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Original Research

Caregiver Burden and Quality of Life among Family Caregivers of the Elderly in Nuwara Eliya District, Sri Lanka: A Cross-sectional Study

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Abstract

Family caregivers, often lacking financial, social, and psychological support, bear the primary responsibility for elderly care. Rapidly aging population of Sri Lanka has intensified the demand for family caregivers in eldercare, particularly in rural areas where institutional support is limited. This study aimed to assess the caregiver burden and quality of life (QoL) among family caregivers in the Nuwara Eliya District, Sri Lanka. A descriptive cross-sectional study was conducted in two selected Medical Officer of Health areas in Nuwara Eliya. Data were collected using a pre-tested interviewer-administered questionnaire. The sample included 166 caregivers selected via convenient sampling. The questionnaire comprised three sections: demographic characteristics, caregiver burden assessed using the Sinhala-translated Zarit Caregiver Burden Interview, and QoL measured with the Sinhala-translated Adult Carer Quality of Life Questionnaire. Data were analysed using SPSS version 25.0, applying descriptive and inferential statistics to identify associations between caregiver burden and sociodemographic factors. The mean (±SD) age of caregivers was 51±11 years, with 69% being female. The caregiver burden was negatively correlated with QoL (p<0.01). Moderate to severe caregiver burden was reported by 58%, while 68% reported a mid-level QoL. Higher QoL was linked to Sense of Value (41%) and Support for Caring (35%), whereas financial strain and caregiving stress were major concerns. The caregiver burden was significantly associated with caring choice (p<0.01), caring stress (p<0.01), money matters (p<0.05) and sense of value (p<0.05). Quality of life was significantly associated with support for caring (p<0.01), caring choice (p<0.01), caring stress (p<0.01), financial matters (p<0.01), sense of value (p<0.01). Caregivers in rural Sri Lanka experienced moderate to severe burden, with most reporting a mid-level quality of life. The caregiver burden was negatively associated with QoL. Higher QoL was associated with social support and a sense of value, while financial strain and caregiving stress were major concerns. These findings highlight the urgent need for culturally appropriate interventions that offer emotional, financial, and practical support to caregivers.

***Keywords**: Caregiver burden, Informal family caregivers, Quality of life*

Introduction

Sri Lanka is undergoing a fast demographic transition, where the percentage of the elderly population is more than 12% of the total population [1]. Aging makes the older population prone to a variety of aging-related complications such as disabilities and chronic diseases, resulting in increased dependency among the elderly. To the majority of families, the biggest challenge is providing caregiving within the home, where family caregivers have a significant load for the older adults residing in their homes, particularly in areas like Nuwara Eliya [2]. Institutional care for older people in these areas has the caregiving responsibility largely on family caregivers, who have a lack of sufficient financial resources and weak social and psychological support [3]. Although Sri Lankan culture has always valued and promoted the tradition of caregiving, the growing demands and complexity of eldercare are exposing informal family caregivers to higher vulnerability in experiencing issues in their physical and mental health and with current economic cost, eventually impacting their quality of life (QoL).

Informal carers, primarily family members, constitute a vital resource in the care of older persons in activities of daily living, their medical conditions, and mental health [4]. This caring role, however, frequently translates into burden in terms of emotions, physical demands, and economic costs on the carers [2,4]. Research has shown that these caregivers tend to experience high levels of psychological distress, such as anxiety, depression, and burnout, because they handle work, domestic, and social responsibilities which tend to adversely affect their own quality of life [4]. Because informal caregiving has multiple factors involved and there are no proper support systems available which may have an unfavorable impact on the quality of life of the informal caregivers of Sri Lanka. The burden that caregivers face is described as a cumulative response to the stresses a caregiver experiences alongside the challenges of looking after a dependent [5]. The informal caregiver burden problem brings in its own set of demographical and social challenges. This is especially true, as most informal family caregivers lack some knowledge concerning the caregiving process, suffer from some financial hardship, and face difficulty in obtaining appropriate healthcare services [6].

