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The Relationship Between Perceived Social Support And Caregiver Burden In Caregivers Of Epileptic Patients

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ABSTRACT
People who care for people with epilepsy face significant emotional, physical, and financial burdens due to the condition's persistent nature, difficulties, and societal stigma. To assess the relationship between Perceived Social Support and Caregiver Burden in CAREGIVERS of epileptic patients. The study had a sample of 15 Caregivers of epileptic patients who were identified from the District Health Quarter and Parveen Akhtar Hospital, Kotli. The study was conducted using a survey research design. The study was correlational. The sample was chosen using a purposive sampling strategy. The caregivers were given the Zarit Caregiver Burden Interview (ZBI) questionnaire and the Multidimensional Perceived Social Support Scale (MSPSS). Perceived Social Support had a negative correlation with burden at a 0.001 level of significance (r=-.783). Implications of this estimate for further development of models of social support.

Key words: Perceived, Social Support, Caregiver Burden, Epileptic, Patients

INTRODUCTION
Providing care for someone you love who has epilepsy can be difficult and demanding. Family members frequently assume the role of caretakers, offering financial, emotional, and physical support. However, this job of providing care can have a big effect on their own health. A loved one's care can cause emotional, physical, and financial pressure on Caregivers, which is known as caregiver load. Research has demonstrated that high levels of stress are frequently experienced by those who care for people with epilepsy, which can have a negative impact on relationships, mental and physical health, and general quality of life. Factors that can reduce caregiver stress and enhance these caregivers' general well-being must be identified.

It has been demonstrated that one such element that is essential to reducing caregiver stress is Perceived Social Support. The degree to which people believe that others care about, support, and value them is known as Perceived Social Support. The burden of caregiving is lessened and caregivers are more prepared to handle its demands when they feel supported by their friends, family, and community. However, little is known about the connection between Caregiver Burden and Perceived Social Support in CAREGIVERS of epileptic patients.

The purpose of this study is to investigate the connection between Caregiver Burden and Perceived Social Support in CAREGIVERS of individuals with epilepsy. The purpose is to better understand the elements that lead to Caregiver Burden and pinpoint possible

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intervention targets by observing this relationship. The ultimate goal of this research is to guide the creation of therapies and support services that can lessen the burden on Caregivers and enhance the general well-being of families with epilepsy.

The results of this investigation will add to the current quantity of knowledge about Perceived Social Support and Caregiver Burden. For medical experts, social workers, and other specialists who assist families with epilepsy, the findings will also have real-world applications. By understanding the connection between Caregiver Burden and Perceived Social Support, these experts can create interventions and support services that better meet the specific requirements of these families.

Statement of the Problem

There was a research gap regarding the relationship between Perceived Social Support and Caregiver Burden in CAREGIVERS of epileptic patients. The relationship between Perceived Social Support and Caregiver Burden in CAREGIVERS of epileptic patients is not well understood. It's unclear how Perceived Social Support affects caregivers' stress and wellbeing when it comes to caring for people with epilepsy. Social support plays a very important role in the lives of patients, especially those having serious mental conditions. Caring for patients with chronic medical and psychiatric disorders is associated with significant burden. Caregivers of patients with epilepsy experience a significant burden while caring for their relatives (Nilufer , Ali , & Deuri, 2015).

Objectives

To determine the relationship between Perceived Social Support and Caregiver Burden in CAREGIVERS of epileptic patients

Hypothesis

There is a significance relationship between Perceived Social Support and Caregiver Burden in CAREGIVERS of epileptic patients

Conceptual Model of the Study

REVIEW OF THE RELATED LITERATURE

Epilepsy

One of the most common neurological conditions in the world is epilepsy. However, even the World Health Organization (WHO) which estimated that there were over 50 million infected people globally in 2004, does not inspire total trust. Furthermore, the percentage of patients with active epilepsy (AE), a category that would need medical intervention, is unknown. According to the International League Against Epilepsy and the International Bureau for Epilepsy (IBE),

—epilepsy‖ and —epileptic seizure‖ are two different things. A brief episode of symptoms initiated by abnormal severe, or extreme synchronous movement in your brain's nerve cells is known as an epileptic seizure. In contrast, epilepsy is a brain disorder categorized by persistent epileptic seizures. This illness affects several areas of the brain in addition to the frequent seizures, which can result in a range of medical, cognitive (related to thinking), psychological, and social problems. To be diagnosed with epilepsy, a person must experience at least one epileptic

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episode. (Fisher , et al., 2005).

