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PHSYCHOLGY

THE BURDENS OF CARE ON INFORMAL CAREGIVERS OF PATIENTS WITH MENTAL DISORDERS ATTENDING CLINICS AT MATHARI TEACHING AND REFERRAL HOSPITAL

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ABSTRACT

Statement of the Problem: Caregiving for patients with mental disorders places significant burdens on informal caregivers, manifesting as physical and psychological strain over extended periods. Most research examining caregiving burden variations has been conducted in Western countries, creating a knowledge gap regarding the specific nature and intensity of these burdens in the Kenyan context, particularly at Mathari National Teaching and Referral Hospital.

Purpose of the Study: This study aimed to investigate the burdens of care experienced by informal caregivers of patients with mental disorders attending clinics at Mathari National Teaching and Referral Hospital.

Methodology: A descriptive survey design was employed, targeting informal caregivers who accompanied patients with mental disorders to Mathari Hospital. Using purposive sampling, 92 caregivers were selected based on the Krejce and Morgan table, with 80 completed questionnaires included in the final analysis. Data collection utilized the Zarit Burden Interview (ZBI), a validated 22-item tool with strong psychometric properties (Cronbach alpha 0.93, test-retest reliability 0.89), alongside a researcher-designed sociodemographic questionnaire. Data analysis employed SPSS version 25, using descriptive and inferential statistics.

Findings: The findings revealed that caregiver burden scores ranged from 8 to 68 on the ZBI scale. A large number of caregivers scored between 31-36 (mild to moderate burden) and 52-58 (moderate to severe burden). This diversity in scores indicated a wide range of experiences among caregivers, with a significant proportion experiencing moderate to severe burdens that potentially put them at risk for developing physical and mental health issues.

Conclusion and Recommendations: Caregivers at Mathari Hospital experience considerable levels of burden that require comprehensive support mechanisms. The study recommended that healthcare systems incorporate caregiver well-being into treatment plans through psychological support, financial aid, and educational programs that help caregivers manage stress and provide better care.

Keywords: *Burdens of Care, Informal Caregivers, Patients, Mental Disorders, Mathari Teaching and Referral Hospital*

INTRODUCTION

The shift toward deinstitutionalization of mental health services, defined as the transition from caring for mentally ill patients in psychiatric hospitals to community-based settings (Mavundla et al., 2009), has significantly increased the caregiving responsibilities of family members. This trend, observed in countries like Britain since the 1960s (Clibbens et al., 2019) and South Africa following the abolishment of apartheid in the 1990s (Mavundla et al., 2009), has resulted in informal caregivers experiencing substantial burdens associated with providing care for relatives with mental disorders. These burdens, defined by Oshodi et al. (2012) as "the presence of difficulties and problems affecting informal caregivers," manifest as physical, emotional, social, and financial challenges that can significantly impact caregivers' quality of life. The concept of caregiving burden represents the multifaceted strain experienced by those providing unpaid care, encompassing both objective difficulties related to caregiving tasks and subjective perceptions of stress and overwhelm associated with the caregiving role.

These burdens typically include emotional burdens (psychological distress, constant worry, fear), social burdens (isolation, reduced social interactions, stigma), financial burdens (direct costs of care, lost income opportunities), physical burdens (fatigue, health problems), and relationship burdens (strained family dynamics) (Nenobais et al., 2019). A European study conducted by Blankthorn-Hazell et al. (2018) across three countries found that specific symptoms of mental illness significantly influenced the severity of burdens experienced, with 89% of caregivers of bipolar patients with hyperactivity and irritability reporting moderate to severe caregiving burdens. Similarly, research from China among informal caregivers of patients with spinal injuries demonstrated that 88% reported moderate to severe burdens of caregiving, with only 11% experiencing mild burdens (Ma et al., 2014). These studies consistently show that the nature and severity of the patient's condition directly impact the level of burden experienced by caregivers.

