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The Influence Of Social Context At Family And Community Levels On Family Caregivers' Experiences In Kenya: A Retrospective Qualitative Study

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Abstract:
Background: *Family caregivers play a significant role in the care of hospitalized patients. they contribute to decision-making, emotional support and enhancing overall patient well-being. The COVID-19 pandemic led to strict visitation restrictions which limited the involvement of caregivers and heightened the challenges of caregiving. Social, economic and community factors, among them being family cohesion, social support, spirituality and stigma have been shown to shape the experiences and coping mechanisms of caregivers during COVID-19 hospitalization period. This retrospective study explores the influence of family and community social contexts on the lived experiences of caregivers of COVID-19 patients in Kenya.*
Methods: *A descriptive phenomenological design was adopted. The study was conducted in Nairobi County, Kenya. the study population was family caregivers of patients admitted with COVID-19 at Kenyatta National Hospital between January and September 2021. A total of 10 caregivers were selected as the sample size for the study. the sample size was determined based on the principle of data saturation. Purposive sampling was used to select participants of the study. data was collected using semi-structured interview guides. In-depth face-to-face interviews were conducted at convenient and private locations. Data collected was transcribed using verbatim and analyzed using inductive thematic analysis with the help of Nvivo 14 software.*
Results: *Three themes were identified through thematic analysis: Adaptation, Burden of Responsibility and Stigma. Adaptation was characterized by reliance on faith, hopefulness and strong support systems at the family level; all of which were found to enhance caregivers' resilience and capacity to cope with hospitalization challenges. Burden of responsibility was evident through economic and logistical pressures experienced by caregivers and included loss of income, financial strain and increased decision-making roles and patient advocacy. Stigma also emerged as a significant societal challenge and influenced interactions of caregivers within the community in addition to contributing to isolation and emotional distress.*
Conclusion: *Social context at family and community levels have a significant influence on caregivers' experiences through adaptation, burden of responsibility and stigma. This highlights the need for holistic support systems that address both patient care and social, economic and emotional needs of caregivers.*

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I. Introduction

Family caregivers are instrumental in the care of patients admitted in hospitals. Their role differs from that of mere visitors. The medical community has long advocated for family involvement and presence in the treatment process. The campaign has been successful in changing the perspective of families as visitors to one of significance to the quality, experience, safety, and outcomes of health care; and removing barriers to family members' inclusion and participation in clinical setting (Dokken *et al.,* 2020). Faced with the catastrophic COVID-19 disease outbreak, medical institutions, around the world found it important to regulate visitation, an aspect that convoluted the participation of family members in caregiving. The measure was aimed at preventing infection and cross-infection and guarantee the safety of patients, health care workers, visitors including family members, and the public (Traverson *et al.,* 2021). Families were not allowed to be present with their loved ones in most cases, and their capacity to contribute to caregiving, planning, and making judgment calls was highly curtailed (Dokken *et al*., 2021). Limited visiting has resulted in a lack of support for the patient, according to Camicia *et al*., (2021), and may increase feelings of social isolation. Psychosocial support must be offered to patients in the face of limited visitation (Arenivas *et al*., 2020). The COVID-19 pandemic, according to Sun et al. (2020), has had a substantial effect on hospitalized COVID-19 positive patients and their family carers. Family members play a vital part in the care of their loved ones who are hospitalized. Critically ill individuals rely on family members to make decisions on their behalf and communicate their requirements.

According to Hammad *et al.,* (2024), family caregiving is understood as a socially embedded process which is shaped by interactions within family structures, community networks and broader socio-economic environments. Salifu *et al.,* (2025) noted that caregivers do not operate in isolation; instead, their experiences are influenced by relational support systems, cultural values, economic capacity and social perceptions of illness. During the COVID-19 pandemic, caregiving challenges intensified due to healthcare access restrictions, increased caregiving responsibilities and reduced social interaction (Gaspar *et al.,* 2023). These circumstances increased caregivers' psychological distress (Beach *et al*., 2021). In addition, they also revealed the protective role of family cohesion, spirituality and community support systems in facilitating coping and resilience (Kent *et al*., 2020).

