours of care per day. Greater burden was also found among younger caregivers (83.6% in those under 60 years, in women (81.4%) and in caregivers who worked outside the home (84.8%). The researcher had given the concluding remarks that providing proper training to the caregivers is pertinent especially in the management of hyperactivity symptoms, which include divergent psychomotor skills and lack of inhibitory control, which do not have an easy pharmacological solution and for which one needs to prioritize nonpharmacological management.

3.Conclusion

Caring for a person with dementia is a full-time responsibility which may become burdensome and extremely stressful for the caregiver affecting their emotional and overall subjective well-being. It's a mammoth task which completely disrupts the life of the family caregiver, often at times leading to challenging circumstances, secluded, isolated lives which is directly proportional to the progress of the disease itself. Coupled with the fear of loss of their closed ones, the caregivers become more and more anxious and show symptoms of acute depression. Under such circumstances, managing this situation alone can be overwhelming without adequate supportive management system. In the long run, with deep commitment towards the person living with dementia the caregivers often are left with no energy to take care of their own needs and consequently it takes toll on their own health and wellbeing. In search of getting adequate support, often the caregivers try to interact with people in similar circumstances to expand their knowledge base about dementia patients and their care and also look for avenues of self-care for some minimal respite while taking care of the persons with dementia. Unfortunately, in our country, the societal norms and political policies are intertwined with the cultural ethos which places a huge expectation on the family being the primary caregiver of the persons with dementia. However, it is imperative to state that both societal and governmental intervention (like self-help groups, NGOs, government policies) in the form of support system is an essential component to facilitate the family caregivers to execute their care effectively towards the persons with dementia along with their own overall subjective well-being.

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