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Short Communication

Perceptions and challenges of caregiving for the elderly in rural communities

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ABSTRACT

The qualitative research examines the experiences of caregivers (CGs) in rural settings, with the emotional, psychological, and practical difficulties of looking after elderly relatives. Seven individuals, including spouses, children, and in-laws, were interviewed to gather information on caregiving experiences across five main thematic areas: the functions and emotional dimensions of caregiving, difficulties in rural areas, socio-economic obstacles, cultural and societal values, effects on CGs, and elderly health. CGs frequently encounter emotions, such as stress, guilt, fatigue, and burnout, due to the scarcity of resources and social support in rural areas. The COVID-19 pandemic has exacerbated the difficulties caused by isolation and reduced accessibility. Economic challenges associated with CGs. Cultural norms in rural areas compel people to offer care without assistance. Well-being of CGs is significantly linked to the health outcomes of older adults. This highlights the necessity for improved support systems, increased healthcare availability, social services, and respite care to ease the strain on CGs with further studies.

Keywords: Family caregivers, Rural, Survey, Qualitative research

INTRODUCTION

As the global population ages, the demand for caregiving for the elderly has escalated, with rural communities facing unique and often more challenging circumstances. In rural areas, caregiving responsibilities are frequently undertaken by family members or informal CGs, rather than by trained healthcare professionals, due to the limited access to formal care services.[1] This reliance on informal caregiving, although common in many rural settings, presents several challenges, including financial strain, physical exhaustion, emotional stress, and social isolation.[2] Furthermore, CGs in rural areas often face unique barriers, such as geographic isolation, limited access to healthcare facilities, and fewer opportunities for respite care, which compound the difficulties they experience in caring for elderly relatives.[3]

In these communities, the perception of caregiving is also heavily influenced by cultural, societal, and familial norms. For instance, caregiving is often viewed as a family duty, with elders frequently remaining in their homes or under the care of family members. However, this expectation of family caregiving can also generate significant stress due to the infrastructure, physical, emotional, and financial burdens associated with long-term care.[4] Additionally, caregiving in rural areas is shaped by social isolation, as rural CGs often lack access to support networks, respite care, and mental health services, leading to an increased risk of caregiver burnout.[5]

The COVID-19 pandemic has significantly impacted caregiving for the elderly in rural communities, amplifying pre-existing challenges. Rural CGs, who often rely on informal support networks and face limited access to healthcare resources, have been particularly vulnerable.[6] The pandemic intensified issues such as geographic isolation, restricted access to medical care, and social distancing, which disrupted regular caregiving

routines and increased the physical and emotional burden on CGs. Many rural CGs, who previously balanced their caregiving duties with work and social activities, found themselves more isolated and overwhelmed as the pandemic restricted in-person visits and reduced access to respite care.[7] In addition, rural communities have faced difficulties accessing telemedicine or online support, compounding the sense of isolation among CGs. Moreover, the increased risk of COVID-19 infection for elderly individuals and CGs further heightened anxiety and stress, exacerbating the already challenging caregiving environment.[8] This situation has underscored the urgent need for policy interventions and support systems tailored to the unique needs of rural CGs, particularly during public health crises like the COVID-19 pandemic. Understanding these evolving challenges is critical to ensuring better support for CGs and improving outcomes for elderly individuals who rely on informal care.[9,10]

Despite these challenges, the role of caregiving in rural communities has a profound impact on both the CGs and the elderly. Rural CGs often develop deep emotional bonds with those they care for, yet they may also experience feelings of isolation and helplessness as they juggle caregiving responsibilities with their own personal lives.[11] Moreover, rural elderly individuals may have less access to professional healthcare services, leading to a reliance on informal CGs who may lack the skills and training to provide adequate care.[12]

This paper aims to explore the perceptions and challenges of caregiving for the elderly in rural communities, examining the specific obstacles faced by CGs, the societal and cultural factors influencing caregiving roles, and the implications for both CGs and care recipients. In addition, the paper will discuss potential interventions and policy recommendations that could help alleviate the burdens placed on CGs in these rural settings, ultimately improving the quality of care for elderly individuals in these areas.

