

The Psychological Burden Of Informal Caregivers Of Stroke Patients In Ghana

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Abstract

Background: Stroke survivors rely heavily on the support of informal caregivers, who often experience significant psychological burdens due to caregiving responsibilities. Understanding the psychological impact of caregiving is crucial for developing effective support strategies. This study aims to investigate the levels of psychological well-being and distress among informal caregivers of stroke patients and explore potential factors contributing to caregiver burden.

Objective: This study aims to investigate the psychological cost of caregiving to informal caregivers of stroke patients, focusing on psychological well-being and distress. Additionally, the study aims to explore the influence of demographic factors, such as age and duration of caregiving, on informal caregivers' psychological outcomes.

Methods: Informal stroke caregivers attending the physiotherapy department at Korle-Bu Teaching Hospital in Accra were included in this cross-sectional survey. Convenience and purposive sampling were used to select 100 informal caregivers and 50 non-caregivers from the community based on inclusion criteria. The Mental Health Inventory (MHI-38) and a demographic questionnaire were utilized for data collection.

Results: The analysis revealed no significant difference in psychological well-being between informal caregivers and non-caregivers. However, informal caregivers exhibited higher levels of psychological distress compared to non-caregivers. Furthermore, a significant difference in psychological well-being and distress was observed between younger and older informal caregivers, with younger informal caregivers reporting higher levels of psychological well-being and older caregivers experiencing more psychological distress. Additionally, there was a positive correlation between the duration of informal caregiving and psychological distress.

Conclusion: These findings emphasize the need for targeted interventions and support services to address informal caregivers' psychological well-being and distress, ultimately enhancing the caregiving experience and improving outcomes for informal caregivers and stroke survivors.

Keywords: Psychological Well-Being, Psychological Distress, Informal Caregivers, Stroke Patient

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I. Introduction

Stroke is a devastating cerebrovascular event characterized by a sudden interruption of blood flow to the brain, resulting in neurological impairments and long-term disability (Coupland et al., 2017). It is a leading cause of mortality and morbidity worldwide, posing significant challenges for individuals, families, and healthcare systems (Barthels & Das, 2020; Mozaffarian et al., 2016). The WHO projected that if secular trends continue, it is estimated that there will be 23 million first-ever strokes and 7.8 million stroke deaths in 2030 (Mendis, 2013). According to Kpessa-Whyte and Tsekpo (2020), stroke (cardiovascular accidents) and cardiovascular disorders are Ghana's main causes of morbidity and mortality. It was shown to be the fourth most common cause of death among inpatients at 32 hospitals in the ten (10) regions of Ghana, according to studies by Sanuade et al. (2019), and it is also one of the major causes of mortality at Komfo Anokye Teaching Hospital (Sidow et al., 2022).

In the aftermath of a stroke, the recovery and rehabilitation process often necessitates substantial support and care from caregivers (Hansson et al., 2021). In most developing countries, family members—rather than hired professionals—are expected to feel responsible for and take responsibility for the well-being of the sick (Perry-Jenkins & Gerstel, 2020). For instance, in Ghana, where hospitals and other medical facilities are dispersed unevenly, and there is a shortage of medical experts, families are the primary institution for providing care for the sick (Kyei-Arthur & Codjoe, 2021). This type of caregiving is referred to as informal caregiving (Kyei-Arthur & Atobrah, 2022; Moura et al., 2021). The role of an informal caregiver can be demanding and challenging, requiring substantial amounts of unpaid time, energy, and emotional investment over an extended period (Okonkwo et al.,

2022). The informal caregiver's responsibilities may include providing physical assistance, administering medications, managing appointments and finances, and offering emotional support to the stroke survivor (Ahmed et al., 2021). This level of caregiving can lead to various mental health concerns or disorders among informal caregivers, often described as a burden that affects their psychological well-being and overall quality of life (Na'imah et al., 2023).