Literature further shows that social, economic and community level factors play a significant role in shaping the experiences and well-being of caregivers. Social support from family members, friends and the wider community has been shown to play a protective role that reduces caregiver's burden, stress and depressive symptoms (Zhong *et al*., 2020; Wang *et al*., 2022; Nasrabadi *et al*., 2022). On the other hand, inadequate social support, low socio-economic status and increased demands from caregiving are linked to rising levels of psychological distress, poor health outcomes and caregiving burden (Kusi *et al*., 2020; Savela *et al*., 2022). In addition, societal stigma and isolation, especially during the COVID-19 pandemic further made caregiving experiences more complex since access to support networks was limited and social interaction discouraged (Bagcchi, 2020; Velilla *et al*., 2022). To overcome these challenges, caregivers have been demonstrated to adopt coping mechanisms such as spirituality and religious faith. These have enhanced emotional resilience and psychological adjustment during uncertainty and stress periods (Pirutinsky *et al*., 2020; Del Castillo *et al*., 2020). Therefore, this study retrospectively explores the influence of social context at family and community levels on the lived experiences of family caregivers of COVID-19 patients in Kenya.

II. Methods

Research Design: This study adopted a descriptive phenomenological design to explore the influence of social context at family and community levels on the lived experiences of family caregivers of COVID-19 patients in Kenya.

Study Area: The study was conducted in Nairobi County, Kenya, where Kenyatta National Hospital served as a primary COVID-19 treatment center.

Study Population: The study targeted family caregivers of patients admitted with COVID-19 at Kenyatta National Hospital between January and September 2021.

Sample Size: A total of 10 caregivers residing in Nairobi participated in in-depth interviews.

Sample Size Calculation: Sample size was determined based on the principle of data saturation as per the guidelines by Creswell (2014) and Starks & Trinidad (2007)

Sampling Technique: Purposive sampling was used to recruit participants with diverse caregiving experiences based on demographic characteristics.

Inclusion Criteria: Participants listed as next of kin of COVID-19 patients admitted at Kenyatta National Hospital and residing in Nairobi County.

Exclusion Criteria: Healthcare workers, individuals who declined consent and unreachable participants were excluded.

Data Collection Tools: Data was collected using semi-structured interview guides.

Data Collection Techniques: Informed consent was obtained from the participants. In-depth face-to-face interviews were conducted at locations convenient and private for participants.

Data Analysis Procedures: Data collected was transcribed using verbatim and analyzed using inductive thematic analysis with the help of NVivo 14 software. The analysis followed Braun and Clarke's (2006) six-phase framework to identify, review, and report emerging themes.

III. Results

The thematic analysis identified three themes which included: Adaptation, Burden of Responsibility and Stigma. These themes reflected the role of family and community social contexts in shaping the experiences of family caregivers of COVID-19 patients during hospitalization.

Adaptation

The second theme that was revealed from the interview responses was Adaptation. Under this theme, the sub-themes including Faith and Hopefulness and Family Unity and Support were identified. These sub-themes outlined reliance on spiritual beliefs and family cohesion by caregivers so as to navigate through hospitalization challenges. From the responses, remarkable resilience demonstrated through faith and hopefulness was notable. Based on the interview responses, caregivers were noted to draw their strength from spiritual beliefs and trust in healthcare providers. This was demonstrated by the following claim from Participant B:

"We kept our patient in prayers. We were very worried and there was nothing more that we could do. Our feeling was that the patient was safe in the hands of the doctors"

Similarly, reliance on faith in coping with fear of loss was also demonstrated by Participant D who indicated the following:

"For most COVID-19 patients, they could be hospitalize and never come out of the hospital alive. I really felt pain in my heart. However, we left all to God. This is because they would go and we hear that they have died"

Improving patient conditions and successful hospital discharges inspired hope. This further strengthened the emotional resilience of caregivers. To reinforce this, Participant F recounted the following:

"As time passed by, I compared his initial condition during admission. I felt so nice. I felt a sigh of relief and joy. He was able to feed by himself. He would talk in addition to being able to take himself to the washroom"

The responses also emphasized on the critical role played by collective family efforts in caregiving. This was demonstrated under the sub-theme Family Unity and Support. For instance, coordinated family actions at the time of hospitalization and post-discharge were described by Participant A as notable in the following comment:

"We called our other in-law who owned a car. Through her help, she took our patient to hospital…Although we were not infected with COVID-19; we tried to adhere to safety measures. This was necessary to offer the needed precautionary measures to the patient and the in-law…our sister also came and helped us understand what was taking place. This was done by explaining to us things related to the illness that we did not know"

Participant D added the following:

"I knew he would get better if I took him to the hospital…When I heard that he would be discharged, I was very happy because he had escaped death"

Based on these examples, it is clear how shared responsibility and communication within families reduced stress and fostered hope.