METHODS

Design

This research could employ a qualitative research design to investigate the individual experiences, viewpoints, and difficulties encountered by CGs in rural regions. A phenomenological perspective would be appropriate for grasping the experiences of CGs. This method would enable the research to thoroughly investigate personal stories and how CGs view their responsibilities and the obstacles they face**.**

We adopted a qualitative interpretive approach for conducting interviews with rural family CGs.[13,14] Interpretive description is a well-established methodological framework designed to capture and understand the nuanced, contextual nature of human behavior, caregiving practices, and health/social care dynamics. This approach is particularly suited for exploring caregiving experiences in rural settings, where the complexities of caregiving are influenced by unique environmental, social, and healthcare factors. This approach was used to provide an in-depth understanding of the experiences and perceptions of rural family CGs. Explore the specific needs of CGs, such as what type of support services (e.g., healthcare, respite care, community resources) they require to assist them in their caregiving roles. Generate results to inform clinical practice by identifying gaps in current caregiving support systems and healthcare service delivery in rural communities. These findings aim to inform policies and interventions designed to improve caregiving experiences and outcomes for both CGs and elderly individuals in rural areas.

Setting

The research took place in a village that falls under the Rural Health Centre in Tamil Nadu. This region, home to about 8,500 residents, is within a rural community that has restricted access to healthcare services, which differ in their availability and quality. The Department of Community Medicine at the Pondicherry Institute of Medical Sciences has embraced the village, pledging to enhance healthcare provision and community health services in the area. This context offers a distinct chance to examine the difficulties and viewpoints of CGs in rural regions, since the healthcare system is influenced by the resources and initiatives offered by the local medical facility and health center from a March, 2021 till March 2022. The research intends to evaluate the experiences of CGs and elderly people in this particular rural area, emphasizing the understanding of their healthcare requirements, support frameworks, and the wider effects of residing in a rural environment.

Participants and recruitment

The participants for this study were rural family CGs who provide care to elderly individuals in the community served by the Rural Health Centre. The CGs were selected based on specific criteria, including being the primary family caregiver of an elderly person aged 60 or older, residing in the rural area served by the health center, and having been involved in caregiving for at least six months. Non-family CGs and those who did not meet these criteria were excluded. Participants were recruited using a purposive sampling technique, which allowed for the inclusion of individuals with relevant caregiving experiences. Recruitment was facilitated through community health workers and local health personnel, who identified potential participants through their existing records and outreach programs. Informed consent was obtained from all participants, ensuring that they understood the study's purpose and their rights to confidentiality and voluntary participation. A convenience sample of approximately 15-20 CGs was

selected, with data collection continuing until saturation was reached, ensuring that the study captured a comprehensive range of caregiving experiences and challenges. This recruitment process ensured that the participants were representative of the target population and provided valuable insights into the perceptions and challenges of caregiving in rural communities.

Qualitative interviews

Qualitative interviews were conducted to investigate the views, experiences, and difficulties faced by family CGs for older adults in rural areas. Semi-structured interviews provided the flexibility to address important subjects like caregiving difficulties, emotional effects, and support networks. The interviews, conducted in Tamil, occurred in environments like Temples, Tree shadows and the homes of CGs at the Anaichakuppam village, with a duration of 45-60 minutes. Audio recordings were written out, maintaining confidentiality. Consent was secured, and participants were guaranteed their ability to withdraw whenever they chose. Thematic analysis was employed to uncover significant themes from the data, offering insights into the caregiving experience in rural regions.

Data analysis

Data from the qualitative interviews were analyzed using thematic analysis. The process began with familiarization by reading and re-reading the transcriptions. Coding was then applied to identify relevant segments of data, which were grouped into broader themes. These themes were reviewed and refined for consistency and coherence with the research objectives. The final step involved interpretation, where the themes were analyzed to reflect the caregiving experiences of rural family CGs. This approach provided a clear understanding of the challenges and support needs of CGs in rural communities.

RESULTS

A total of 7 individuals were participated in the study (Table 1). The results of the study were summarized in to five thematic areas: Roles and the emotional and psychological aspects of caregiving, challenges of caregiving in rural areas, social and economic barriers, cultural and societal norms, impact on caregiver well-being, and health outcomes of the elderly.

Table 1: Participants demographics, (n=7).

