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Caregiver profiles and determinants of caregiving burden in Ghana



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ABSTRACT

Objectives: Due to the growing elderly population, the high cost of care in Ghana and low coverage of the National Health Insurance Scheme, demands for family caregiving have become more imperative in Ghana than ever before. Many caregivers experience high burdens, yet literature on caregiving in Ghana is lacking. This study examined caregiver profiles and determinants of the burden of caregiving in Ghana.

Study design: Cross-sectional study.

Methods: This study used data from Wave 1 of the World Health Organization (WHO) Study on Global Ageing and Adult Health (2007–2008). In total, 238 caregivers were analysed in the study. The burden of caregiving was measured using the WHO Impact of Caregiving Scale. Independent sample t-tests, correlations and analysis of variance were used to investigate associations between background characteristics and the burden of caregiving. Linear regression was used to examine determinants of the burden of caregiving.

Results: The mean age of caregivers was 61 years (standard deviation 14.5), and the male:female ratio was approximately equal. On average, approximately two adults per household required care. Less than five percent of caregivers received financial, emotional, health, physical and personal care support. Place of residence, provision of financial, health and physical support to care recipients, and receipt of financial, physical and health support were significant determinants of the burden of caregiving.

Conclusions: This study found a mismatch between the number of people needing care and the number of people providing care. In order to improve the health of caregivers and care recipients, there is a need to provide financial support for caregivers. In addition, pro-caregiving government programmes and policies should be established.

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Introduction

A family caregiver is defined as a friend or relative who provides unpaid assistance (physical, emotional and often financial support) to a person (adult or child) who is unable to care for him/herself due to illness, injury, disability or other conditions.^{1,2} Globally, family caregiving serves as a critical extension of the formal health care system. Hence, family caregivers assist care recipients with daily life activities such as getting food, bathing, laundry, going to the toilet and administering medicine.^{3–5} In the USA, 80% of adults requiring long-term care currently live at home or in the community, and unpaid family caregivers provide 90% of their care.^{1,2,6} In low- and middle-income countries, family caregivers provide approximately half of the care needs of care recipients.^{4,5} In Ghana, the demand for family caregivers is projected to increase from 0.8 million in 2010 to 2.2 million by 2050⁷ due to rapid population aging, an increase in non-communicable diseases and the health system's inability to treat them, high cost of care and an ineffective National Health Insurance Scheme.^{8–11}

In Ghana, caregiving is not a priority for public health. It has not received the necessary attention because it is considered to be part of the informal system of care in the country. Historically, caregiving is a practice that enables Ghanaians to see themselves as part of a larger community, and to return the favour received from elderly people during their childhood.⁴ However, this notion of collectivism is beginning to fade in Ghana due to globalization, urbanization, westernization, high cost of care and unfavourable economic conditions.^{12–14} The breakdown of collectivism therefore opens up increases in the burden of caregiving in Ghana.¹⁵

The burden of caregiving may manifest in the following: depression;¹⁶ reduction in the time that caregivers spend with family and friends;¹⁷ and adverse health effects, such as difficulty with sleeping, frequent headaches, and weight loss or gain.¹⁸ The burden of caregiving may be great depending on the types of care being provided and the person who is providing the care. As such, this burden can lead to a decline

in the health of caregivers and their ability to provide good care. This places both groups at high risk of poor health.^{19–21}

Despite the continued relevance of caregivers, there is a dearth of literature on this subject in Ghana. The few studies that have been undertaken have reported that caregivers experience distress when caring for the sick.¹⁵ However, these studies were not nationally representative. The inadequate research on caregiving in Ghana means that uncertainty exists regarding the extent of care needed by adults, characteristics of people who provide care in Ghanaian households, types of support received by caregivers, and the level of the burden of caregiving in the country. An understanding of these issues is required to make appropriate interventions to address care needs and minimize the burden of caregiving in Ghana. As such, this study examined caregiver profiles and determinants of the burden of caregiving in Ghana.

Conceptual framework on burden of caregiving

This study adopted the stress process model developed by Conde-Sala et al.²² The conceptual framework emphasizes the interdependence and independence of all factors related to stress of family caregivers. The model defines the correlates of the burden of caregiving as contextual stressors, primary stressors and secondary stressors. Social support, social resources and treatments are considered as interventions to reduce the burden of care.³ The conceptual framework informed the selection of predictors of the burden of caregiving in this study.