The psychological impact of informal caregiving is a well-documented phenomenon that has garnered considerable attention in the literature (Liu et al., 2022). For instance, a systematic review by Moura et al. (2021) examined the quality of life of informal caregivers of stroke patients and reported a high prevalence of mental health issues such as depression, anxiety, and caregiver distress. Similarly, a study by Suksatan et al. (2022) found that informal caregivers of stroke patients experienced higher levels of caregiver burden, depression, and reduced quality of life than non-caregivers. Research has demonstrated that the psychological well-being and distress experienced by informal caregivers can influence their ability to provide optimal care and support to stroke survivors (Cheng et al., 2022). Psychological distress among informal caregivers has been associated with adverse outcomes, such as decreased caregiver self-efficacy, decreased quality of life, increased healthcare utilization, and increased risk of caregiver burden (Putri et al., 2022; Rohde et al., 2019). It is, therefore, crucial to explore multiple dimensions of psychological well-being and distress experienced by informal caregivers of stroke patients. Understanding the specific domains affected by informal caregiving can inform the development of targeted interventions and support strategies to address the unique needs of informal caregivers.

Furthermore, demographic factors such as age and duration of caregiving have been shown to influence informal caregiver experiences (Riffin et al., 2019). Younger caregivers may face distinct challenges and stressors compared to older caregivers, impacting their psychological well-being and distress (Lindt et al., 2020). Additionally, the duration of caregiving has been associated with increased caregiver burden and psychological distress as the cumulative demands and responsibilities of caregiving intensify over time (Cheung & Leung, 2011; Haley et al., 2004). Despite the existing research highlighting the influence of demographic factors, such as age and duration of caregiving, on caregiver experiences and psychological well-being, there is a gap in the literature regarding a comprehensive examination of the interplay between these factors and informal caregiver distress. Specifically, there is a need to investigate the differential impact of age and duration of caregiving on psychological well-being and distress, considering their potential cumulative effects and distinct stressors faced by younger and older informal caregivers.

To contribute to understanding the psychological cost of caregiving among informal caregivers of stroke patients, the present study aims to investigate the levels of psychological well-being and distress experienced by informal caregivers. Specifically, the study will compare the psychological burden experienced by informal caregivers with non-caregivers. Additionally, the study will explore the influence of demographic factors, such as age and duration of caregiving, on informal caregivers' psychological outcomes. The findings of this study will contribute to the existing knowledge base by shedding light on the psychological challenges faced by informal caregivers of stroke patients. Again, recognizing the psychological impact on informal caregivers is essential in developing targeted interventions and support systems to enhance their well-being and ultimately improve the rehabilitation process for stroke survivors. Finally, the findings will inform healthcare professionals, policymakers, and support organizations about informal caregivers' specific psychological challenges and highlight the need for tailored interventions to support their Well-being.

II. Methodology

Study Design and participants:

This study employed a cross-sectional survey design to gather data on the psychological impact of caregiving on informal caregivers of stroke patients. The study focused on informal stroke caregivers who visit the physiotherapy department at Korle-Bu Teaching Hospital in Accra. The convenience and purposive sampling designs were utilized to achieve a sample size of 150 for the study, which included 100 informal caregivers of stroke patients and 50 non-caregivers who do not have caregiving responsibilities. These non-caregivers were purposively sampled as a comparison group. The inclusion criteria for the informal caregivers' group required participants to be family members aged 18 years and above, serving as the primary informal caregiver responsible for assisting the stroke survivor in activities of daily living (ADL) and accompanying them to medical appointments, with a minimum caregiving duration of six months. For the non-caregivers group, the inclusion criteria stipulated that participants should not be a formal caregiver or health worker, should be aged 18 years and above, not serving as a primary informal caregiver for a family member with a disability, and not belong to the same family as the informal caregivers to avoid potential overlap of caregiving responsibilities within a single family.

Data Collection Instruments:

Psychological well-being and psychological distress

The Mental Health Inventory (MHI-38), developed by Veit and Ware (1983), was employed in this study to assess psychological well-being and distress among the participants. The MHI-38 comprises 38 items grouped into five subscales: Anxiety, Depression, Behavioral/Emotional control, General Positive Affect, and Emotional Ties. These subscales were further categorized into two global subscales: psychological well-being and psychological distress. General Positive Affect and Emotional Ties measured psychological well-being, whereas psychological distress was assessed by Anxiety, Depression, and Loss of Behavioral/Emotional control. Each item was rated on a 6-point Likert scale, with higher scores indicating greater levels of the respective construct. The internal consistency of the MHI-38 has been established through various studies. Additionally, demographic information such as age, gender, educational level, relationship to the stroke survivor, and duration of caregiving was collected using a structured questionnaire.