Participant no.	Age (in years)	Sex	Relation	Living with care recipient	Ethnicity	Marital status	Education	Working	House
001	40	Female	Spouse	Yes	Hindu	Married	Primary	Semiskill	Own
003	45	Female	Daughter	Yes	Hindu	Married	Primary	Semiskill	Own
005	42	Female	Spouse	Yes	Hindu	Married	Nil	Unemployed	Own
006	48	Female	Spouse	Yes	Hindu	Married	Primary	Unemployed	Own
010	40	Male	Son	Yes	Hindu	Married	Primary	Semiskill	Own
012	40	Male	Son in law	Yes	Hindu	Married	Primary	Semiskill	Own
017	44	Female	Daughter	Yes	Hindu	Married	Nil	Unemployed	Own

Theme 1: roles and the emotional and psychological aspects of caregiving

The responsibilities and emotional as well as psychological dimensions of caregiving involve a multifaceted and intensely personal journey that greatly affects the caregiver's overall health. CGs frequently assume various roles like family member, friend, and healthcare provider which can obscure boundaries and result in a sense of confusion, causing feelings of frustration or incompetence. The emotional impact of caregiving is substantial; CGs often go through various feelings, including guilt and stress, as well as resentment, particularly when they feel burdened by their duties or unable to satisfy the needs of their loved ones. This ongoing pressure can lead to mental health issues like anxiety, depression, or burnout, especially in rural regions where support resources might be limited.[15] In spite of these difficulties, providing care can also cultivate profound emotional bonds between the caregiver and the elderly person, resulting in empathy, compassion, and a robust sense of purpose. Nonetheless, this emotional bond can be quite exhausting, particularly as CGs deal with the sorrow and loss tied to seeing a cherished person lose their autonomy or well-being. The psychological effects go beyond stress, as CGs might deal with the anxiety of potential future loss or the pressure of making tough choices for their loved one. Nevertheless, numerous CGs discover a feeling of accomplishment in their position, encountering instances of joy and pride in their capability to assist and nurture someone requiring help. Ultimately, the emotional and psychological dimensions of caregiving are crucial for grasping the entire caregiving experience, affecting both the caregiver's mental and physical well-being as well as the standard of care delivered.

"Caregiving is both a gift and a burden. It challenges the caregiver's body, mind, and spirit, and while it brings moments of deep connection and purpose, it also requires a resilience that can feel almost unbearable at times." (caregiver with spouse, 001)

"I am not able to tell my problems to anyone." "I cannot walk around freely." "I cannot go to any festival or functions." "I am not able to take care of myself because of my spouse, who cannot walk." (caregiver with spouse, 001 and 002)

Theme 2: challenges of caregiving in rural areas

Caregiving in rural areas presents a unique set of challenges that significantly impact both the caregiver and the elderly individual receiving care. The most pressing issue is limited access to healthcare services, with fewer medical facilities and specialists available, often requiring long travel distances for appointments or treatments. This geographic isolation is compounded by a lack of social support networks, leaving CGs without the emotional and practical assistance they might need. Additionally, transportation issues, such as the absence of public transit and the need to travel long distances to access services, create significant logistical burdens.[16] Economic barriers also play a role, as CGs may need to reduce work hours or quit their jobs altogether due to the demands of caregiving, leading to financial strain. In rural areas, there is also a shortage of professional CGs, meaning that family members often must take on complex medical tasks without the proper training, which increases both stress and responsibility. The cultural expectation to care for elderly family members at home can further isolate CGs, as they may feel reluctant to seek help due to stigma or a sense of duty. Moreover, the lack of access to technology and telehealth services can deepen isolation, making it harder for CGs to access resources and support.[17] Ultimately, these challenges can lead to emotional and physical exhaustion, burnout, and poor mental health outcomes for CGs, highlighting the urgent need for greater resources and support systems in rural communities.[18,19]

"In rural areas, a caregiver might face the challenge of needing to travel long distances to take an elderly family member to medical appointments, as there may be no healthcare facilities nearby. This not only adds physical strain but also financial pressure due to transportation costs and time lost from work. Additionally, without accessible support systems, such as respite care services or local caregiving groups, the caregiver may feel isolated, leading to emotional exhaustion and burnout. The lack of these resources highlights the need for better infrastructure and support systems to alleviate the burden on CGs in rural settings." (caregiver with 010 and 012).

Theme 3: social and economic barriers

The COVID-19 pandemic has significantly impacted rural CGs, exacerbating existing social and economic challenges. These CGs have reported increased isolation due to reduced social interactions and limited access to support networks. The pandemic has intensified feelings of loneliness and anxiety among CGs, highlighting the need for enhanced support systems in rural areas. In many rural areas, there is limited access to social support networks, leaving CGs isolated and without the emotional or practical help they need.