There are about 50 million people universally, and 80 percent of them live in developing regions. Epilepsy is a long-term condition that impacts the patients as well as their entire family. An individual is diagnosed with epilepsy if two or more unprovoked seizures take place more than twenty-four hours apart. The brain's irregular electrical activity causes seizures which can manifest in several ways, including tonic-clonic activity of one or more limbs, staring, blinking of the eyes, unexpected jerks, and sudden loss of tone that results in falls. They may also manifest as a sensation that the patient perceives as abnormal. Some people continue to have frequent seizures even after receiving the best anti-seizure medication; however, within five years of diagnosis, more than 70% of patients who get treatment experience long-term remission or seizure independence. Seizures are typically brief, lasting 1 to 2 minutes, but some can be prolonged, lasting more than 5 minutes, in which case the patient is diagnosed with status epilepticus (Al-Thaqib, Raidah Saleem, & Bashir, 3-2018).

According to this process, a particular combination can cause a seizure to occur easily even when there is no known reason in or around the central nervous system (brain and spinal cord). According to studies, it is more prevalent among elderly persons, who are more likely to experience stroke, brain degeneration, and other health issues. Instead of having generalized seizures that impact the entire brain, nearly as many kids have localized seizures that only occur in one area of the brain. The features of a community and the extent of medical examination determine the underlying etiology of epilepsy. In high-income countries, however, even after review, all but half of the instances will lack a known cause. Epilepsy has a usually favorable prognosis, in that the majority of individuals with this diagnosis will be able to live lives free from seizures. The frequency of epilepsy is comparable in high-income and low-income nations, and many individuals with the disorder do not receive the appropriate care. The prognosis of epilepsy is generally good, in that most people with this diagnosis will be able to live seizurefree lives. High-income countries have epilepsy rates similar to low-income countries, where many people with the condition do not get proper treatment. These similarities could occur from false positives, transient disease resulting in seizures, and/or a higher rate of death found only in some areas. Roughly 50% of epileptics can remain seizure-free for an extended period.

Variability in these patterns has been reported in recent studies on the long-term outcomes of epilepsy; some patients exhibit remission episodes early in the course of their condition, while others relapse and resize during the condition or change from an expanding pattern to one that features period's assaults once more (55-59). The age, seizure type, and underlying cause all affect the lifetime risk of death for those with epilepsy. In general, epilepsy as a condition carries a minimal risk of death. People with nocturnal epilepsy, drug refectory(treatment-resistant) epilepsy, and generalized tonic-clonic seizures are far more likely to experience sudden unexpected death from epilepsy (Beghi, 2020).

Incidence of Epilepsy

From 1935 until 1984, a study was led in Rochester, Minnesota, USA to regulate the prevalence of epilepsy and all unprovoked seizures in the local community. After adjusting for age, the incidence rate of epilepsy was 44 out of every 100,000 person-years. Men have a considerably greater incidence rate than women. The incidence peaked in the first year and was extreme in those 75 years of age or older. Two-thirds of newly diagnosed epilepsy cases had an unidentified cause, and 60% of these cases included partial seizures. The most frequent cause, representing 11% of the cases, was cerebrovascular illness.

In 8% of the circumstances, neurologic abnormalities from genetics, mental obstacles,

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and/or cerebral palsy were the second most prevalent prior conditions. The increasing rate of epilepsy was 3.1% by the age of 74. The age-adjusted occurrence rate was 61 out of every 100,000 person-years for all unprovoked seizures. Like epilepsy, there were patterns in the occurrence of unprovoked seizures by age and gender, but a higher proportion of these people experienced generalized onset seizures for which there was no known cause. The increasing incidence of all unprovoked seizures was 4.1% at the age of 74. With time, the prevalence of epilepsy and spontaneous seizures reduced in children but enlarged in the elderly. (Hauser,
Annegers, & Kurland, 1993).

Every year, there are between 29 and 39 cases of acute symptomatic seizures for every 100,000 people. These seizures are most common in men, older persons (over 65), and very young children (less than 12 months old). One symptomatic seizure can occur anywhere between 23 and 61 times per 100,00 person-years. Similar to epilepsy, these symptomatic seizures are most common in men, younger persons, and the elderly. There are few studies on the mortality rate specifically linked to acute symptomatic seizures. However, those who experience one unprovoked seizure have a standardized mortality ratio (SMR) of 2.3, meaning that their risk of dying is more than twice that of the general population. (Hauser & Beghi, 2008).