Burden of Responsibility

Another theme that was revealed from the interview responses was Burden of Responsibility. Under this theme, the sub-themes Loss of Source of Revenue**,** Financial Hardship**, and** Accountability/Personal Advocacy were revealed. These sub-themes were a reflection of the economic and logistical pressures faced by caregivers. Evident from the interview responses, caregiving was demonstrated to place a heavy responsibility on caregivers. This was worsened by economic pressures. This was shown to be made worse by loss of income and employment during the period of lockdown which affected the capacity of the caregivers to provide for their loved ones. This was evident from the following response by Participant H:

"I was hit twice. I had to double on working and taking care of the children. I experienced very long 17 days with no sleep"

Another persistent concern shown by the responses was financial hardship. This was shown by the following explanation by Participant A:

"Financially, we were drained. The charges at the hospital were high. We had to make daily contributions to meet the patient's bills"

Caregivers also assumed roles that required accountability and personal advocacy in the management of hospital procedures, authorizations and measures of isolation. This is reflected in the following response by Participant H:

"I took him to the hospital. When they needed anything, they would call me…anytime a payment was needed, they would ask me. I was also required to authorize tests, some of which I did not understand"

Stigma

Stigma was also notable as an experience that affected social interactions and decisions regarding patient care of the caregivers. In addition, the responses demonstrated that the social experiences and decision making of the caregivers was affected by stigma. The following reply by Participant B on community reactions demonstrates the experience of stigma by caregivers:

"Neighbors in our apartment were scared to interact with use. We preferred that the patient is quarantined. At the time, there was a lot of stigma. People could hear that one is infected with COVID-19 and stay away from you. They feared being infected"

IV. Discussion

The findings of this study established that family and social contexts had a significant influence on the experiences of family caregivers. This was notable through adaptation, burden of responsibility and stigma. Regarding adaptation, the findings demonstrated reliance on faith, hopefulness and family unity as mechanisms of coping by the caregivers during hospitalization. The use of spiritual coping strategy aligns with Rehman *et al.,* (2023) who indicated that due to isolation and social distancing during the period of COVID-19, access to traditional social support systems was limited. This forced caregivers to rely on internal coping resources such as spirituality. In another study, Akhtar (2024) established that in the absence of external emotional support and affirmation, caregivers would rely on personal belief systems and close family bonds to enhance psychological stability.

From the findings, it was evident that family unity and shared responsibility played a role in reducing stress in caregivers and promoting emotional strength. This supports Savela *et al.,* (2022) who found that when there are strong social relationships and family cohesion, then there is a reduction in psychological distress and loneliness among caregivers during a pandemic. On the other hand, Smaling *et al.,* (2022) showed that limited family interactions and restrictions due to social distancing increased psychological challenges among caregivers. This is because it disrupted support networks.

The theme burden of responsibility established that caregiving during COVID-19 came with economic hardships, logistical challenges and increased responsibilities in decision-making. The findings on loss of source of revenue and financial hardship is in concurrence with Honda *et al.,* (2024) who stated that role overload was experienced by caregivers during the pandemic. Caregivers were required to balance between caregiving with economic activities so as to survive. The findings also agree with Rehman *et al.,* (2023) who observed that disruptions related to COVID-19 exposed caregivers to socio-economic challenges that increased psychological distress and caregiving strain. Caregivers also indicated experiencing financial pressures. This aligns with Fenton *et al.,* (2022) who demonstrated that visitation restrictions and a reduction in communication from the hospital led to increased stress by caregivers which limited their ability to take place in planning for the patient care and decision-making process. The findings on accountability and personal advocacy showed the complex responsibilities assumed by caregivers while going through hospital procedures and coordinating patient care. These findings are reinforced by Chu *et al.,* (2022) who found that when caregivers are unable to undertake heir caregiving roles due to hospital restrictions and barriers in communication, they experience trauma and helplessness.

Stigma also emerged as an experience among caregivers. Social stigma linked to COVID-19 infection led to fear, isolation and reduced social interaction among caregivers. This is supported by Rehman *et al.,* (2023) who found that due to social distancing and fear of infection, there is a reduction in community support systems which increases loneliness and emotional distress among caregivers. Similarly, Savela *et al.,* (2022) support these findings by reporting that social isolation contributed to heightened psychological distress and depression among caregivers during COVID-19 pandemic.

V. Conclusion

It can be concluded from the interview responses that the social context at family and community levels had a significant effect on the experiences of caregivers. This was demonstrated through mechanisms of adaptation, economic and logistical burden and stigma. To navigate through these challenges, caregivers relied on spiritual faith, hope and family cohesion. However, this was complicated by financial challenges, personal advocacy and stigma. An understanding of these factors implies that holistic support systems should be put in place. Such systems should not only consider the needs by the patients but also the environment at the family and community levels.

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