In African settings, studies have documented particularly high levels of caregiving burdens. Lasebikan and Ayinde (2013), in their research among Nigerian caregivers of patients with schizophrenia, identified two distinct dimensions of caregiving burden: objective burdens (effects on household routines, economic impacts, effects on other family members) and subjective burdens (feelings of being overwhelmed by caregiving responsibilities). Their study revealed a remarkably high prevalence of caregiving burdens at 85% among these caregivers. In Ethiopia, research among caregivers of patients with severe mental illness found that caregivers experienced significant financial, emotional, and social burdens due to their caregiving roles, with up to 56% reporting psychological distress (Sintayehu et al., 2015). A Zimbabwean study by Marimbe et al. (2016) similarly found that most caregivers experienced substantial burdens, with many reporting negative impacts on their quality of life, social relationships, and economic stability. These findings from African contexts suggest that caregiving burdens may be particularly pronounced in settings with limited mental health resources and support systems.

In the Kenyan context, the burden on informal caregivers is substantial, with the Ministry of Health estimating that approximately 475,633 Kenyans have severe mental illness requiring full-time caregiving by informal caregivers in communities (Ministry of Health, 2015). This significant number underscores the magnitude of caregiving responsibilities and associated burdens in Kenya. Specifically, at Mathari National Teaching and Referral hospital, a study conducted by Ndetei et al. (2009) concluded that caregivers of patients with mental disorders experienced high levels of caregiving burdens and psychological distress. These burdens were found to significantly impact caregivers' quality of life and ability to provide effective care. Despite this evidence, limited attention is typically directed toward assessing and addressing the burdens experienced by these informal caregivers when they accompany their relatives to mental health facilities in Kenya, with most resources focused exclusively on patient care.

STATEMENT OF THE PROBLEM

Caregiving for patients with mental disorders places significant burdens on informal caregivers, manifesting as physical and psychological strain over extended periods accompanied by high levels of unpredictability and uncontrollability. These burdens can vary considerably based on caregiver characteristics such as age, gender, and relationship to the patient. As noted by Oshodi et al. (2012), there appear to be differences in caregiving burdens between first-degree relatives such as spouses and other informal caregivers. However, most research examining these variations has been conducted in Western countries and a limited number of African nations, creating a knowledge gap regarding the specific nature and intensity of caregiving burdens in the Kenyan context. Furthermore, the few studies conducted in Kenya have primarily focused on caregivers of children with mental disorders, without thoroughly investigating the role of demographic factors in relation to burdens experienced by those caring for adult patients with mental illness. This limited understanding of caregiver burden patterns at Mathari National Teaching and Referral Hospital impedes the development of targeted interventions to support this critical population.

The Kenya Mental Health Policy 2015-2030 acknowledges that approximately 475,633 Kenyans have severe mental illness requiring full-time caregiving in communities (Ministry of Health, 2015), yet the burdens experienced by these caregivers remain largely unassessed when they accompany patients to mental health facilities. As observed by the researcher during interactions with caregivers at Mathari Hospital, the institutional focus typically centers exclusively on the mentally ill patients, "completely forgetting the caregiver who accompanied the patient." This systematic neglect occurs despite evidence that informal caregivers experience high levels of caregiving burdens due to various factors including social isolation and career sacrifices (Wilborn-Lee, 2015). The absence of recent, context-specific studies at Mathari National Teaching and Referral Hospital regarding the nature, extent, and variations of caregiving burdens creates a critical gap in understanding how to effectively support these essential members of the mental healthcare system.

RESEARCH OBJECTIVE

To investigate the burdens of care on informal caregivers of patients with mental disorders attending clinics at Mathari Teaching and Referral Hospital.

RESEARCH QUESTION

What are the burdens of care on informal caregivers of patients with mental disorders attending clinics at Mathari Teaching and Referral Hospital?