Moreover, social expectations in some cultures, a given social support network, and the self-resilience of the individual markedly alter the degree of caregiver burden [7]. For instance, Asian culture places a lot of emphasis on family participation in caregiving, which elevates burden [8]. In Sri Lanka, a Jaffna study also pointed out the contribution of family members to the care of older people. Caregiving is part of their culture and is viewed as a cost they pay for the wellbeing of their loved ones, particularly due to the poor government support for elder care in the region [9].

Though Sri Lanka has an escalating population of elderly persons [1], the country lacks a formal support and education system for informal carers who primarily care for the elderly. Therefore, these informal carers may have difficulties in adapting to disease conditions, which negatively affect both the physical and mental health of the carers and the caregivers [1]. Furthermore, the

majority of informal carers perceive caregiving as an obligation they must reconcile, and in doing so, they can gain a sense of meaning and responsibility due to ingrained cultural expectations. This may lead to unrecognised stress and self-sacrifice among family caregivers. Some studies have shown that, although the caregivers may find their role rewarding, they continue to be tired and socially isolated due to caregiving pressures [8]. Gender disparities in caregiving also usually emerge, and social expectations have mainly allocated the care responsibility to women.

Therefore, there is an increased need to assess the caregiver burden of informal caregivers, especially in districts like Nuwara Eliya. Determining the levels of caregiver burden and quality of life is of great importance in the development of effective interventions to decrease the burden and promote the wellbeing of caregivers. Therefore, the present study was carried out to assess the levels of caregiver burden and quality of life in older adult family caregivers of Nuwara Eliya District, Sri Lanka.

Methods

A quantitative approach was utilised in this descriptive cross-sectional study. Ethical approval for the study was obtained from the Ethics Review Committee of KAATSU International University (KIU_ERC_2024_205) and institutional approval was obtained from the Regional Director's Office of Nuwara Eliya District. The research was conducted in two selected Medical Officer of Health (MOH) areas: Ambagamuwa and Walapane under the Nuwara Eliya District, Sri Lanka. Data collection was completed within two weeks, from the 13th to the 27th of November 2024, by home visiting informal caregivers within the MOH areas.

The sample size was calculated using Daniel's formula [11]. Sampling was conducted using convenient sampling. The original target was 411 participants, however, the actual sample consisted of 166 caregivers due to the limited number of caregivers. Informal caregivers were first identified through home visits made by the researchers. Homes containing elderly bedridden adults and identifying the lead informal caregiver having cared for at least six months were selected through these visits. Researchers explained the purpose of the research and obtained informed consent from those participants who were willing to participate. Data were collected using a pre-tested, interviewer-administered questionnaire with three sections. The first section assessed demographic variables, including age, educational attainment, and economic status. The second section assessed caregiver burden using the Sinhala translation (Written communication, the 10/66 Dementia Research Group-Sri Lanka, May 2023) of the Zarit Caregiver Burden (ZBI) Questionnaire [5], which contained 22 items. The third phase measured quality of life using Sinhala translation of the Adult Carer Quality of Life Questionnaire (AC-QoL) [12] with 40 items and eight subscales.

ZBI is a widely applied self-reporting subjective care-burden measure among carers [5] and has been translated and adapted into Sinhalese for application in Sri Lanka [1]. It consists of 22 items, with a scoring of 0-4 per item. All the items are measured using a 5-point Likert scale. Item scores can be summed up to yield an overall 0-

88, with higher scores indicating higher burden. 0-20 indicates 'little or no burden', 21-40 'mild to moderate burden', 41-60 'moderate to severe burden' and 61-88 'severe burden', respectively. A score of 24 or more indicates high risk of depression in the carer.