Prevalence of Epilepsy

To define the prevalence of epilepsy throughout a lifetime (LTE) and the quantity of individuals with active epilepsy (AE), researchers examined internet databases and chose pertinent publications based on predetermined standards. They employed statistics techniques to determine the average prevalence in industrialized nations as well as in developing nations' urban and rural areas. They also examined the impact of various study features on the occurrence estimations. The frequency of lifelong epilepsy (LTE) in wealthy nations ranged from an average of 5.8 out of 1000 (the 5th to 95th percentile range is 2.7–12.4). With large variations, the average LTE popularity in developing nations is higher at 15.4 per 1000(From 4.8 to 49.6) in rural regions and 10.3 out of every 1,000(2.8-37.7) in urban areas.

In affluent nations, the average prevalence of active epilepsy (AE) was 4.9 out of every 1,000(2.3-10.3); in poor nations, it was 12.7 out of every 1,000(3.5-45.5) people in rural regions and 5.9 out of every 1,000(from 3.4 to10.2) people in urban areas. These estimates put the overall number of LTE users in industrialized nations between 3.2 and 14.7 million, or roughly 6.8 million. The estimate for AE ranges from 2.7 to 12.2 million, with an average of 5.7 million.

The predictions for developing nations are significantly higher; 45 (14-145) million with LTE and 17 (10-133) million with AE in rural regions. About 17(from 5 to 61) million people in developing cities have LTE, and 10 (from 5 to 17) million have AE (Ngugi, Bottomley, Kleinschmidt, Sander, & Newton, 2010).

Prevalence rates were greater in studies focusing exclusively on grownups or all age groups than in research on children. In smaller studies and rural locations, higher prevalence rates were also seen. The prevalence of epilepsy is estimated worldwide by this research, which also emphasizes the need for treatment for the large number of individuals who have active epilepsy, particularly in emerging nations.

According to the prevalence surveys, there are four to ten cases of active epilepsy for every 1000 people in wealthy nations. 4 to 7 cases per 1,000 people are the typical prevalence reported in most research. According to a methodical analysis, the occurrence of active epilepsy in Europe ranges from 3.3 to 7.8 cases per 1,000 persons, with a median of 5.2

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cases. Italy has the lowest recorded prevalence rates,3.01 per 1,000 on the Aeolian Island and 3.3 per 1,000 in Sicily. The authors of this research hypothesize that these lower rates could be explained by the stigma associated with epilepsy and the subsequent desire of those affected to conceal their condition to avoid social repercussions.

Recent research from Norway and Ireland raises the possibility that prevalence rates in Western nations may be greater. In Norway, the incidence of crude prevalence was 11.7 out of every 1,000 people, whereas the rate of epilepsy was 6.7 out of every 1,000 people. In Ireland, treated epilepsy accounted for 8.3 to 9.0 per 1,000 people, with a lifetime frequency of 10 per

1,000. In affluent nations, the estimated lifetime prevalence (Neligan & Sander, 2009) (Neligan & Sander, 2009)nce of epilepsy ranges from 2.7 to 12.4 out of every 1,000 people. The median prevalence is 5.8 per 1,000 people. With a range of 2.3 to 10.3 per 1,000, the average prevalence of active epilepsy is approximately 4.9 per 1,000.

According to a 2011 survey research conducted in Italy, the raw incidence of epilepsy was 7.9 per 1,000 people, with men having a slightly higher rate (8.1) than women (7.7). The age group under 25 and the age group 75 and above had the highest occurrence. The chance of having a non-febrile epileptic attack at some stage in one's life is known as the lifetime prevalence of seizures, and it ranges from 2% to 5%. The inconsistency between the lifespan prevalence and the occurrence of active epilepsy indicates that most individuals with the disorder either experience remission or pass away. Studies conducted in the community have revealed that 70-80% of epileptics will experience remission, typically at an early stage of illness. However, the longer the epilepsy remains, the poorer the prognosis becomes (Neligan & Sander, 2009).

With the new definition of epilepsy, the estimated 50 million people worldwide who suffer from the ailment are projected to increase. It is believed that approximately 9.99 out of every 1,000 people in Pakistan suffer from epilepsy, despite the lack of comprehensive studies in this area. Individuals under 30 exhibit the highest incidence. Accordingly, about 2 million individuals in Pakistan suffer from epilepsy, accounting for roughly 10% of the condition's worldwide prevalence. There are now more than 180 million people living in Pakistan.

