Caregiver Burden in Major Depression: A Single Case Study

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Area/Section: Health Science **Type of the Paper:** Review Paper

Type of Review: Peer Reviewed as per COPE guidance.

Indexed in: OpenAIRE.

DOI: https://doi.org/10.5281/zenodo.14854327

Google Scholar Citation: IJHSP

How to Cite this Paper:

Sindhu, C.V. & Dr. Devaseelan S. (2025). Caregiver Burden in Major Depression: A Single Case Study . *International Journal of Health Sciences and Pharmacy (IJHSP)*, 9(1),1-11.

DOI: https://doi.org/10.5281/zenodo.14854327

International Journal of Health Sciences and Pharmacy (IJHSP)

A Refereed International Journal of Srinivas University, India.

Crossref DOI: https://doi.org/10.47992/IJHSP.2581.6411.0127

Received on: 18/01/2025 Published on: 12/02/2025

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Caregiver Burden in Major Depression: A Single Case Study

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ABSTRACT

Purpose: Major Depression is an enervating mental health ailment that touches millions of human beings worldwide. It has been confirmed that major depression has negative effects on patients, but less is shown about how it affects their carer, particularly their spouse. This unique case study looks at the encounters of a woman spousal caregiver and assesses the carer's pressure using the Zarit-Burden Interview (ZBI) scale.

Design/Methodology/Approach: The study's primary focus was on a single case, a female caregiver, who provided care to her husband diagnosed with Major Depression for the past five years. In-depth talks were done to collect detailed information concerning her caregiving experiences, emotional health, and the difficulties she faced, The ZBI tool was also used to quantify the perceived strain of the caregiver.

Findings/Result: The scale yielded a score of 71, indicating heavy stress on caregivers. This study also explored an extensive caregiving experience marked by role stress, emotional discomfort, and social isolation. The caregiver reported feelings of guilt, exhaustion, and helplessness, which significantly affected her overall quality of life. This result highlights the significant influence of caregiving on the life of female spouse carer.

Originality/Value: This unique case study highlights the often-overlooked aspect of caregiver load in the context of Major Depression and addresses the significance of a caregiver's well-being within the broader mental framework of healthcare.

Paper Type: Single Case study

Keywords: Major Depression, Caregiver Burden, Female Caregiver

1. INTRODUCTION:

Major depression also noted as clinical depression, is among the most prevalent mental diseases and the main cause of disability worldwide. WHO. (2010). Almost 30% of the world's population gets mental illness in any given year. It makes up around 20% of the nation's total population. WHO. (2020)

Carers of relatives with mental ailments who have the bulk of caregiving responsibilities often experience a wide range of burdens that lead to poor health and ruined family life. Studies conducted by Walke et al. (2018). [1] concluded that 40.9% of the carers had severe burdens while 59.1% experienced mild to moderate burdens. A similar study conducted by Stanley et al. (2015). [2] on spouses of psychotic patients reported that spouses as caregivers had severe to extreme depression and anxiety associated with increased stress owing to the load of care. In India, the overall caregiver burden for spouses was 54%, and a majority had experienced severe to extreme severe burden. Stanley et al. (2015). [2].

While limited research has consistently confirmed the burdens faced by family caregivers of mentally ill relatives, little is known about the potential differing impacts of disorders with emotion on the quality of that burden. The assistance that family members render to mentally ill patients is claimed to be misery

from the hardships that a caregiver bears. The requirements of the carers are not deemed to be crucial in India's existing healthcare system. Collaboration of members of the family for patient care with chronic illnesses is crucial to give a cornerstone of helping hands for them. Stanley et al. (2015). [2].

The family's emotional bonds were disrupted and eventually became emotionally detached because of caring for her husband with severe psychological issues. Emotional weariness results from poor supportive services, despite the carers' valiant efforts to safeguard their families. The Loss of identity results from caregiving duties interfering with their numerous other obligations and serving as a resource for family issues. Because they had to adjust to a caregiver job without any help, they went through psychological distress. Awad & Voruganti. (2008). [3], & Östman & Hansson. (2004). [4].

The theoretical basis for the consideration of the care circumstances has been explained in the Transactional Model of Lazarus & Folkman. (1987). [5]. The Transactional Model illustrates how the carer evaluates stress and available resources to manage stressful situations. The main evaluation addressed the unique significance of a particular stressor, in this example, the care arrangement. The caregiver's resources and talent to handle these circumstances were examined in the secondary appraisal. Based on this, the carer employs coping mechanisms to manage the stressful circumstances.

