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Psycho-Spiritual Well-Being and Stress Levels among Informal Caregivers of the Terminally Ill Within the Rwandan Households

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ABSTRACT

The increasing prevalence of non-communicable diseases and the global shift toward home-based palliative care have placed significant caregiving responsibilities on informal caregivers, particularly within family-centered societies such as Rwanda. Guided by the Integrated Spiritual Well-Being and Resilience-Coping Theory and the Caregiver Stress Process Model, this study examined psycho-spiritual well-being and stress levels among informal caregivers of terminally ill family members in Rwandan households. A descriptive cross-sectional design was employed, involving a purposive sample of 30 caregivers. Data were collected using the Kingston Caregiver Stress Scale (KCSS) and the Psycho-Spiritual Well-Being Scale (P-SWBS), and analysed using descriptive statistics and Spearman correlation. Findings revealed that caregivers reported high levels of psycho-spiritual well-being across domains such as compassion, connectedness, and meaningfulness. Despite this, caregivers experienced moderate to high levels of stress, particularly related to financial difficulties, family conflicts, and caregiving burden. Notably, no significant relationship was found between psycho-spiritual well-being and stress levels. These results suggest that while spiritual resources enhance resilience and meaning-making, they may not sufficiently mitigate stress in the presence of substantial structural and contextual challenges. The study concludes that caregivers in Rwanda demonstrate strong internal coping capacities but operate within environments characterized by limited external support. Therefore, strengthening formal support systems alongside psycho-spiritual resources is essential to effectively reduce caregiver stress and improve overall well-being.

Keywords: Psycho-spiritual well-being; caregiver stress; Umuryango, informal caregivers; palliative care; home-based care; resilience; spirituality; Rwanda.

INTRODUCTION

The global health system is increasingly challenged by a growing ageing population and a rising burden of non-communicable diseases, which has led to a greater demand for palliative care services (World Health Organization [WHO], 2020). Palliative care focuses on improving the quality of life of individuals with life-threatening conditions as well as supporting their families and caregivers. In recent years, there has been a notable shift toward home-based care, as many patients prefer to receive end-of-life care within their homes rather than in institutional settings (Gomes et al., 2013). As a result, informal caregivers, who are often family members, have assumed a central role in providing physical, emotional, and spiritual care.

In the Rwandan context, caregiving is deeply embedded in cultural and family values, particularly the concept of *Umuryango (family unit)*, which emphasizes collective responsibility and interconnectedness. Caring for a terminally ill family member is therefore not only a practical obligation but also a moral and social duty. However, despite this strong cultural foundation, caregivers often face significant challenges, including limited financial resources, lack of formal support systems, and prolonged caregiving responsibilities, which may negatively affect their psychological and emotional well-being. The intersection of these responsibilities often results in significant psychological and spiritual strain. Psycho-spiritual well-being is defined as an individual's

integrative emotional and spiritual health functioning within their specific cultural context (Egunjobi et al., 2023). When the demands of caregiving exceed the available resources, caregivers experience stress, a state of mental tension resulting from difficult life situations (WHO, 2023). Emerging research highlights a collective burden in Rwandan families, where the stress of a terminal diagnosis is distributed across the household (Dushimiyimana et al., 2024). This creates an inter-generational trickle-down effect, where the psychological vulnerability of primary caregivers negatively impacts the well-being of both children and the elderly within the home (Batamuliza & Nsereko, 2023).

Central to this dynamic is the tension between cultural expectations and practical limitations. The cultural value of *Agaciro* (dignity) dictates that honoring a patient's final wishes and maintaining spiritual rituals are essential internal resources for resilience. When these obligations are fulfilled, caregivers experience a sense of purpose and stability; however, financial constraints or physical exhaustion often disrupt these rituals, leading to spiritual distress and increased burnout (Uwimana & Mtshali, 2022). Despite these critical nuances, current research in Rwanda remains predominantly focused on institutional settings, leaving a gap in our understanding of the lived experiences of domestic caregivers.