Incidence and Prevalence of Epilepsy by Sex and Age

Men are more likely than women to have epilepsy. The discrepancy might result from racial variations in the risk factors for epilepsy or from certain cultures' tendency to hide seizures in women. The risk of epilepsy is higher in those over the age of eighty and in newborns. About 86 out of every 1,000 babies have epilepsy diagnosed during their first year. Among people aged 30-59, rates are approximately 23 to31 per100 thousand. Yet, broken down by those over 85 it rises again to around 280 per 100,000. The incidence of epilepsy in children drops to that of adults by the time a child reaches ten years old. The largest burden of epilepsy is in children living in low-and middle-income states (LMICs). It might be because of low awareness and diagnosis of the disease in older people or the young population structure there.

Perceived Social Support

One theory of social support, for example (Cohen & Wills, 1985)includes various components -- informational, emotional, and functional support. This study adopts their theory and operationalizes these dimensions as follows.

Informational support involves the receipt of information, advice, or feedback. Becoming that pillar of emotional support is a process like emotionally listening, caring assuring, and

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respecting the trust someone puts on.

Functional support is a counseling and time and assistance provision to those who have trouble managing the challenges.

Social support is a reciprocal process through which information sought and provided by individuals during the experience of an event may vary with context. It is a form of support that varies in the way it is provided, from case to situation, and is negotiated always between the providers and recipients.

One of the most important effects of the presence or absence, size, and ―strength‖ involving a person's social system, is about facing difficult life situations. Meaningful connection is imperative when battling a chronic illness, and all variations of social support are key to lowering stress during difficult times (K€ahkonen, Kankkunen, Miettinen, Lamidi, & Saaranen, 2017).

The researchers rigorously examined the connotation between Perceived Social Support and academic, behavioral, and social outcomes. They systematically compared levels of social support and their well-being results in students. A critical examination and comparison of some traditionally used methods to measure social support was undertaken, leading to valuable knowledge about the impact upon students when low versus high levels of support are present.

This study, (Demaray & Malecki, 2002) examined Perceived Social Support in two formats: as a continuous and discontinuous variable—low, average, or high. Practical implications of the study for administering and scoring the Child and Adolescent Social Support Scale (CASSS) are defined utilizing dividing students into low, average, or high perceived support. For example, the paper indicates key thresholds between what children with differing perceptions of support do and don't look like in different academic, behavioral, or social outcomes. The interest is in how these levels of perceived support are associated with the presence (or absence) of positive and negative outcomes.

Perceived Social Support is the degree to which people believe they are respected, cared for, accepted, and involved in an open communication relationship. It is the belief that one can get social support from people in their social network. Social support refers to helping people overcome challenges, defend themselves, and enhance their health. Previously, social support was thought to be a one-dimensional term. However, some researchers discovered that it is multi-dimensional. Perceived Social Support measures a person’s sense of value, care, acceptance and open communication (Hina , 2021).

Since then, social support has been well-defined in many ways over the years. The current study aligned with the broad theoretical perspective presented by Tardy (1985) for operationalizing social support. Tardy proposed a five-dimensional model of social support consisting:

Direction: Turning this about whether the support is being provided or received.

Disposition: are supportive behaviors on offer or only selectively deployed

Description/Evaluation: This asks whether the individual is asked only to describe what support they receive or also evaluate its effectiveness. Content—the type of support offered is emotional, instrumental (such as help with a physical task), information-based appraisal streaming from peers; and Network which is a family, workmates, or peers who provide social and emotional support.

Social support in this study refers to the individual-level perception of general (felt) or specific supportive behaviors from individuals within one's social network. The purpose of this support is to strengthen their functionality or protect them from adverse consequences. This definition is broad and includes emotional, instrumental, informational, as well as appraisal support. The concepts of social support and the Tardy

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model used in this study were implemented to develop the Child and Adolescent Social Support Scale (CASSS) for diagnosing and measuring crude measurement social assistance outperformed by studies.

Perceived Social Support is the cognitive perception that everyone has formed dependable bonds with others and that others support them. Provided social support refers to the behavior and actions others exhibit; in other words, it is regarded as a behavioral assessment of support. In those senses, social support is an individual's self-evaluation. It is argued that people who are loved and wanted in different aspects of life and who seek support when they need it are more satisfied with their close relationships and feel that they are supported by others (Kaya, Akgemci, & Celik, 2012).

Social exclusion occurs and links with friends or donating increased time to relationships can be poorer which is induced by epilepsy. Yet social interactions that promote supportive actions and behaviors can be beneficial. They offer encouragement and bond people to share positive experiences as well as give comfort when things are not going right. That often means managing medications, which might mean helping someone with epilepsy keep up their treatment. Studies have found that social support, particularly in the area of adherence to medical management regimes is associated with better self-management and less variability across outcomes in epilepsy. Additionally, it is known that supportive relationships can improve the quality of life (QOL) in People with epilepsy. In other words, better mental health is also strongly linked to the QOL. Also, persons with epilepsy who feel more socially comfortable experience a higher QOL (DiIorio, Whatley, & Yeager, 2010).