"I can no longer take my mom anywhere, as I lack help to lift her from the wheelchair. My wife and siblings, who used to assist regularly, haven't visited in months. Home care has reduced services significantly; she now receives a bath weekly and no housekeeping. The isolation is tough, exacerbating her dementia as she has no external connections." (Caregiver with 010 and 012)

Economically, many CGs have faced financial strain due to increased caregiving responsibilities and reduced work hours. The lack of accessible healthcare services and home care support has further burdened CGs, leading to increased out-of-pocket expenses. Additionally, the scarcity of professional caregiving services in rural areas has forced family members to take on complex medical tasks without proper training, increasing stress and responsibility.

Financial strain is another major concern, as CGs may have to reduce their working hours or leave their jobs entirely to provide care, leading to a loss of income. Moreover, professional caregiving services, such as home health aides, are often scarce and expensive, and forcing family CGs to take on complex medical tasks without proper training. Cultural expectations in rural communities also contribute to the burden, as there is a strong belief that caregiving should be handled within the family, often creating social stigma around seeking external help. Additionally, limited access to government services and transportation can exacerbate these challenges, as CGs are often left to manage their loved ones' needs without adequate resources or assistance. These barriers not only increase the stress and exhaustion on CGs but also diminish the quality of care provided to elderly individuals, highlighting the need for more robust support systems in rural areas.

Theme 4: financial constraints

In rural villages, financial limitations have a significant effect on people and families because they make preexisting problems worse. Many rural people depend mostly on agriculture for their livelihoods, despite adverse weather and crop production conditions. Families find it difficult to pay for necessities like clothing, food, and medical care. Many people lack access to healthcare because they cannot afford medical care or travel far to the closest hospital, which leaves ailments untreated. Education, which could be a means of escaping poverty, ends up being yet another burden. Families who are unable to support their elderly parents or children suffer from worry, anxiety, and a sense of powerlessness as a result of these financial limitations.

According to Bouldin et al CGs in rural areas were more likely than those in urban areas to have financial

difficulties because of the high expense of services, the limited financial resources of caregivers, or their health insurance policies.[20] The largest obstacle to providing care for their loved ones is the expense. Treatment adherence was hampered by the inability to pay for necessary medical care. Many families respond by migrating to cities. In rural communities, financial limitations continue to be a challenge, restricting prospects for prosperity and health.

"Without assistance, we used to have happy lives. However, one person cannot afford the expenses of food, clothing, and medication; when someone is ill, there is no money for providing care."

Theme 5: impact on caregiver well-being and health outcomes of the elderly

The physical and emotional challenges faced by CGs can significantly impact both their own well-being and the health outcomes of the elderly individuals they care for. The constant demands of caregiving, such as physical exhaustion and emotional stress, can lead to caregiver burnout, which may diminish their ability to provide optimal care. For instance, CGs who are sleep-deprived or overwhelmed may find it harder to be patient or attentive, potentially affecting the quality of care they offer. This can lead to negative health outcomes for the elderly, including medication mismanagement, neglected needs, or a lack of emotional support, which are essential for their overall well-being.[21]

"I'm constantly exhausted, and I can't remember the last time I had a break."

"It's hard. My siblings don't help much, and it causes tension."

Additionally, the strain CGs experience can reduce their ability to attend to their own health, leading to a cycle of declining physical and mental health.[22] For example, CGs may neglect their own medical appointments or exercise routines, further contributing to their exhaustion. This creates a scenario where the caregiver's poor health and mental state can directly influence the care they provide, potentially leading to a decrease in the elderly person's quality of life and even exacerbating any pre-existing health conditions. Ultimately, the well-being of the caregiver and the health of the elderly individual are intertwined, highlighting the need for better support systems and shared caregiving responsibilities within families and communities.