This study addresses this gap by examining the relationship between psycho-spiritual well-being and stress levels among caregivers of the terminally ill in Rwanda. The research is anchored in the Integrated Spiritual Well-being and Resilience-Coping Theory, which posits that spirituality acts as a protective shield against adversity (Clark et al., 2010), and the Caregiver Stress Process Model, which views caregiver strain as a dynamic process leading to adverse physical and emotional outcomes (Pearlin et al., 1990). By leveraging the communal framework of *Umuryango*, this research seeks to provide a culturally grounded analysis of how family-based spiritual frameworks can be utilized to mitigate stress and prevent caregiver burnout in Rwandan households.

Research objective

i) To assess the level of psycho-spiritual well-being among caregivers of terminally ill family members in Rwanda.

ii) To determine the level of stress experienced by these caregivers.

iii) To examine the relationship between the caregivers' psycho-spiritual well-being and their stress levels.

METHODOLOGY

A descriptive cross-sectional design was used to examine psycho-spiritual well-being and perceived stress among informal caregivers of terminally ill family members in Rwanda. All variables were measured once, and no manipulation or intervention was implemented. A purposive sample of 30 informal caregivers was selected. Two standardized self-report measures were administered to assess caregiver stress and psycho-spiritual well-being. Caregiver stress was measured with the Kingston Caregiver Stress Scale (KCSS), a multi-domain instrument assessing stress related to caregiving tasks, family dynamics, and financial pressures. The KCSS was contextually adapted to reflect the Rwandan home-based caregiving context while retaining the underlying constructs of the scale. Psycho-spiritual well-being was assessed with the Psycho-Spiritual Well-Being Scale (P-SWBS; Egunjobi et al., 2023), which measures five domains: self-awareness, connectedness, meaningfulness, compassion, and self-transcendence. After recruitment, participants completed the KCSS and the P-SWBS. Responses were collected once per participant and were used only for research purposes.

Spearman correlation and descriptive statistics (frequencies, percentages, and means) were used to summarize participant characteristics and overall levels of psycho-spiritual well-being and caregiver stress. To examine the association between psycho-spiritual well-being and caregiver stress, a bivariate correlation analysis was conducted.

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FINDINGS

Objective I: Level of Psycho-Spiritual Well-being

Table 1: Psycho-Spiritual Well-being of Caregivers (N = 30)

Variable	Somewhat Agree (%)	Agree (%)	Strongly Agree (%)	Interpretation
Self-awareness	10%	50%	40%	High level
Connectedness	10%	40%	50%	High level
Meaningfulness	10%	46%	43%	High level
Compassion	3%	30%	66%	Very high
Self-transcendence	6%	46%	46%	High level

Objective II: Level of stress among caregivers

Table 2: Level of stress experienced by caregivers (N = 30)

Stress indicator	No stress (%)	Some stress (%)	Moderate (%)	High (%)	Extreme (%)
Feeling overwhelmed	16%	26%	40%	13%	3%
Relationship changes	6%	13%	20%	43%	16%
Social life changes	10%	23%	46%	20%	—
Conflict with duties	6%	33%	36%	23%	—
Feeling trapped	13%	46%	26%	6%	6%
Lack of confidence	—	13%	40%	26%	16%
Future concerns	—	16%	26%	30%	26%
Family conflicts	3%	10%	33%	30%	20%
Support conflicts	—	3%	26%	53%	16%
Financial difficulties	3%	3%	13%	30%	50%

Table 3: Comparison of objectives to findings

Objective	Key finding
Objective I	High psycho-spiritual well-being
Objective II	Moderate to high stress levels
Objective III	No significant relationship

Table 4: Demographic characteristics of respondents (N = 30)

Variable	Category (Age group)	Frequency (n)	Percentage (%)
Age	18-29	4	13.3%
	30-44	14	46.7%
	45-59	9	30.0%

	60+	3	10.0%
Gender	Male	19	63.3%
	Female	11	36.7%
Marital status	Married	30	100%
Religion (Faith)	Christian	18	60.0%
	Muslim	12	40.0%
Religious practice	Daily	12	40.0%
	Weekly	2	6.7%
	Occasionally	6	20.0%
	Rarely	10	33.3%
Relationship to patient	Parent	18	60.0%
	Child	7	23.3%
	Spouse	3	10.0%
	Sibling	2	6.7%
Duration of caregiving	6-12 months	6	20.0%
	1-3 years	17	56.7%
	>3 years	7	23.3%
Hours of caregiving	Full-time	30	100%
Primary caregiver	Yes	30	100%
Receive support	No	30	100%