Social support is the perception of how much others can provide help to an individual through interpersonal relationships and social networks, a belief that they are cared for by interpersonal begins (Wang, Mann, Lloyd-Evans, Ma, & Johnson, 2018).

The human reaction to challenges, whether they be disease or natural disaster, is straightforward; social support from family or friends protects every threatened individual (every single case of low weight at birth) against a wide array of health problems: arthritis and tuberculosis as well as depression and alcoholism up to mortality itself!)…and presumably protection includes morbidity…like handy household servants who manage just about everything within reach so-to-speak—making homemade mayonnaise for school lunch sandwiches—or drill machine gun posts during insurrection. Moreover, social support can reduce medication requirements as well as lead to faster recovery and adherence (Cobb, 1976).

Students' need for social support is a acute area in the context of learning and teaching where ―the function of social support is linked to the increase in goal mastery and the subsequent critique of perceived inadequacies‖. Generally, social support remains a critical position for students because it helps them get motivated, cooperate, and adapt to the school. Simultaneously, the minimum necessary amount of social support that ensures the student with a feeling of security and acceptance is different for all students. In the context of real learning, a measure of a student's need for social support and the ―worthiness‖ of such support from a student are the parameters of the position of the available social support. It mentioned that ―the correlational research suggests that the more the students' feeling of self-worth is tied directly to their performance outcomes, the higher the satisfaction they obtain from learning they can do well with minimal help‖. In other words, social support, including well-meaning support in the form of ―high-level directive‖, or feedback on performance updates or help on homework, may be perceived as a sign of the teacher's or group members' low regard for the person's abilities. Students may reject even well-meaning well-functioning support if it is perceived as something that should be

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obtained by someone who is ―needed‖ for the schoolwork. Thus, students who regard social support as ―crucial for schoolwork‖ and who feel satisfied with the support are likely to talk about the school as supportive of learning. ―As a rule, this group of students achieves higher happiness indicators in the school culture and higher satisfaction indicators for the school system, which leads to a higher well-being declaration‖. In contrast, students who are

―in need of support‖ but are dissatisfied with the school support they receive, will display low well-being reports (Vedder, Boekaerts, & Seegers, 2005)..

Social support is characterized as having individuals throughout your life you can trust, who demonstrate they give a second thought about your esteem and love. Social support has been classically conceptualized in two essential dimensions: structural and functional. The structural dimension concerns the size, composition, and intricacy of your social network. The functional field addresses the various forms of assistance that can be provided or are available (e.g., emotional, instrumental, and informational support) or exchange conditions.

Secondly, the function of social support takes place in two forms: perceived and received. Perceived support concerns how much he or she feels supported if needed, enough to be satisfied, as well as the quality of this available support. In contrast, received support refers to the concrete assistance provided and how often particular types were made available.

Social support can take several forms, such as offering practical assistance, tying a person to a system of social protection and love, or encouraging loyalty to a respectable social organization. As per this idea, societal support encourages putting out seen as both perceived and given social support. Research on this topic has shown a tendency to focus on people's perception of how supportive social interactions are, or how they are regarded. Perceived Social Support is the amount of support or lack thereof that an individual feels from their social network. Perceived Social Support refers to an individual's evaluation of the level of support provided by their social network (Driscoll , Brough, & Kalliath, 2004). Literature over the last three decades has certainly agreed that social support is beneficial for both psychological adjustment and health/well-being. Despite these results, we still know remarkably little about how social functioning operates or by what mechanisms it secures its advantages (del-Pino-Casado, Ruzafa-Martnez, Fras-Osuna, Palomino-Moral, & Ramos-

Morcillo, 2018).

Every relationship that is important in the life of a person and one who gives emotional support, physical help, or mental assistance when required comes under the head of Social Support Systems. It keeps away from the systems of bodies to not be in a proper working state. Social support is known to protect physical health as well as bounce overall function and wellbeing, reflecting the degree of availability of family or relatives helping their older ones in times they need it (Kahriman & Zaybak, 2015).

Social Support Theory

Social support theory proposes that social support from family, friends, and the community can have a positive influence on an individual's physical and mental health by helping them cope with stress, anxiety, and other negative emotions. Social support theory suggests that encouraging compassion, volunteerism, and kindness are significant cultural ideals (Butler, 2018). According to the current study, social support theory suggests that social support from friends, family, and other social networks can be extremely important in reducing caregiver stress and enhancing the well-being of those who take care pf people with epilepsy.