Sinhala-translated Adult Carer Quality of Life (AC-QoL) scale [12] was employed within this study. The instrument was pre-tested on 20 family carers to ensure it was as understandable as possible. The instrument consisted of items which fell into eight subscales: carer stress, financial impact, personal wellbeing, support for caring, carer satisfaction, relationship with the care recipient, impact on personal time, and perceived social support. The AC-QoL is made up of 40 four-point scale items (0 = "never"; 1 = "some of the time"; 2 = "a lot of the time"; 3 = "always"), grouped in eight subscales: support for caring (items 1–5), caring choice (items 6–10), caring stress (items 11–15), financial matters (items 16–20), personal growth (items 21–25), sense of value (items 26–30), ability to care (items 31–35), and carer satisfaction (items 36–40). Total scores range from 0 to 120, and poor quality of life is scored 0–40, moderate quality of life 41–80, and good quality of life a score of over 80. Individual subscales also have a range of 0 to 15, with higher scores indicating improved quality of life within that particular area. A range of 0 to 5 represents a poor quality of life, which may translate to difficulties, 6 to 10 represents a mid-quality of life, and 11 or more represents a good quality of life on the subscale.

Data collected were statistically analysed with the help of SPSS Statistics version 25.0. Descriptive statistics including frequencies, percentages, means, and standard deviations were used in summarising demographic and caregiving-related variables. Normality of data was tested by Kolmogorov-Smirnov test, which revealed non-normal distribution of Zarit Burden Interview Questionnaire (ZBI) and Quality of Life (QoL) scores (p<0.05). Therefore, inferential analysis with non-parametric statistical tests was performed. Spearman's correlation test was used to examine the correlation between caregiver burden, QoL, and subscales of the AcQoL. A significance level of p<0.05 was considered as statistically significant.

Results

The mean ±SD age of the caregivers was 51±11 years. The sample included more women (n=115, 69%) than men (n=51, 31%). Most participants were Buddhists (n=157, 95%) and married (n=150, 90%). Economically, half of them were unemployed (n=84, 51%). Most were educated up to G.C.E O/Ls (n=100, 60%), and most had an income of between 10,000 to 100,000 LKR monthly (n=110, 66%). (Table 01)

Concerning the involvement of care recipients, 30% (n=52) of the caregivers reported that they were caring for their mother. Most of the caregivers (n=91, 55%) had been caring for less than five years, and 42% (n=70) reported caregiving for 1–5 years. The mean±SD caregiving hours per week were 31±24. (Table 01)

The caregiver burden (mean±SD) and quality of life was 41±7 and 72±1, respectively. The most significant caregiver burden was moderate to severe (n=97, 58.4%), followed by mild to moderate burden (n=68, 41%). (Table 02). In the case of quality of life, the majority of the

caregivers (n=112, 68%) had a mid-range quality of life, and 28% (n=47) had a high quality of life. (Table 02)

Table 01 Demographic details of the participants (n=166)

Variable	Frequency n (%)
Age (mean±SD)	51±11
Gender category	
Male	51 (31%)
Female	115 (69%)
Ethnicity	
Buddhist	152 (92%)
Hindu	6 (4%)
Islam	3 (2%)
Catholic	5 (3%)
Marital status	
Married	150 (90%)
Unmarried	13 (8%)
Widowed	3 (2%)
Educational level	
No formal education	22 (13%)
Up to G.C.E. O/L	100 (60%)
Up to G.C.E. A/L	38 (23%)
Graduate	6 (4%)
Occupation	
Government	14 (8%)
Private	19 (11%)
Self employed	49 (30%)
Unemployed	84 (51%)
Monthly income (LKR)	
<10000	49 (30%)
10000 – 100000	110 (66%)
>100000	7 (4%)
Characteristic of caregiving	
Relationship with carer	
Mother	51 (31%)
Father	38 (23%)
Spouse	30 (18%)
Children	1 (1%)
Other	46 (28%)
How long have you been caring	
<1 year	91 (55%)
1-5 year	70 (42%)
5-10 year	5 (3%)
Hours spent caring mean per week (mean±SD)	31±24

Able to Care (69%), Personal Growth (69%), and Caring Stress (61%) comprised the highest percentage of respondents in the mid-QoL range. On the other hand, Sense of Value (41%) and Support for Caring (35%) comprised the highest percentage of respondents in the high-QoL range. Similarly, Caring for Choice (35%) and Financial Matters (34%) also comprised a high percentage of respondents reporting high QoL (Figure 01)