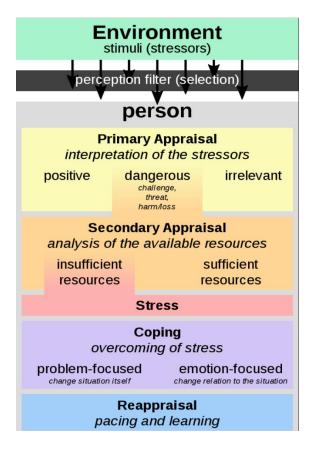


Figure 1: Richard Lazarus Transactional Model of Stress and Coping

2. OBJECTIVE:

The researcher was interested in getting to know the female caregiver burden by using only one case study.

3. REVIEW OF LITERATURE/ RELATED WORKS:

Table 1: Summary of literature review

Sl. No	Area & Focus of the Research	The result of the Research	Reference
1	Using a sample of 283 senior spouse carers, this study investigated gender differences in the perceptions of primary and secondary caring stressors, indicators of depression, and their relationship with each other.	Findings reveal that, even if reports of stressors associated with caregiving may differ across men and women, the complexity of the experience seems to be rather consistent for both.	[7] Bookwala & Schulz. (2000).
2	The purpose of this study was to compare the hardship that carers of individuals with mood disorders and schizophrenia, as well as to identify the connection between stigma and carer burden.	Findings show that, compared to affective diseases, the carer burden for schizophrenia was substantially higher. The burden faced by female care providers was noticeably greater than that of male carers. 22% of the variation in carer burden was predicted by the diagnosis, the caregiver's gender, and stigma, with gender being a significant predictor.	[8] Fernando et al. (2017).
3	To assess the effects of service changes in situations where standards of caretaker functioning	Despite progress in policy and services, negative caregiving experiences persist, and carers continue to face significant challenges in supporting individuals with mental illness.	[9] Hayes et al. (2015).
4	This piece of work discusses how delivering care for someone with a mental or physical illness can impact the caregiver's health and wellbeing.	This article explains the challenges faced by caregivers while providing care for someone with a mental or physical illness. It highlights the crucial role of caregivers as "partners in care," yet often neglects their health and wellbeing.	[10] Cormac & Tihanyi. (2006).
5	To evaluate the degree of emotional suffering and caring pressure experienced by	It found out that, Bipolar Disorder with Manic Period is; • More demanding than depressive episodes.	[11] Arciszewska et al. (2015)

	spouses of patients with bipolar disorder.	 Greater burdens for spouses. Women typically bear more patient care. Both individuals and partners experience severe psychological suffering. 	
6	The impacts of family caring on both mental and physical health were investigated in this study.	This study concluded that the caregiving threats and effects as; • Long-term physical and psychological strain. • Secondary tension in interactions with coworkers and family. • Effects moderated by age, socioeconomic status, and informal support availability.	[12] Schulz & Sherwood (2008).
7	This study sought to evaluate the care load on their close loved ones and investigate a range of clinical and sociodemographic characteristics related to the patient's care burden.	The study revealed that the caregiving load was greater for married people, couples living together, urban origins, those between the ages of 41 and 50, and low-income groups, particularly laborers and farmers.	[13] Agarwal et al. (2017).
8	Study on Personal Care vs Instrumental Care Investigates the differences in stressor impact on spouses and wives with impacts of care length, volume, and type on depressive symptoms over two years.	The result indicates; • Wives show increased depressive symptoms. • No primary stressors associated with personal care. • Husbands show no differences.	[14] Kim at el. (2017).
9	To look into the interplay	The finding highlights the significance of context and variability in comprehending family burden and suffering. The factors identified were burden types, gender, ethnicity, diagnosis, and living arrangement.	[15] Jenkins & Schumacher. (1999).

A few flaws have been identified in previous research. Several pieces of literature from the Indian context have highlighted the burden on carers. Most research has been stationed on carer strain in patients with psychosis, and fewer considerations given to caregivers dealing with depression. Furthermore, little is understood about the challenges faced by female spouse caregivers when caring for their life partners with major depressive disorder. To address this, attempts have been made to uncover the problems encountered by this female caregiver.

4. METHOD & MATERIALS:

A cross-sectional investigation of this case was carried out in August 2023 in a private clinic in Kerala, India. The caregiver was selected conveniently. Consent in writing was obtained from the caregiver before the study. Confidentiality has been assured to family members. The names have changed, and all moral principles have been considered.