DISCUSSION

This study is anchored on the Integrated Spiritual Well-Being and Resilience-Coping Theory and the Caregiver Stress Process Model, which together provide a comprehensive psycho-spiritual and stress-oriented framework. The Caregiver Stress Process Model was developed in 1990 by Leonard I. Pearlin and colleagues, explaining caregiving stress as a process involving primary stressors (care demands), secondary stressors (role strains), mediators (coping and social support), and outcomes (psychological distress or well-being). The Integrated Spiritual Well-Being and Resilience-Coping Theory, emerging from resilience and spiritual well-being scholarship in the early 21st century, particularly influenced by the work of Kenneth I. Pargament on religious coping, emphasizes spirituality as an internal resilience resource that fosters meaning-making, hope, inner strength, and adaptive coping during adversity. The tendency of these theories is integrative and multidimensional: the Stress Process Model takes a socio-psychological approach to understanding stress progression, while the Spiritual Well-Being and Resilience perspective highlights protective psycho-spiritual resources that buffer stress effects. In this study, caregiving for terminally ill family members within Rwandan households constitutes the primary stressor, while psycho-spiritual well-being (faith, meaning, connectedness, transcendence, and resilience) functions as a mediating resource influencing how caregivers experience and manage stress. The selection of these theories is justified because together they allow the study to examine both the structural process of caregiver stress and the culturally relevant psycho-spiritual strengths that may mitigate stress outcomes, offering a contextually appropriate framework for understanding caregiver experiences within Rwanda’s relational and faith-informed social environment.

The findings indicate that the majority of caregivers were male (63.3%), while females constituted 36.7% of the sample. All respondents were married (100%), suggesting that caregiving responsibilities are largely assumed

within family units where individuals already have established household roles and obligations. This finding is consistent with studies indicating that caregiving often occurs within family systems and is influenced by existing social and marital roles (Schulz & Sherwood, 2008).

With regard to religious affiliation, the majority of participants identified as Christians (60%), followed by Muslims (40%). A considerable proportion of respondents reported engaging in religious practices on a daily basis (40%), highlighting the potential importance of spirituality in the lives of caregivers. Previous research has shown that religious involvement plays a significant role in coping with stress and maintaining psychological well-being among caregivers (Koenig, 2012; Pargament, 1997).

In terms of caregiving characteristics, most respondents were caring for their parents (60%), followed by their children (23.3%), spouses (10%), and siblings (6.7%). This indicates that caregiving is predominantly directed toward immediate family members, particularly older parents, which is consistent with family-centered caregiving patterns observed in many societies (Pearlin et al., 1990). Furthermore, more than half of the caregivers (56.7%) had been providing care for a moderate duration, while 23.3% had been engaged in caregiving for more than three years, suggesting prolonged exposure to caregiving demands. Prolonged caregiving has been associated with increased stress and burden over time (Schulz & Sherwood, 2008).

Notably, all respondents reported being full-time caregivers (100%) and primary caregivers (100%), and none indicated receiving any form of external support (100%). This finding reflects a high level of caregiving responsibility and dependency placed on individuals within the household. According to the Caregiver Stress Process Model, the absence of support systems significantly intensifies caregiver burden and contributes to stress outcomes (Pearlin et al., 1990).

Overall, these characteristics suggest that caregivers in this study operate under conditions of substantial responsibility with limited external assistance, which may contribute to increased levels of stress and burden. At the same time, the prominence of religious engagement among respondents may serve as an important psycho-spiritual resource for coping with these challenges (Pargament, 1997; Koenig, 2012).

According to Pargament (1997), individuals facing stressful life events often rely on religious and spiritual beliefs to construct meaning and maintain emotional stability. In the present study, caregivers appear to interpret caregiving not only as a burden but also as a meaningful and compassionate responsibility, which enhances their psycho-spiritual well-being. Similarly, research has shown that spiritual well-being is positively associated with resilience and psychological adjustment in stressful caregiving contexts (Koenig, 2012).

Despite this high level of psycho-spiritual well-being, the study found that caregivers experience moderate to high levels of stress**,** particularly in relation to financial difficulties, family conflicts, and role strain. These findings strongly align with the Caregiver Stress Process Model proposed by Pearlin et al. (1990), which conceptualizes caregiving stress as a multidimensional process involving primary stressors (care demands), secondary stressors (role conflicts and financial strain), and outcomes such as psychological distress.