Table 02 Caregiver burden and quality of life

Variable	Mean ± SD	Category	Frequency n (%)
Caregiver burden	41±7	No to Mild	1 (1%)
		Mild to Moderate	68 (41%)
		Moderate to Severe	97 (58%)
Quality of life	72±1	Low QoL	7 (5%)
		Mid-range QoL	112 (68%)
		High QoL	47 (28%)

In contrast to this, Carer Satisfaction (9%), Caring for Choice (9%), and Ability to Care (10%) had the lowest sample percentage in the low-QoL category. However, Caring Stress (17%), Support for Caring (17%), and Financial Matters (14%) had slightly larger percentages in the low-QoL category. (Figure 01)

The correlation revealed a statistically significant negative correlation (r = -.250, p<0.01) between total Quality of Life (QoL) and total Zarit Burden Interview Questionnaire (ZBIQ). Moreover, total caregiver burden (ZBIQ) was significantly correlated with caring stress (p<0.01) and caring choice (p<0.01) and inversely related to sense of value (p<0.05) and financial matters (p<0.05). The overall quality of life (QoL) was strongly associated with support for caring (p<0.01), choice to care (p<0.01), stress in caring (p<0.01), money (p<0.01), personal growth (p<0.01), sense of worth (p<0.01), being able to care (p<0.01), and satisfaction in carers (p<0.05).

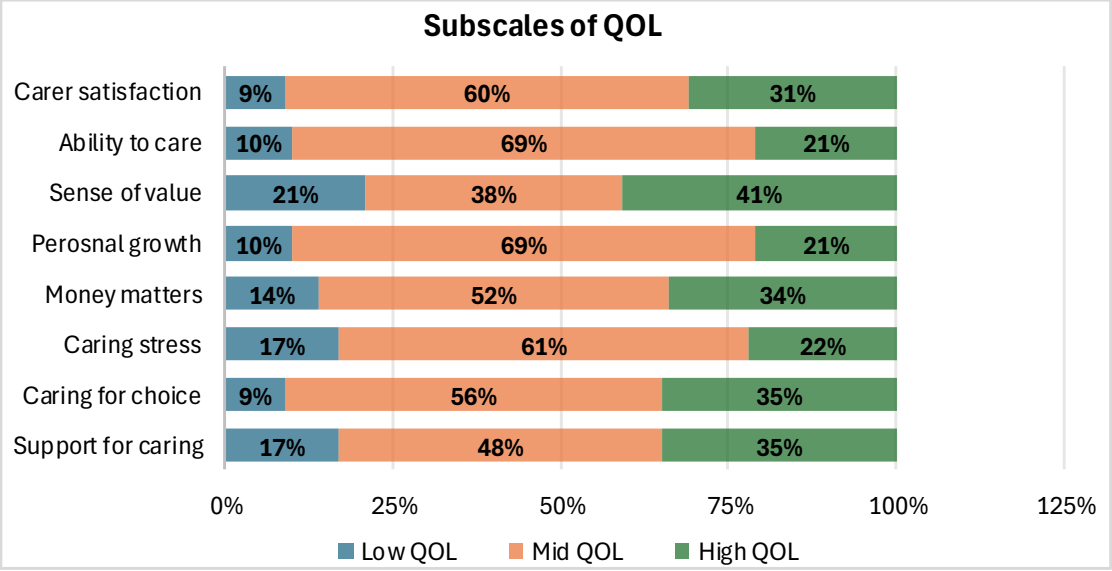

Figure 01: Distribution of sub-scale QoL levels

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Table 03 Association of caregiver burden and quality of life (n=166)