The Zarit-Burden Interview (ZBI) is an instrument developed by Zarit, Reever, and Bach-Peterson in 1980. It has been extensively utilized in research and clinical settings for measuring caregiver burden. The ZBI is a 22-item questionnaire used by carers to assess their performance using a five-point Likert rating scale (from "never" to "nearly always"). The carer is asked to rate the extent of the burden she feels. The ZBI has established excellent validity and reliability, with high internal consistency and test-retest reliability. Zarit & Bach-Peterson. (1980). [6],

The ZBI has the benefit of being simple to administer, as it is self-administered or provided by a healthcare professional and only takes ten minutes to complete. It has been used by diverse populations and translated into many other languages. Table 1 presents an outline of the carer burden domains measured using the ZBI.

Table 1: The caregiver's perceived burden with areas of assessment

Sl. no	Name of Domain	Areas of Assessment	
1	Personal strain	Asses the emotional distress experienced by the caregiver, such as	
		feelings of worry, anger, frustration, and depression.	
2	Role strain:	Assess the caregiver's ability to be involved in leisure activities	
		maintain friendships, and attend to personal needs, which helps to	
		realize the effects of providing care on the caregiver's role and	
		responsibilities.	
3	Financial strain	Assess the financial burden on the caregiver, the costs connected	
		with patient care, and its effect on the carer's employment.	
4	Social strain	Assesses the consequences of providing care on the caregiver's	
		social life, including the strain on relationships with kin and	
		companions, and social isolation.	
5	Psychological well-	Assesses the caregiver's overall sense of psychological well-being,	
	being:	including feelings of happiness, satisfaction, and self-esteem.	
6	Perceptions of the	To evaluate the level of assistance the patient requires from the	
	Caregiver on patient's	caregiver daily.	
	level of dependence		

Overall, the ZBI assesses care provider load in multiple domains, providing the knowledge of the caregiver's experience comprehensively and helping healthcare professionals to recognize the areas where focused strategies can minimize the load and optimize the wellness of both the carer and the client.

5. BRIEF CASE HISTORY:

Mr. Xavier Pinto and Mrs. Maryam come from a low socio-economic status nuclear family. They got married 26 years ago. The eldest son expired due to a road accident when he was 20 years old. Their youngest daughter, aged 17, lives with them. Pinto worked as a security guard, and his wife worked as an office assistant. Pinto refused work and lost his job. Ever since their son passed away in a tragic situation, they developed a crisis in their family. Pinto could not accept the demise of their son and gradually became withdrawn, having crying spells, sleeplessness, guilt, and suicidal ideas. These symptoms persisted for a few months. A psychiatrist diagnosed him with major depression. He received antidepressants (SSRIs), underwent cognitive behavior therapy, and had electroconvulsive therapy. However, his condition

deteriorated despite treatment. He became dependent on his wife. Maryam quit her job to take care of her husband Pinto. Eventually, she became a full-time caregiver.

Maryam still loves her spouse precisely as she did the day she married, but she is anxious and confused about how to reconcile her new obligations as a spouse and a care provider. She reported that caring for her husband is emotionally challenging. She experienced feelings of sadness, anxiety, and frustration as she watched her husband struggle and live with depression.

Maryam's husband's needs have impacted her social life and personal time due to the changes she adopted in her daily schedule. The demands of providing care also left her physically worn and exhausted. "I feel like I'm fighting a lost battle. He was uninterested in looking after himself. Showering, brushing teeth, and changing clothes are examples of basic hygiene that he does not find enjoyable. I have no time to do laundry, cook, clean the floors, or do any other household chores in the interim. I have no one to assist me."

Maryam claims that because she doesn't have much support from friends or family, she feels alone and alone in her duty as a carer. "I'm feeling very alone right now, and I just want some alone time," she says. "I would like to spare time with my daughter, but my husband is my priority." "I need some alone time free from worries." And "It's hard to communicate how much of an influence it has on my life, but giving care for my husband is an overwhelming responsibility, marked by episodes characterized by emotional mistreatment and his expression of anger, often leading to the destruction of household belongings and property, and these experiences often trigger profound and intense self-disdain.". "For me, it is very difficult to accept. I feel empathetic, although this is not an appropriate response. I am his needs top priority in all of my decisions." She also conveyed her worries about what was ahead. Losing one's own life and time (friends, interests, and relationships) because of providing care and worrying about the future. "How will things look in the future if everything continues as it is"?

She expressed frustration and sadness at the lack of progress her husband has made in his treatment, despite their efforts to appeal for help from various healthcare professionals. "I do not know why he is not back to his normal. Sometimes I feel that he is strange and different. He behaves differently. For the past 2.5 years, he has been on medication. However, nothing has changed"

"It is more than hard to deal with the verbal and physical assaults I get from him and handling such circumstances is beyond description, and the hurtful words we endure from him are devastating to our spirits. "Providing awareness that he possesses a psychological illness that has an impact on every aspect of him including his relationships and daily activities".