In this study, caregiving for terminally ill family members represents a significant primary stressor**,** as all respondents were full-time caregivers without support. Secondary stressors are evident in the high levels of financial difficulties, family conflicts, and disruptions in social life. These findings are consistent with previous research indicating that caregiving responsibilities often lead to increased stress, burden, and reduced quality of life (Schulz & Sherwood, 2008).

A key finding of this study is that there is no significant relationship between psycho-spiritual well-being and stress levels**.** This result suggests that, although caregivers possess strong internal spiritual resources, these may not be sufficient to significantly reduce stress in the presence of overwhelming external demands. This finding is supported by Pearlin et al. (1990), who argue that structural and contextual stressors can outweigh the effects of coping resources.

At the same time, the findings do not contradict the resilience-coping perspective but rather extend it. While spirituality enhances caregivers' ability to endure stress and maintain a sense of meaning, it does not eliminate the objective burdens associated with caregiving. Similar findings have been reported in studies showing that spiritual coping improves emotional resilience but does not necessarily reduce perceived stress when external pressures are high (Park, 2005).

Within the Rwandan context, where strong cultural and religious values emphasise family responsibility and faith, caregivers may rely heavily on psycho-spiritual resources. However, the absence of formal support systems and the presence of financial constraints may limit the effectiveness of these internal coping mechanisms. Therefore, the coexistence of high psycho-spiritual well-being and high stress reflects a situation in which caregivers are resilient but structurally unsupported.

CONCLUSION

The findings of this study provide important insights when interpreted through the lens of the Caregiver Stress Process Model and the Integrated Spiritual Well-Being and Resilience-Coping Theory. While caregivers demonstrated high levels of psycho-spiritual well-being, particularly in compassion, meaningfulness, and connectedness, this did not significantly correlate with reduced stress levels. This suggests that although spirituality serves as an important internal coping mechanism, it may not be sufficient to counterbalance the intense structural stressors associated with caregiving, such as financial strain, lack of support, and role overload. In line with Pearlin's Stress Process Model, the caregiving experience in this study reflects a progression from primary stressors (care demands) to secondary stressors (family conflict and financial burden), resulting in psychological distress. At the same time, Pargament's framework helps explain the caregivers' resilience and sustained sense of purpose. Therefore, the findings highlight the need to complement psycho-spiritual strengths with external support systems in order to effectively reduce caregiver stress within the Rwandan context.

RECOMMENDATIONS:

Recommendations for government and policymakers

The study revealed that caregivers experience high stress**,** particularly due to financial difficulties and lack of support (100%)**.**

Therefore, the government should establish caregiver support programs**,** including financial assistance (subsidies or stipends), inclusion of caregivers in social protection schemes**,** developing community-based palliative care services to reduce the burden on family caregivers, integrating caregiver needs into national health policies, especially within home-based care programs, and chronic and terminal illness management systems. This addresses primary and secondary stressors identified in the Caregiver Stress Process Model (Pearlin et al., 1990).

Recommendations for health care institutions

Findings show caregivers are full-time, unsupported, and overwhelmed. Health institutions should provide caregiver training programs on basic patient care skills, stress management techniques, introduction of routine psychological screening for caregivers during hospital visits, establishment of caregiver counselling services within hospitals, and promote respite care services (temporary relief for caregivers) to reduce care burden and improve coping capacity.

Recommendations for the community and NGOs

The study shows strong spiritual well-being, but weak external support systems. NGOs and community organisations should create caregiver support groups (Peer sharing and Emotional support. Faith-based support systems should be strengthened (Church/mosque involvement in caregiving assistance and spiritual counselling programs. The community volunteer programs should be developed to assist with caregiving tasks and reduce caregiver isolation.

Recommendations for families

Family conflict and lack of support were major stressors. There, families should Promote shared caregiving responsibilities and improve communication and decision-making. Families should provide emotional and practical support to the primary caregiver to reduce the secondary stressors (family conflict, role strain).

Recommendations for caregivers

Although caregivers show strong resilience, stress remains high. Caregivers are encouraged to engage in stress management practices such as Relaxation techniques and Time management. Caregivers are encouraged to continue using spiritual coping strategies. They should continue prayer, meditation and faith engagement. They also have to seek social and professional support when available

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