LITERATURE REVIEW

THEORETICAL FRAMEWORK

The Caregivers Stress Process Theory, which originated from the transactional stress theory developed by Lazarus and Folkman (1984), provides a comprehensive framework for understanding how caregiving burdens develop and manifest among informal caregivers. According to Pearlin et al. (1990), caregiving transforms into a significant burden particularly when the care recipient is a relative with mental illness, as the impairment leads to increased dependency in accomplishing activities of daily living. This theory posits that caregivers experience stress and burden through a complex process influenced by multiple interrelated factors. At its core, the theory explains that caregiving roles can occupy the entire time of the caregiver, leading to increased burdens that manifest as physical strain, emotional exhaustion, and psychological distress including anxiety and depression (Pearlin, 1981). What makes this theoretical framework particularly valuable for studying caregiver burden is its recognition that informal caregivers are affected differently under similar caregiving circumstances—some may experience severe negative effects while others demonstrate resilience—due to variations in background characteristics, stressor exposure, and personal resources. The theory's multidimensional approach acknowledges that caregiver burden is not a singular experience but rather a complex phenomenon influenced by the interplay of various factors, making it an ideal theoretical lens through which to examine the diverse burdens experienced by caregivers of mentally ill patients at Mathari National Teaching and Referral Hospital.

The Caregivers Stress Process Theory identifies four key components that collectively determine the nature and severity of burden experienced by caregivers. The first component—background and contextual characteristics—encompasses the caregiver's demographic attributes (age, gender, education level), socioeconomic status, and relationship history with the patient. According to Pearlin et al. (1981), these background factors significantly influence how caregivers perceive and respond to caregiving challenges. The second component involves primary and secondary stressors. Primary stressors stem directly from the care recipient's needs and behaviors, including the level of surveillance required to prevent self-harm or harm to others, the degree of dependency, and the management of problematic behaviors associated with mental illness. Secondary stressors emerge as consequences of primary stressors and often manifest as economic strain due to reduced work capacity or increased healthcare expenses, and social isolation resulting from diminished opportunities for social engagement. The third component—intrapsychic strains—focuses on the caregiver's self-concept and psychological state, with research indicating that prolonged exposure to caregiving hardships can damage an individual's self-concept, leading to diminished self-esteem and increased vulnerability to psychological distress (Pearlin et al., 1981). The final component addresses outcomes, particularly the physical and mental wellbeing of caregivers, with common manifestations including anxiety, depression, cognitive disruption, and irritability (Wilborn-Lee, 2015).

For the third objective of this study, which aims to investigate burdens of care on informal caregivers at Mathari Hospital, the Caregivers Stress Process Theory offers invaluable guidance by providing a systematic structure for categorizing and analyzing different aspects of burden. The theory's emphasis on background characteristics enables the examination of how factors such as age, gender, education level, and relationship to the patient influence the experience of burden among caregivers in this specific Kenyan context. Its delineation of primary and secondary stressors facilitates the identification of direct caregiving challenges (such as managing psychiatric symptoms or medication adherence) and their indirect consequences (including financial strain and social isolation) that collectively contribute to caregiver burden. The theory's attention to intrapsychic strains provides a framework for understanding the psychological impact of caregiving, particularly relevant given the stigma often associated with mental illness in many African contexts. Furthermore, the theory's recognition of outcomes guides the assessment of how burdens ultimately affect caregiver wellbeing, which is crucial for developing effective interventions. While the Caregivers Stress Process Theory has some limitations—such as assuming environmental and contextual influences as primary determinants of caregiver experiences without fully accounting for individual thought processes—it nonetheless provides a robust theoretical foundation for investigating the multifaceted burdens experienced by caregivers at Mathari Hospital.

EMPIRICAL REVIEW

Informal caregivers providing care for patients with mental illnesses have been found to experience higher level of burdens as compared to Informal caregivers of patients with other chronic medical conditions such as stroke and HIV. In America, a meta-analysis was done with the aim of identifying major burdens of caregiving experienced by caregivers of patients with mental illness. The analysis revealed that many caregivers reported to be experiencing burdens of caregiving such as emotional burdens, social burdens and financial burdens (Nenobais et al., 2019).