Maryam claims to feel remorse for feeling angry with her husband, whom she adores dearly. She accepts that she often feels inadequate in her role as a care provider and a spouse since she identifies it challenging to control her feelings while attending to her husband's demands. Maryam observed that the strain of providing care negatively impacted her physical health, manifesting in symptoms such as loss of appetite, insomnia, and recurrent headaches.

Maryam says, "All relatives of mine and husbands neglect me. I could not even open up with my daughter, because she stays in a hostel for her studies. I do not want to disturb my studies. I am alone". This suggests that her family failed to provide her with sufficient emotional support. She was unable to express her feelings or concerns. Still, she managed the patient's medications and provided emotional support and encouragement.

6. RESULTS AND DISCUSSION:

When a carer receives a score of 71 on the Zarit Burden Interview (ZBI), it indicates an increased degree of strain and load. It is a noteworthy study, spotlight that the carer may be more vulnerable to issues related to their psychological and physical well-being when providing care. According to previous studies, couples who render care with mental health issues frequently endure significant levels of stress, depression, and physical health issues. Stanley et al. (2015). [2]. This realization is following Maryam's experience. Even though investigations have revealed that caring for others puts a greater strain on

relationships and maximizes the occurrence of depressive symptoms compared to couples with male partners, few studies show no gender differences. Bookwala & Schulz. (2000). [7]. For women who frequently take on primary care responsibilities and face additional social and cultural pressures to put their caregiving obligations ahead of their own needs, the burden of caregiving can be particularly difficult.

The absence of social support may further increase the stress on the carer. Being a carer can be a solitary experience, especially if the carer works full-time. The dynamics of marriage are likely to change considerably when a husband or wife starts needing care because of mental illness. Favorite hobbies may not be possible, and caregivers are forcefully required to choose to either abandon or modify some of them. Caregivers may have limited opportunities to socialize with friends or family members. Apart from these alterations in their social interactions, certain caregivers and their partners might experience a sentiment of reluctance to speak about their circumstances with friends, because persons could experience feeling ashamed of how their marriage is changing. This adjustment can prove to be quite challenging. Caregiving can consume a significant amount of the caregiver's time and energy, which ends in a loss of identity and purpose outside of the caregiving role. Sometimes, the responsibilities of caregiving can demand a considerable part of the caregiver's time and energy, resulting in a diminished sense of personal identity and purpose beyond their caregiving duties. Caregivers may, at times, encounter friends and family who are less empathetic than anticipated regarding their new role as a caregiver or spouse, and these loved ones may struggle to accept the caregiver's reduced capacity to participate in previous activities. Studies indicate that individuals in caregiving roles are ten times more prone to experiencing social isolation and have notably lower levels of living standards compared to similar individuals in the community. Fernando et al. (2017). [8].

Caregivers without a strong network of friends or close relatives to provide support are more prone to encounter feelings of isolation and loneliness, which could cause them to continue to boost their burden. Hayes et al. (2015). [9].

Caregiver's own physiological and mental well-being could also be significant in their level of burden. Providing care to a spouse can be emotionally challenging, especially if the spouse has a chronic psychiatric illness or disability. Maryam experienced feelings of guilt, anger, frustration, and sadness. Nevertheless, managing the spectrum of emotions triggered by the responsibility of supporting one's spouse can be exceptionally exhausting. According to research conducted by Cormac & Tihanyi. (2006). [10] approximately one-third of kin with mental illnesses go through emotional turmoil. This distress may include emotions such as grief, unease, and suffering.

The daily demands of caregiving, including tasks such as bathing, dressing, and feeding the spouse, can be physically exhausting and affect very badly the caregiver's health. Carers frequently have to forgo their desires, put themselves through hardships, and receive little respect. Providing care drains one's emotions, and carers experience more depression in contrast to the general population.

In addition, studies prove that female spousal carers may be more prone than others, those they care for to develop depression. Arciszewska et al. (2015). [11]. Numerous emotional challenges can act as catalysts for depression. For example, their spouse is not anymore capable of realizing or relating to them, or they might be inept at being engaged in physical intimacy. Carers might believe that they have lost the person they know because of this. Moreover, caregiving is a chronic stress experience that may arise from stress on body and mind, unpredictability, and uncontrollability, such as medical emergencies and financial crises. This could make it difficult for them to feel in charge of their own lives. Schulz & Sherwood (2008). [12]. They are also prone to secondary stress in multiple areas of life.