Data Collection Procedure:

Trained research assistants approach potential participants in the physiotherapy department and explain the study's purpose and procedures. Informed consent was obtained from all participants. Participants then complete the self-administered questionnaires in a private and quiet setting. Research assistants were available to clarify any questions or concerns that may arise during the data collection process.

Data Analysis:

Data collected from the questionnaires were entered into a statistical software program for analysis. Descriptive statistics, such as means and standard deviations, were computed for demographic variables. Independent t-tests or non-parametric tests were conducted for continuous variables to examine differences between informal caregivers and non-caregivers. Pearson r Test was employed to analyze the duration of caregiving and psychological distress.

Ethical Considerations:

This study followed ethical guidelines and ensured the privacy and confidentiality of all participants. Informed consent was obtained, and participants had the right to withdraw from the study at any point without consequences. The study also considered potential emotional distress and provides appropriate support or referrals to mental health professionals if needed.

III. Results

The table below (Table 1) presents the demographic characteristics of the study's respondents.

Table 1: Descriptive frequency of informal caregiver (IFC) and non-caregiver (NC)

Variable	Category	IFC (n-100)		NC (n-50)	
		Frequency (%)	Frequency (%)	Frequency (%)	Frequency (%)
Gender	Male	49 (49%)		24 (48%)	
	Female	51 (51%)		26 (52%)	
Age	18-24	18 (18%)		6 (12%)	
	25-34	56 (56%)		22 (44%)	
	35-44	7 (7%)		4 (8%)	
	45-54	16 (16%)		17 (34%)	
	55+	3 (3%)		1 (2%)	
Marital Status	Single		73 (73%)	30 (60%)	
	Married	25 (25%)		20 (40%)	
	Widow		2 (2%)	-	
Religion	Christian	77 (77%)		33 (66%)	
	Muslim	23 (23%)		17 (34%)	
Employment Status	Employed	52 (52%)		27 (54%)	
	Unemployed		45 (45%)	19 (38%)	
	Retired		3 (3%)	4 (8%)	
Educational Level	Primary	8 (8%)		-	
	JHS		23 (23%)	6 (12%)	
	SHS		37 (37%)	16 (32%)	
	Tertiary	27 (27%)		28 (56%)	
	Others		5 (5%)	-	

Test of informal caregivers and non-caregivers psychological well-being and psychological distress.

The study utilized an independent sample t-test to compare psychological well-being and distress levels between informal caregivers and non-caregivers. The findings in Table 2 demonstrate no significant difference in the mean and standard deviation of psychological well-being between informal caregivers (M = 59.21, SD = 11.24) and non-caregivers (M = 56.16, SD = 10.69). The independent t-test ($t = 1.59$, $df = 148$, $p > .05$) further confirms no statistically significant distinction in psychological well-being between the two groups. However, the results in the table highlight a significant difference in psychological distress between informal caregivers of stroke patients and non-caregivers ($t = 2.46$, $df = 148$, $p < .05$). Specifically, the mean scores indicate that informal caregivers of stroke patients experienced higher levels of psychological distress (M = 58.00, SD = 18.25) compared to non-caregivers (M = 50.78, SD = 13.82). This difference is statistically significant at the .05 significance level.

Table 2: Result of the independent sample t-test comparing informal caregivers and non-caregivers on psychological well-being and psychological distress.

Variables	Informal caregivers			Non-caregivers			df	t	p
	N	Mean	SD	N	Mean	SD			
Psych. Well-being	100	59.21	11.24	50	56.16	10.69	148	1.59	.11
Psych. Distress	100	58.00	18.25	50	50.78	13.82	148	2.46	.02

Note: * $p < .05$. ** $p < .01$. *** $p < .001$.

Abbreviations: Psych. Well-being = Psychological well-being, Psych. distress = Psychological distress, N= number of participants, t= t-values, p =alpha values.

Test of younger and older informal caregivers' psychological well-being and psychological distress.