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Caregiving burden

Each person has different psychological and social factors that affect how stress influences their health and well-being. The caregiver's personal traits, the needs of the person they're caring for, their shared past, and the social, economic, and cultural environment all shape the variety of stressful situations they may face and how they deal with them. Despite this complexity, there are some common sources of stress that many caregivers experience, such as a decline in self-esteem and emotional health.

People usually have multiple roles in life, like being a family member or an employee. When someone becomes a caregiver for a child with a long-term disability, this adds another role to their life, requiring them to adjust their priorities and shift their focus. This new responsibility can cause stress not only on a personal level but also in relationships with others connected to them through their other roles. These people might react negatively because the caregiver's attention and time are now more focused on caregiving. Most research tends to focus on the stress caused by directly providing care. However, as pointed out by Aneshensel et al. (1995), it's important to also consider stress from the larger social environment in which the caregiver lives. This helps to fully understand the range of stress and its effects on caregivers.

The strain that caregiving can put on a person's health is illustrated by a well-known case in Canada, called the Latimer case. In this case, a father killed his disabled daughter. He explained his actions by saying that the stress of caring for her, the pain she was in, and his hopelessness about her future led him to do it. This case sparked a lot of debate between two groups: one that advocated for the rights of people with disabilities, and another that believed "mercy killing" or assisted suicide can be justified in certain situations.

The Supreme Court of Canada eventually ruled on the case, charging the father with second-degree murder and sentencing him to 10 years in prison. The court reinforced the idea that every life, whether disabled or not, should be treated equally and protected by the law.

Interestingly, public opinion did not support the court's decision. Most people who were asked felt that the father's actions were understandable, given the challenges of his daughter's disability. This reaction highlights how many people view caring for a disabled person as an overwhelming and possibly unmanageable burden, to the point that some believe it might not always be worth the effort.

Caregiver Burden is a multidimensional reaction to the unfavorable assessment and perceived strain that accompanies providing care for an unwell person. The functional, emotional, psychological, and physical well-being of caregivers is at risk. Caregivers frequently suffer from depression, engage in maladaptive coping strategies, and voice concerns about their
low quality of life. (Kim, Chang, Rose, & Kim, 2012).

A study that used qualitative methods discovered that some characteristics related to caregiving were linked to burden, such as the kinds of tasks that need to be completed, the degree of support, and the capacity to handle the care recipient's worries. It has been demonstrated that vulnerable caregivers who lack access to services for support are more likely to feel stress than those who have access to such resources. (Sussman & Regehr, 2009).

The burden of eldercare is growing for informal caregivers who also work in the Western world. This is because populations are getting older (OECD/European Commission, 2013; The
World Bank, 2017), and people are retiring later in life (Yeandle & Buckner, 2017). In

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England,

65% of people aged 65 and older who need help with daily tasks (known as Activities of Daily

Living or ADLs) rely entirely on informal caregivers. For more complex tasks, called Instrumental Activities of Daily Living (IADLs), like managing finances or cooking, 74% of older people rely on informal caregivers (Health and Social Care Information Centre, 2017). Informal caregivers are unpaid individuals, usually family members or friends, who provide care while also managing their own paid jobs.

In Occupational Health Psychology (OHP), most research has focused on caregiving for children or the balance between work and family life in general, rather than on eldercare specifically (Calvano, 2013). However, more studies are now being done on working informal caregivers of older people, though these studies come from different fields, so the information is scattered. To better understand the challenges of eldercare, it's important to look closely at how these caregivers manage both their caregiving duties and their jobs, and how this affects their work, health, and well-being.

Bringing together the research from these different fields could help create a clear framework for OHP. This framework would guide future research and help organizations support working caregivers. By doing so, they can make informal eldercare more sustainable while helping caregivers maintain their jobs.

The Organization for Economic Co-operation and Development (OECD) defines eldercare as a type of long-term care that involves helping older adults with daily tasks like bathing, getting dressed, and other personal care activities. It also includes helping with household chores such as cleaning and cooking, as well as providing certain types of medical care.

In the past 30 years, caregiving has become an important topic in research and public health. Caregivers play a key role in health and social systems by helping people with disabilities and taking care of older adults. For example, in the UK, over one million individuals spend at least 50 hours a week caregiving. In the USA, the worth of caregiving by family members was likely at $450 billion in 2009. Since most caregiving happens informally, without being part of the formal care system, many low-income countries don’t have good data on how much

caregivers contribute.