Emotional stress can have an indisputable effect on physical well-being. Maryam expressed the harshness of the emotional trauma she experienced every day and its effects on her physical health. The literature supports this finding. Lack of sleep, hypertension, increased or decreased weight, headaches, etc. might be the outcome of uncontrolled stress. Agarwal et al. (2017). [13]. Caregivers who already possess issues

with their physical or mental health ailments may find it difficult to manage the demands of caregiving, which causes an increased burden.

The finding that the caregiver in this scenario was a woman was also significant. Women seem noticeably more inclined than men to take on a caring role, which elevates the expectation that they will experience heavy burdens. The data indicate that female carers have a top-level burden compared to male carers. Kim at el. (2017). [14]. Another study by Bookwala & Schulz. (2000). [7] supports this evidence that caregiving wives come across more strain and indicators of depression than their male partners do.

The financial strain is also one important factor, that contributes to the burden on the caregiver. Caregiving can be expensive, particularly if the spouse requires long-term treatment. Sometimes the caregivers have to reduce their work hours or quit their jobs altogether, leading to financial strain. According to a prior study, severe load was more frequent among partners than among siblings and was more prevalent in the lower socioeconomic group in contrast to the higher socioeconomic group. Lots of people pay attention to their loved ones with mental illnesses give up their jobs or work fewer hours to attend to the wants of their family members. Jenkins & Schumacher. (1999). [15].

Time spent on caring makes the caregiver withdraw partially or fully from the workforce. This affects the caregivers' 'own future', which is another personal impact region. Few literary pieces report that the burden is more on persons who devoted themselves to assisting people with mental illness for longer years in contrast with individuals who take care of them for shorter periods. Walke et al (2018). [1], Agarwal et al. (2017). [13], & Diminic et al. (2017). [16].

Stigma is another notable factor implicated in the caregiver's burden. Shame and prejudice can make things tougher for caregivers to receive the help they need, which makes situations tougher for them to manage their loved one's needs. Lauber et al. (2003). [17], & Park & Kar (2016). 18].

In this specific case scenario, the caregiver is a female who is caring for a person with major depression. Major depression is known to be an appalling form of mental condition that can have a deleterious effect on the life of a caregiver. The caregiver has experienced many challenges, which affect the caregiver in various aspects.

Female carers may face higher emotional strain because of providing care, and greater difficulties juggling caregiving duties with job and family obligations. There are lots of measures that may be implemented to assist carers who are under stress. These include giving carer assistance and tools to ensure their wellbeing and the greatest results for both the carer and the patient. Kumar & Mohanty. (2007). [19]. The burden of caregiving must be addressed holistically, which means that additionally meeting the requirements of the care recipient, the carer must also avail the resources and assistance. This could include financial aid, respite care, and counseling or treatment. Spousal carers can benefit from carer support groups, which convey a feeling of inclusion and peer assistance.

7. IMPLICATION:

A study on the difficulty of providing care for a depressed client on a female spouse could have a handful of effects. It would shed light on the unique challenges that female caregivers overcome when caring for people with depression. Understanding the specific challenges faced by female caregivers in this scenario could help healthcare providers and support services develop more targeted interventions to alleviate the caregiver burden and enhance the overall standard of care provided to clients with depression.

8. RECOMMENDATIONS:

One of this study's shortcomings was it used a single case. It is advised that a mixed-method study design is implemented to study enormous numbers of samples involving caregivers. Also recommended to recruit a diverse sample of participants which would help to ensure the outcome of the study is generalizable to a wider population of female spousal caregivers.

9. CONCLUSION:

The predominant gender expectations that label women as care providers, the additional demands placed on women's time and energy due to work and family obligations, and the physical and emotional toll of caregiving are the various factors that might precipitate the caregiver burden, especially in females. The female caregiver in this particular case report plays a significant part in delivering care for her husband with major depression. She provides both practical and emotional support, and her involvement 1 in her husband's treatment has been essential to his recovery., In the absence of adequate supportive measures, continued caring compels the spouse to handle different responsibilities and control various problems that occur in the family. Unexpected and poorly prepared duties of a caregiver cause psychological distress. Prior studies conducted on female spousal caregivers validated the figures of this study. These studies found significantly greater total burden and burden in the areas of the caregiver's routine, the patient's behavior, and assistance from the members of the family, from the client and caregivers' coping strategies. Chen & Greenberg. (2004). [20]. However, caregiving can be difficult, so the female caregiver needs adequate support to handle the challenges of their role effectively. Therefore, they need information, training, and other resources as supporting measures to manage the challenges of caregiving.

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