To compare the levels of psychological well-being and distress between younger and older informal caregivers, an independent sample t-test was utilized. The findings, presented in Table 3, indicate that there is a statistically significant difference in the mean scores of psychological well-being between younger informal caregivers (M = 61.20, SD = 10.70) and older informal caregivers (M = 53.54, SD = 10.98) ($t = 3.12$, $df = 98$, $p < .05$). These results suggest that younger informal caregivers tend to report significantly higher levels of psychological well-being compared to older informal caregivers. Furthermore, the results demonstrate a significant difference in psychological distress between younger informal caregivers (M = 53.96, SD = 18.15) and older informal caregivers (M = 69.50, SD = 13.10) ($t = -4.01$, $df = 98$, $p < .05$), with older informal caregivers reporting higher levels of psychological distress.

Table 3: The summary result of the independent sample t-test comparing younger and older informal caregivers' psychological well-being and psychological distress.

Variables	Younger informal caregivers			Older informal caregivers			df	t	p
	N	Mean	SD	N	Mean	SD			
Psych. Well-being	74	61.20	10.70	26	53.54	10.98	98	3.12	.002
Psych. Distress	74	53.96	18.15	26	69.50	13.10	98	-4.01	.000

Note: * $p < .05$. ** $p < .01$. *** $p < .001$.

Abbreviations: Psych. Well-being = Psychological Well-being, Psych. distress = Psychological distress, N= number of participants, t= t-values, p =alpha values.

Test of the duration of informal caregiving and psychological distress.

The study utilized Pearson's correlation coefficient to examine the association between the duration of informal caregiving and psychological distress. The results, presented in Table 4, reveal a significant positive relationship between the duration of informal caregiving (M = 12.56, SD = 7.14) and psychological distress (M = 58.00, SD = 18.25) ($r = .21$, $p < .05$). This indicates that as the duration of caregiving increases, there is a corresponding increase in psychological distress among the informal caregivers.

Table 4: Summary of Pearson r Test, Means, SD of the duration of informal caregiving and psychological distress.

Variables	N	Mean	SD	r	p
Duration	100	12.56	7.14	.21	.04
Psychological distress	100	58.00	18.25		

Note: * $p < .05$. ** $p < .01$. *** $p < .001$.

Abbreviations: Psych. Well-being = Psychological Well-being, Psych. distress = Psychological distress, N= number of participants, r = Pearson's r, p =alpha values.

IV. Discussion

The present study aimed to investigate the psychological cost of caregiving to informal caregivers of stroke patients, focusing on psychological well-being and distress. The findings contribute to our understanding of the psychological impact of informal caregiving and shed light on potential factors associated with informal caregiver burden.

Informal caregivers, Non-caregivers, and Psychological well-being and distress

The study's findings revealed no significant difference in psychological well-being between informal caregivers and non-caregivers. This finding suggests that despite the challenges and demands of caregiving, informal caregivers did not experience significantly lower psychological well-being levels than individuals without caregiving responsibilities. These findings may result from caregivers' resilience and adaptability in coping with their role's psychological demands. As stated by Ahmed et al. (2021), caregivers with high resilience and adaptability can experience higher psychological well-being despite the stress of caregiving. On the other hand, the study discovered that informal caregivers are more psychologically distressed than non-caregivers. Informal caregivers reported higher levels of psychological distress, indicating that the caregiving role can negatively impact caregivers' mental health. This could be because strokes typically occur suddenly, leaving families unprepared yet still required to care for survivors and cope with the circumstance (Lutz et al., 2017). Because most stroke survivors become dependent on family caregivers for day-to-day tasks, depending on the severity of the stroke, it strains the physical and psychological well-being of informal caregivers that non-caregivers do not feel. Stress can sometimes be overpowering, leading to other major psychological issues like depression (Lutz et al., 2017). Unsurprisingly, informal caregivers had higher levels of depression, anxiety, and loss of behavioural or emotional control than non-caregivers. This finding is consistent with previous research highlighting the psychological distress experienced by informal caregivers of stroke patients. (Bobinac et al., 2011; Lee et al., 2020).