Blankthorn-Hazel et al. (2018) conducted a study in 3 European countries from 2016 to 2017.The study population comprised informal caregivers taking care of patients diagnosed with schizophrenia and or bipolar accompanied by agitation in the community. This study used a survey design, and its aim was to assess types of burdens experienced by informal caregivers of patients diagnosed with schizophrenia and bipolar. This study reported higher levels of social burdens, economic burdens and lastly emotional burdens among care providers for relatives with mental health illnesses. They attributed this to the amount of care and time required by such patients. They found out that 44% of caregivers taking care of schizophrenia patients and 65% of caregivers taking care of bipolar patients required up to 8 hours in a day to satisfy the basic needs of these patients (Blankthorn-Hazell et al., 2018).

In addition, this study by Blankthorn-Hazell et al. (2018) also showed that other than contact hours of caregiving, specific symptoms of the patient being cared for can also increase burdens of caregiving on informal caregivers. For example, this study reported that positive signs of schizophrenia such as hallucinations brought higher burdens of care to caregivers as compared to negative symptoms (Blankthorn-Hazell et al., 2018). Secondly, this study also found out that 89% of caregivers of bipolar patients with symptoms such as hyperactivity and irritability reported moderate to severe burdens of caregiving. In addition to this, a study done in China among informal caregivers taking care of relatives with spinal injury reported moderate to severe burdens of caregiving. The average score for the Zarit burden Index was 52.9. This represented moderate to severe burdens. Additionally, 88% of the caregivers reported moderate to severe burdens of caregiving. Mild burdens were reported by only 11% of caregivers (Ma et al.,2014).

Similarly, another study was done in India among caregivers of patients with mental illnesses. The study setting was a psychiatric hospital in South India, and it was a cross sectional study. This study concluded that up to 52% of the caregivers experienced moderate to severe burdens of caregiving. The study went ahead and found out that the types of burdens were similar among caregivers of patient taking care of patients with different mental illnesses (Nagarajan et al., 2021). Lasebikan and Ayinde (2013) in their study done in Nigeria among caregivers of patients with schizophrenia found out that there exists two dimensions to caregivers' burden; objective burdens and subjective burdens. Objective burdens included household level effects such as effects on family routine, economic effects and sometimes effects on children living in the house. On the other hand, subjective burdens were mostly perceived as feelings of being overwhelmed by caregiving roles. This study aimed at determining the prevalence of Caregiving burdens among these caregivers. Additionally, the study found out that the prevalence of care burdens was up to 85 %.

These recent studies have begun to provide insights into burdens of caregiving experienced by informal caregivers. Across the world in different countries, caregivers are experiencing different levels of burdens such as economic, social and psychological and are applying different coping mechanisms in their day-to-day activities. One limitation of these past studies is their focus on burdens of caregiving only without looking at coping strategies applied by these caregivers. This means that there could be a knowledge gap on how these caregivers cope with the burdens they face in their caregiving duties. Therefore, this study added to the knowledge of caregivers' burdens by looking at how different ages of caregivers influence the burdens they experienced and how they cope.

RESEARCH METHODOLOGY

To investigate caregiving burdens, this study employed a descriptive survey design targeting informal caregivers who accompanied patients with mental disorders to Mathari National Teaching and Referral Hospital. Using purposive sampling, 92 caregivers were selected based on the Krejce and Morgan table. The primary data collection instrument for measuring caregiver burden was the Zarit Burden Interview (ZBI), a validated 22-item tool with a 5-point Likert scale that assesses physical, emotional, and social burdens experienced by caregivers. The ZBI has demonstrated strong psychometric properties with a Cronbach alpha value of 0.93 and test-retest reliability of 0.89 in validation studies (Seng et al., 2010). Complementary data was collected using a researcher-designed sociodemographic questionnaire to examine the relationship between caregiver characteristics and burden levels. Data was analysed using SPSS version 25, employing descriptive statistics to determine the prevalence and severity of caregiving burdens and inferential statistics to identify relationships between sociodemographic factors and burden levels.