Several factors highlight the rising importance of older grownups as caregivers. By 2050, the worldwide number of people aged 60 or older will multiply. This means not only will there be elder people who need care, but also older adults who will become caregivers themselves. It’s

becoming more common for people in their 60s and 70s to care for parents aged 90 or older.

Changes in health systems, like shorter hospital visits and less finance for home and community care, are also putting more pressure on informal caregivers. In addition, smaller family sizes, changing cultural traditions, and more people moving away from their caregivers mean there are fewer family members available to help with care. As a result, caregiving responsibilities will fall on fewer people, with spousal care making up a larger share of informal care.

Lastly, medical advances have extended the lives of people with disabilities, meaning that children born with disabilities may now live longer than their parents, increasing the long-term caregiving demands.

This is the second of two reports that go along with the main study called Caregiving in the U.S. 2015. This report focuses on 1,087 unpaid family Caregivers who look after adults aged 50 and older. The first report, Caregivers of Younger Adults: A Focused Look at

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Those Caring for Someone Age 18 to 49, focuses on caregivers of younger adults.

RESEARCH METHODOLOGY

Research Design

Quantitative study was used to examine the relationship between Perceived Social Support and Caregiver Burden in caregivers of epileptic patients. The current study was conducted using a correlational research design.

Population

As part of the study, we collected data from two hospitals in two months: DHQ Hospital and Parveen Akhtar Hospital. The aim of the research was to identify patients who are epileptic and then gather valuable insight from their Caregivers. Within two months, we identified 15 patients and then we approached their caregivers who willingly participated in the study. Through in-depth interviews and surveys, we collected data from the caregivers, focusing on their experiences, challenges, and perceptions of caring for a loved one with epilepsy. This data will help us better understand the impact of epilepsy on caregivers and identify potential areas for support and intervention.

Sample

The objective of this study was to examine the experience of primary caregivers of patients diagnosed with epilepsy in Kotli Azad Kashmir. A total of 15 caregivers were taken for this study who have been taking care of their epileptic family members for at least six months. Caregivers are aged between 25 to 60 years, regardless of gender. The study aimed to better understand the challenges and needs of primary caregivers of epileptic patients in Kotli.

Research Instruments

Data was gathered from the participants using a questionnaire that contained two scales. The Multidimensional Perceived Social Support (MSPSS) and the Zarit Burden Interview(ZBI-
12).

Data Collection

As purposive sampling was used for this study, the researcher approached the participants by visiting hospitals where epileptic patients were receiving treatment and then invited them to participate in the study. Firstly, the researcher clearly explained the purpose of the study to the participants. Ethical considerations were kept in mind, informed consent was obtained from the participants, explaining the goals, and advantages of the study along with their rights and confidentiality. After the briefing, the researcher provided the questionnaire to the participant to fill out and after completion, the questionnaire was taken back. Data collection for this study was conducted using quantitative methods, and purposive sampling was used. A standardized questionnaire was used to gather data on Caregiver Burden and Perceived Social Support. Every interview was transcribed for analysis after being recorded.

Data Analysis

Data collected from the participants was analyzed using a statistical package for social sciences(SPSS). Pearson correlation analysis was used to find out the relationship between Perceived Social Support and Caregiver Burden among caregivers of persons with

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epilepsy.

RESULTS

The study examined the relationship between Perceived Social Support and Caregiver Burden in caregivers of epilepsy patients. The data presented in the paper were based on descriptive and statistical analyses. Descriptive analyses in the form of Pearson correlation coefficients were used to examine the nature of the relationships between the variables; Perceived Social Support, and Caregiver Burden. The findings suggest that Perceived Social Support plays a crucial role in reducing Caregiver Burden among CAREGIVERS of epilepsy patients. In more detail, this chapter takes out the significance of these findings for future evaluation of the relationship between Perceived Social Support and Caregiver Burden in caregivers of epilepsy patients.

Table 1 Descriptive statistics

Variables	N	Min	Max	M	SD
PSS	15	24.00	43.00	34.46	4.96
ZCB	15	11.00	18.00	15.00	2.00
Valid N	15				

Of 15 people with epilepsy family caregivers, the score of Perceived Social Support was 34.46 ±4.969 indicating that, on average participants perceive a low level of support and the total score of Caregiver Burden was 15.00 ±2.00 indicating a relatively moderate level of Caregiver
Burden.