Variables	1	2	3	4	5	6	7	8	9	10
1. Total ZBIQ value	—									
2. Total QoL value	–.250**	—								
3.Support for Caring	–.118	.701**	—							
4.Caring Choice	.253**	.255**	.140	—						
5.Caring Stress	.336**	.440**	.231**	.284**	—					
6.Money Matters	–.173*	.700**	.490**	.088	.425**	—				
7.Personal Growth	–.038	.574**	.236**	–.108	.115	.279**	—			
8.Sense of Value	–.183*	.770**	.510**	–.068	.148	.453**	.561**	—		
9.Ability to Care	–.134	.441**	.193*	.020	.068	.208**	.325**	.287**	—	
10.Carer Satisfaction	–.140	.176*	–.017	.007	–.087	–.071	.163*	.174*	.210**	—

Note: Spearman's rho coefficients are reported. *ZBIQ = Zarit Burden Interview Questionnaire Total; QoL Total = Quality of Life. p*<0.01**; *p*<0.05*

Discussion

This study found that middle-aged women, mostly Buddhists, made up the majority of carers. A significant number of these women were unemployed and had only completed G.C.E O/L. The majority of carers have spent 31 hours a week on average taking care of their parents. The results showed a mid-range quality of life and a moderate to severe caregiver burden, with social support, financial security, and stress all being important factors in their wellbeing. Furthermore, quality of life and caregiver burden were significantly correlated negatively. Higher quality of life scores were also positively correlated with social support, financial stability, and a sense of worth in providing care. Reduced quality of life was associated with carer stress and financial difficulties.

The current study findings are consistent with those of earlier research that found similar sociodemographic outcomes in different settings. The family structure and cultural customs in Sri

Lanka, where providing care is socially normalised as a female role, could be responsible for the study's finding that 69% of carers were women. Furthermore, the greater percentage of women who are carers may be explained by the fact that they are less likely to be employed in the area, which enables them to take on domestic duties more easily. The results of a study carried out in the Batticaloa District, which also discovered that more women were taking on caregiving, are in line with this finding [13].

Wives (21%) and daughters (38%) were likewise the most common caregiver types in this study, reflecting again women's burden of responsibility from marital and family obligations that is a usual attribute in Sri Lankan society. The observation of wives and daughters as the most common caregiving types has also been observed in other previous research [1]. This gender disparity has also been evidenced in foreign literature, describing the influence of conventional assumptions concerning gender roles in dividing the caregiving responsibilities unevenly between the sexes [7, 10].

The study also found that 51% of carers were unemployed, which may indicate that caregiving obligations can interfere with one's ability to do their job. This may be because of the time required for caregiving, which is further exacerbated by the lack of an efficient support system, which forces caregivers, mostly women to quit their jobs. This result is also in line with earlier research that found that carers frequently experience work disruptions, which leads to both financial strain and insecurity [14]. Additionally, it was shown in a Chinese study that carers experience a higher financial burden as a result of their intense caregiving responsibilities and work commitment [15]. Economic burden to caregivers in Sri Lanka is also increased by the absence of institutional eldercare services, which places even greater pressure on informal caregivers to remain at home and care.

The educational level of the caregivers is also an important demographic attribute observed in the current study, with most caregivers (60%) having attained only secondary-level education. This could be due to the socio-economic level of the area, such that access and support for higher education is scarce. This supports the findings of a previous study, where 69% of the caregivers had a GCE O/L level of education [10]. Low levels of education among informal caregivers are a problem for their ability to follow medical orders, access appropriate health care, and advocate for care recipients in situations of need. This is an important issue seen in most low- and middle-income countries, where low educational levels are associated with low health literacy and poorer caregiving skills [16].

Besides, this research revealed that 58% of the informal caregivers had a moderate to high burden. The high burden can be caused by many factors, such as the exhaustive responsibility of caregiving, lack of support systems, physical and emotional exhaustion as a result of long-term caregiving. Another Sri Lankan study also found that 62% of caregivers had a moderate burden [10]. In one other study, 26% were found to have moderate to severe burden and 42.9% with mild to moderate burden according to the ZBI scale [1]. The caregiver burden was lower in Nepal [3] and China [17], perhaps because more potent community support systems exist in these

settings. These differences can also be seen as a reflection of the effects of socio-economic and cultural determinants on the lives of the caregivers.