FINDINGS AND DISCUSSIONS

The study focused on examining the burdens experienced by informal caregivers of patients with mental disorders at Mathari Mental Hospital, using the Zarit Burden Interview as the assessment tool. According to the Zarit Burden Interview score interpretations, a score of 0-21 indicates little or no burden, 21-40 represents mild to moderate burden, 41-60 signifies moderate to severe burden, and 61-88 indicates severe burden. The study results are summarized in Table 1.

Table 1: Burdens Experienced by Caregivers

Score	Frequency	Percent
8	1	1.3
10	1	1.3
17	2	2.5
20	1	1.3
26	2	2.5
29	2	2.5
30	2	2.5
31	3	3.8
32	6	7.5
33	3	3.8
34	3	3.8
35	3	3.8
36	3	3.8
38	2	2.5
39	1	1.3
40	1	1.3
41	1	1.3
42	4	5
43	2	2.5
45	2	2.5
47	1	1.3
48	2	2.5
49	1	1.3
50	2	2.5
52	3	3.8
54	2	2.5
55	3	3.8
56	2	2.5
57	2	2.5
58	5	6.3
59	1	1.3
61	2	2.5
62	1	1.3
63	2	2.5
64	2	2.5
65	2	2.5
66	1	1.3
68	1	1.3
Total	80	100

Table 1 revealed that the scores ranged from as low as 8 to as high as 68, with varying frequencies. Notably, a large number of caregivers scored between 31-36 and 52-58, falling into the categories of mild to moderate burden and moderate to severe burden, respectively.

This diversity in scores indicates a wide range of experiences among caregivers, with a significant proportion experiencing moderate to severe burdens. The implication of these results was profound, considering that many caregivers fell into the moderate to severe burden category. This level of burden potentially puts caregivers at risk for developing physical and mental health issues, including stress, anxiety, and depression, which could in turn adversely affect the quality of care they can provide. The data suggested that caregivers were in a vulnerable position, and more so for those who scored higher on the burden scale. This underlines the need for support systems tailored to mitigate these burdens, from offering mental health services to respite care, and underscores the urgency to address this issue in a comprehensive manner.

Another noteworthy aspect is that there were caregivers who fell into the little or no burden and mild to moderate burden categories. This variation indicated that caregiving experience is not universally negative and that some factors may be protective or alleviative. Understanding what differentiates these caregivers from those experiencing higher levels of burden could provide insights into effective coping strategies or resources that can be developed or shared. The fact that the data was collected from caregivers attending a mental hospital also has its own implications. It could suggest that those who seek medical help or guidance might be experiencing higher levels of burden compared to those who do not, or it might indicate the opposite-that they have access to some level of support, given that they are engaged with a healthcare facility. Thus, the results of this study provided a compelling call to action for healthcare providers, policymakers, and communities to understand and address the multi-faceted burdens that caregivers face.

CONCLUSION

The conclusion drawn is that caregivers at Mathari National Referral Hospital frequently experience a considerable level of burden, ranging from moderate to severe. This points to an acute need for comprehensive support mechanisms that address not only the mental but also the practical burdens of caregiving. However, it’s also noteworthy that a subset of caregivers reported less burden, suggesting that individual experiences and coping capacities differ. This could indicate that some caregivers have either access to resources or coping strategies that mitigate the burdens they face, which could be explored further for targeted interventions.

RECOMMENDATIONS

The extensive burden that caregiving places on individuals highlights the need for a broad support system. This system should go beyond just mental health support and offer practical, hands-on help, perhaps in the form of respite care or skills training workshops. Community support groups could be set up, offering a platform for caregivers to share experiences, advice, and coping strategies. Specialized education sessions teaching caregiving skills, such as managing patient behavior or understanding medical jargon, could also be beneficial. Moreover, attention should be directed towards caregivers who report lower levels of burden to understand what coping strategies or external resources they are utilizing effectively. Such strategies could then be incorporated into broader caregiver support initiatives.

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