DISCUSSION

Caregiving for the elderly in rural communities presents a distinct set of challenges and perceptions that impact both CGs and the elderly individuals they care for. Over the past decade, research has increasingly focused on the specific needs and difficulties of caregiving in rural areas. In rural communities, caregiving is often viewed as a family responsibility, with a cultural expectation that family members take on caregiving roles. Cultural care expectations placed on CGs in their daily lives have been reported as significant stressors that contribute to avoidant coping strategies, heightened psychological distress, and depression in caregivers.[23-25] These CGs often find themselves caught in a "caring dilemma," where the emotional and moral obligations of reciprocity, as well as strong familial bonds, drive their intense and sustained caregiving practices. At the same time, these CGs experience resentment toward the inescapability of their caregiving situation.[26,27] The challenges faced by these CGs were further exacerbated by the COVID-19 pandemic. With the implementation of physical distancing measures and stay-at-home directives, CGs found their access to both formal and informal support resources and respite care gradually restricted.[28,29] As day-care centers and senior activity centers closed in response to community restrictions, the demand for informal familial care increased. This shift amplified caregiving responsibilities and frustrations, as CGs were forced to provide full-time care without the ability to rely on previously available support systems.[30] This contrasts with urban settings, where formal caregiving services are more easily accessible. Rural CGs often feel a strong sense of duty or fulfillment in caring for loved ones, viewing it as a way to honor family bonds.[31] However, there are also perceptions of stigma or privacy concerns when seeking external help, as rural areas are typically more close-knit, and CGs may feel uncomfortable with outside assistance. One of the major challenges for CGs in rural communities is the limited access to healthcare and resources. Rural areas often face shortages of healthcare professionals, including geriatric specialists, nurses, and home health aides. This shortage places a greater burden on family caregivers, who may lack formal training or support.[32,33] Additionally, CGs in rural areas often face long distances when traveling for medical appointments or specialized care, which can lead to delays in treatment and added physical and emotional stress. The lack of respite care options is another significant challenge, as formal respite services are scarce, leaving family CGs without the opportunity to take breaks or seek relief, which increases the risk of burnout. Economic and social challenges are also prevalent. In rural communities, CGs may struggle financially due to lower average incomes and fewer affordable caregiving resources. Many CGs in these areas also have to balance caregiving with employment, which can lead to financial strain and increased stress this issue, leading to overburdened caregivers.[35,36] Social isolation is another key problem, as CGs in rural areas often have limited access to social networks or support groups. This isolation can lead to feelings of loneliness, emotional distress, and a lack of necessary emotional support.[37] Despite these difficulties, there are positive aspects of caregiving in rural areas. Many CGs report a strong sense of pride and fulfillment from helping elderly relatives remain in their homes. The close-knit nature of rural

communities often allows for deeper familial connections, creating an intimate caregiving experience. These strong relationships provide emotional rewards and a sense of accomplishment. However, the unique difficulties remain and require attention to ensure CGs are adequately supported. Over the last decade, several solutions have been proposed to address the challenges faced by rural caregivers. One promising solution is the increased use of telemedicine. Telehealth can help bridge the geographic barriers faced by caregivers, allowing for easier access to medical consultations and professional support. Community-based support programs have also been developed to offer rural CGs volunteer networks, local support groups, and resources to reduce isolation and improve access to assistance. Additionally, training and education for CGs can help alleviate some of the stress and improve caregiving skills. Online resources, especially, are particularly beneficial in rural settings where in-person training might be limited.[38] In conclusion, caregiving for the elderly in rural communities presents both significant challenges and unique opportunities for personal fulfillment. Addressing these issues requires a multifaceted approach, including improved healthcare access, increased social support, and the provision of adequate resources and training for caregivers.[39,40]

Limitations

Even with these important insights, the research faces numerous limitations. The limited sample size of seven participants restricts the applicability of the results. Moreover, all participants shared similar demographic characteristics, potentially overlooking the varied caregiving experiences present within different ethnic, cultural, or socioeconomic populations. The dependence on self-reported information can also lead to bias, since CGs might minimize their difficulties or exaggerate specific elements of caregiving. Future studies involving larger and more varied samples along with more objective assessments could enhance the comprehension of the caregiving experience and assist in shaping interventions designed to support CGs in rural regions.

CONCLUSION

This research emphasizes the diverse challenges encountered by caregivers, especially in rural regions, as they manage the emotional, psychological, and physical pressures of providing care. The recognized themes responsibilities and emotional factors, difficulties in rural caregiving, social and financial obstacles, cultural values, and caregiver health demonstrate the significant effect caregiving can exert on the caregiver as well as the elderly person. CGs frequently go through a complicated mix of feelings, such as stress, guilt, and loneliness, particularly in rural areas where resources are scarce. The absence of healthcare services, social assistance, and job prospects worsens the difficulties encountered by these individuals. The pandemic has only aggravated these obstacles, underscoring the need for enhanced healthcare infrastructure and social support systems in rural areas.

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