Caregiver burden can also be seen to have a detectable impact on the QoL of caregivers. In this study, 67% of the caregivers reported an average QoL, and 4% had a low QoL. The study also observed that QoL was negatively correlated with caregiver burden. The results presented here highlight the significant impact caregiving burden can have on QoL, primarily due to the psychological and emotional aspects of caregiving and without coping abilities or facilities. More emotional issues in 90% of the caregivers were reported in one study as a result of caregiving [18]. Informal caregivers were reported to have poor QoL, particularly in mental health, in another study due to stress and emotional issues they went through [3]. It is thus evident that caregiving impacts the caregivers considerably and indicates the need for particular interventions to empower and support them.

In the present study, the majority of the caregivers had a moderate quality of life, particularly in ability to care subscale, personal growth, and stress of caring. This suggests that even though the caregivers are successful in their caregiving tasks, they are still experiencing a great deal of stress. Further, the QoL scores were enhanced in the sense of value subscales and caring support, indicating that most caregivers derive gratification from caregiving tasks and receiving care significantly enhances their quality of life. The fact that most caregivers in this study perceived a greater sense of value is akin to [19], where caregivers perceived positive feelings such as happiness and gratitude. This can also be because Sri Lanka has high family bonds, which are resilience factors, and thus a greater sense of worth in caregiving. The ‘money matters’ theme of the QoL subscale and care stress, however, had vast differences at varying levels of QoL.

The current research gives a new perspective on the challenges faced by informal caregivers in Nuwara Eliya. The research also identifies culturally relevant demographic data and caring patterns, which render the results more applicable to the Sri Lankan context. The results demonstrate the need for the implementation of caregiver educational programs to promote health literacy among informal family caregivers. In addition, the research determines the major factors to be taken into consideration when attempting to improve a caregiver's quality of life. The focus on gender distinction also suggests that interventions must be gender-specific based on the caregiver's gender. The results also suggest some policy modifications that should be established to improve the general wellbeing of caregivers and care recipients.

However, there are a few limitations that should be mentioned. The reliance on self-reported data can lead to bias. Furthermore, since this study aimed at one area in Sri Lanka, generalization may be limited, as patterns of caregiving vary across different regions of the country. The cross-sectional design does not enable causal conclusions, and variation in caregiver experience by coping strategies or presence of extended family support was not explored in detail. Also, the inability to achieve the required sample size due to purposive sampling results in bias data interpretation. Completing these gaps

with mixed-method and longitudinal research would provide an improved understanding.

Future research must come to grips with interventions such as community-based respite care, financial support, and rural caregiver mental health services. Longitudinal studies could track the impact of caregiving on health status as it changes over time, and telemedicine and mobile health app studies could offer new solutions. The inclusion of urban caregivers in studies would allow for comparison, and policy-oriented research on workplace support and social welfare policies could inform national strategies to enhance caregiver wellbeing.

Conclusion

This study assessed the caregiving burden and QoL of older persons' caregivers in the Nuwara Eliya District, Sri Lanka. The results showed that most caregivers were unemployed, middle-aged females with moderate to high burden and mid-range quality of life. Caregiver burden negatively correlated with QoL. Overall, emotional satisfaction and external support subscales of QoL were more likely to be associated with improved QoL, and financial hardship was a longstanding issue. These findings highlight the urgent need for culturally appropriate interventions offering emotional, financial, and practical support to caregivers. Management of these complex factors is important for improving caregiver wellbeing and informing supportive policies and services.

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Ethical considerations

This study was approved by the Ethics Review Committee of KIU University (KIU_ERC_2024_205) on July 14, 2024.

Declaration of conflicting interest

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Author contributions

KNR and HSS supported the study design and provided contextual and methodological insights during data interpretation. KNR and HSS were involved in the overall study conception and design, oversight of study implementation, and provision of methodological guidance to field coordinators. KNR critically revised the manuscript for intellectual content. MIT, SRM, MCD, SKG, and KKK were responsible for data collection, while KNR and HSS facilitated access to the data collection settings. All authors read and approved the final manuscript.

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