Age and Mental health among Informal caregivers:

The study findings again revealed a statistically significant difference in psychological well-being between younger and older informal caregivers. Younger informal caregivers reported significantly higher levels of psychological well-being compared to older informal caregivers. This finding suggests that younger informal caregivers experience better psychological well-being in the context of caregiving than their older counterparts. These findings align with previous studies (Hawken et al., 2018; Lindt et al., 2020), which suggest that younger caregivers possess greater resilience, adaptability, or coping skills, enabling them to maintain higher well-being levels despite caregiving challenges. Additionally, younger informal caregivers might have more resources, such as social support networks or access to information and services, which can positively impact their well-being (Trepte & Scharkow, 2016).

Furthermore, the study identified a significant difference in psychological distress between younger and older informal caregivers. Older informal caregivers reported higher levels of psychological distress compared to younger informal caregivers. This finding suggests that older informal caregivers experience more psychological distress in caregiving. Older informal caregivers may face unique challenges related to their age, such as physical limitations, health issues, or the cumulative effects of caregiving over time. The literature has identified these factors contribute to increased distress among older caregivers (Hawken et al., 2018). It is crucial to recognize older informal caregivers' specific needs and vulnerabilities and provide tailored support to address their psychological well-being. The findings underscore the importance of considering the age factor when examining the psychological impact of informal caregiving. Tailored interventions and support programs should be developed to address the distinct needs of younger and older informal caregivers. For younger informal caregivers, interventions may focus on maintaining and enhancing their psychological well-being, while for older informal caregivers, interventions may aim to reduce distress and promote mental health. These interventions could include stress management techniques, social support networks, respite care, and educational resources.

Duration of informl caregiving and psychological distress among informal caregivers:

Finally, the study analyzed the relationship between the duration of informal caregiving and psychological distress. The findings reveal that as the duration of informal caregiving increases, there is a corresponding increase in psychological distress. This positive correlation suggests that the longer individuals have been providing care for stroke patients, the higher their levels of psychological distress. This finding is consistent with previous studies highlighting the cumulative impact of caregiving over time on informal caregivers' psychological distress (Hastrup et al., 2011; Riffin et al., 2019). The positive correlation indicates that the demands and challenges associated with caregiving may take a toll on informal caregivers' psychological well-being. Informl caregivers who have been providing care for longer may experience higher stress levels, burnout, and emotional strain, leading to increased psychological distress (Oliva-Moreno et al., 2018). Physical exhaustion,

social isolation, financial strain, and personal and social life disruptions can also contribute to this distress (Schure et al., 2006). Understanding the relationship between the duration of informal caregiving and psychological distress is crucial for developing effective interventions and support systems. It emphasizes the need for early recognition and proactive support for informal caregivers, particularly as the duration of caregiving increases. Implementing respite care, support groups, counselling services, and caregiver education programs can help alleviate psychological distress and enhance the overall well-being of informal caregivers.

Conclusion:

This study examined the psychological cost of caregiving among informal caregivers of stroke patients. The study utilized the Mental Health Inventory (MHI-38) to assess psychological well-being and distress. The results indicated that informal caregivers did not report significantly lower levels of psychological well-being compared to non-caregivers, suggesting their resilience and adaptability in coping with the demands of caregiving. However, informal caregivers did experience higher levels of psychological distress, highlighting the need for interventions to address their mental health needs.

Furthermore, the study explored the psychological well-being and distress differences between younger and older informal caregivers. Younger informal caregivers reported higher levels of psychological well-being, while older informal caregivers experienced more psychological distress. Tailored interventions should be developed to support the specific needs of both age groups, considering their unique challenges and vulnerabilities. Additionally, the study found a positive correlation between the duration of informal caregiving and psychological distress, indicating that prolonged caregiving responsibilities contribute to increased psychological distress among informal caregivers. Early recognition and proactive support for informal caregivers, including respite care, support groups, and counselling services, can help alleviate this distress and promote their overall well-being. Overall, the study highlights the importance of recognizing and addressing the psychological impact of caregiving on informal caregivers of stroke patients. By providing adequate support, resources, and targeted interventions, healthcare professionals and support systems can help mitigate caregiver burden, enhance their psychological well-being, and improve the overall quality of life for informal caregivers and stroke survivors.

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