Table 2 Descriptive Statistics and correlation

Variables	N	M	SD	1	2
1. MSPSS	15	34.46	4.96	-	
2. ZBI	15	15.00	2.00	-.783**	-

**. Correlation is significant at the 0.01 level (2-tailed).

The Pearson correlation coefficient (r=-.783**, p=0.001) indicates a negative correlation between Perceived Social Support and Caregiver Burden in caregivers of epilepsy patients. This suggests that the relationship between Perceived Social Support and Caregiver Burden is
statistically significant and reliable.

DISCUSSION

The findings of this study suggest that there is a significant relationship between Perceived Social Support and Caregiver Burden in caregivers of epilepsy patients. Caregivers of patients with epilepsy experience a significant burden while caring for their relatives. Hypothesis
H1 is accepted: There is a significant relationship between Perceived Social Support and Caregiver Burden in caregivers of epileptic patients. The existence of social support is

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valuable for parental well-being, regulation, and caregiving. Social support in different areas of parenting and caregiving disturbs the numerous areas of caregivers' burden. However, it has been proven that social support directly affects the burden on the caregivers. Social support assists as a source that reduces parenting stress and burden; afterward, applies beneficial effects on caregiving
(Nilufer , Ali , & Deuri, 2015).

With a mean score of 34.46 (SD = 4.96), which ranges from 24 to 43, the results show that participants reported low levels of Perceived Social Support (MSPSS). On the ZBI 12-item scale, on the other hand, caregivers reported comparatively moderate burden, with a mean score of 15.00 (SD = 2.00), which ranged from 11 to 18. This implies that the stress of caregiving may be lessened by the Perceived Social Support, underscoring the significance of social support networks in reducing the adverse effects of caregiving.

For the hypothesis test, our p-value is 0.001. This p-value is less than any reasonable (0.01) significance level. Consequently, we can reject the null hypothesis and conclude that the relationship is statistically significant. Hypothesis H1 is accepted. There is a significant relationship between Perceived Social Support and Caregiver Burden in CAREGIVERS of epileptic patients. A higher level of family agreement, care management self-efficacy, and a wider family support network were linked to less burden. A significant interaction between functional dependency and family agreement was found; the relationship between Caregiver Burden and caregiver-recipient functional dependency was moderated by a greater level of family agreement (Casado & Sacco, 2012).

The participants in this study generally reported a low level of Perceived Social Support and a moderate level of Caregiver Burden. These results are also consistent with the study which found that most caregivers for children with chronic illness face a modest to moderate burden (Hajbaghery & Ahmadi, 2019).

Limitations

This study focuses on primary caregivers for family members with epilepsy, including parents and spouses. Secondary caregivers, such as siblings or friends were not included. To participate in this study, caregivers need to be between the ages of 25 to 65. This implies that caregivers under the age of 25 or over the age of 65 were not included. This study is based on a small sample with on 15 participants which allows us to provide individualized care to every individual but research findings may not be generalized to wider population. The current study uses self-report measures, including surveys and questionnaire, to collect data from participants as opposed to observational or objective measures. The analysis only utilizes the Multidimensional Perceived Social Support scale(MSMSPSS) and Zarit Caregiver Burden Interview(ZBI) as measured methods which limits the analysis to specific variables and interactions. Acknowledging these limitations will help to understand the study's findings within these boundaries.

Conclusion

Perceived Social Support from family was associated with caregivers' burden in this study. The results of this study indicates that there is significant relationship between Perceived Social Support and Caregiver Burden in caregivers of epileptic patients. Social support playing an important role in reducing the stress and burden associated with caregiving**.** These findings highlight the value of social support in reducing Caregiver Burden and enhancing caregiver wellbeing. Healthcare providers can help reduce the burden of caregiving and enhance the overall quality of life for patient and caregivers by offering education, training, and support to caregivers. The study's findings also mention that

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healthcare administrators give priority to the development of interventions and support services for caregivers of epileptic patients.

Recommendations

Healthcare providers and support service must help caregivers of epileptic patients with emotional and practical needs.

Develop and implement powerful interventions, including support groups and counselling, that considerably increase Perceived Social Support to sustainably reduce Caregiver Burden and improve well-being.

Caregiving responsibilities and emotional support should be shared among several family members to reduce the large burden on a single family caregiver.

Effective communication among at least three family members is necessary. Each member should share their feelings, concern and needs. This process will guarantee that all family members are in agreement and cooperate to support both the caregiver and the patient.

Further research could examine the value of at least several interventions designed to increase Perceived Social Support in order to reduce Caregiver Burden, along with improving the well-being of an important number of CAREGIVERS of epileptic patients

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