Contextual stressors, secondary stressors and social support variables were included as predictors of the burden of caregiving (Fig. 1). At the contextual level, caregiving-related factors (e.g. type of caregiver) and sociodemographic factors of caregivers (e.g. age, sex, marital status, place of residence, level of education, religion and employment status) were considered. The variables included as secondary stressors were types of care provided by caregivers (e.g. financial, physical, health, social and personal). The social support

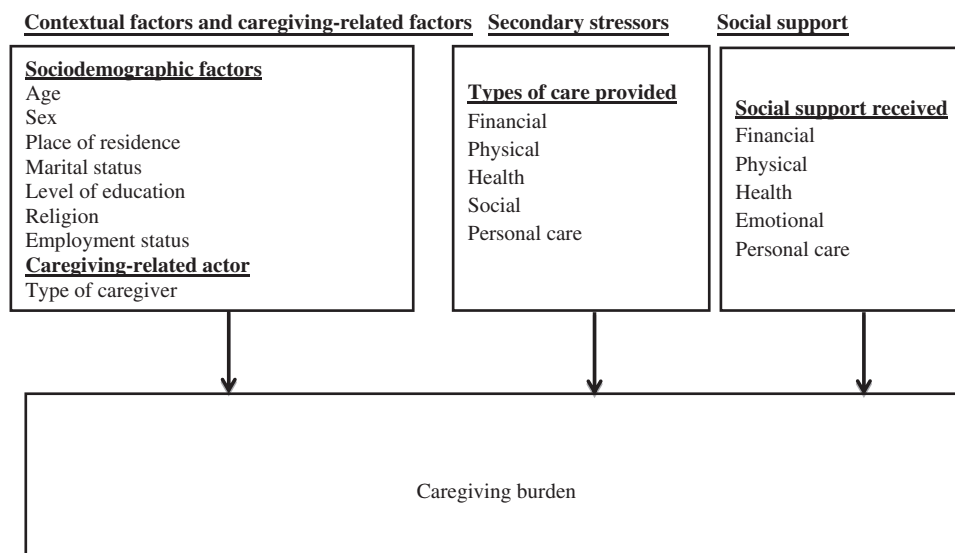


Fig. 1 – Conceptual framework.

variables examined included financial, emotional, physical, health and personal care supports. Research has shown that these variables influence the burden of caregiving.^{23,24}

Methods

Data

This study used data from Wave 1 of the World Health Organization (WHO) Survey on Global Ageing and Adult Health (SAGE) conducted between 2007 and 2008.²⁵ It was a longitudinal study on health and well-being of the adult population and the ageing process. WHO SAGE used a multistage cluster design, and was a nationally representative survey that targeted the de-facto population aged ≥ 18 years.^{25,26} The primary sampling units were stratified by administrative region (Ashanti, Brong Ahafo, Central, Eastern, Greater Accra, Northern, Upper East, Upper West, Volta and Western) and type of locality (urban/rural). Based on this, a total of 20 strata were developed.^{27,28} From each stratum, 10–15 enumeration areas were selected according to the size of the population.

All people aged ≥ 50 years in 'older' households (households with at least one individual aged ≥ 50 years) were invited to participate, whereas only one person was selected at random in 'younger' households (households with no individuals aged ≥ 50 years). The questionnaires were translated into the local language, following a translation protocol, and modified to consider the local context where necessary.²⁸ In total, 5573 individuals were interviewed and 238 individuals reported that they were providing care for any member of the household at the time of the survey. Permission was received from WHO to use the data.

Measures

The analysis included sociodemographic characteristics of caregivers and non-caregivers such as age, sex, place of residence, level of education, marital status, religion, employment status and type of caregiver. Age was measured as a continuous variable. The characteristics of non-caregivers were included specifically for comparative purposes. However, analysis of caregiver profiles and burden did not include information on non-caregivers as these are not applicable to this group.

Respondents who indicated that any members of their household (adults or children) needed care or support for any reason over the 12 months preceding the survey were referred to as 'caregivers'. Caregivers who indicated that they were the main person providing care for the care recipients were classified as 'primary caregivers'. Caregiver profiles were examined by looking at: number of people needing care in a household; types of care provided for care recipients; conditions for providing care; and support received by caregivers. The number of people in need of care in a household was measured as a continuous variable. The types of support received were categorized into five categories: financial, emotional, physical, health and personal care. This support was received from family outside of the household, neighbours, community, government, church, non-governmental organization and other groups. Financial support

included cash, paying for bills, fees, food or medicines, clothing or other provisions. Emotional support covered social support, counselling and time with friends. Health support was in the form of provision of health care, administering medicine, changing bandages and making appointments with healthcare providers. Physical support included assisting with household chores and transportation, while personal care support included helping with bathing, eating, toileting and moving around. A dummy was generated for each type of support, where 1 = received support and 0 = did not receive support. In addition, the types of care provided by caregivers were categorized into five categories: financial, social, physical, health and personal care.

The burden of caregiving was measured using the WHO Impact of Caregiving Scale.²⁵ This contained 10 items and each item was rated on a five-point scale [none (1), mild (2), moderate (3), severe (4), extreme (5)]. The questions focused on difficulties that caregivers had experienced in providing care for any member of the household over the last 12 months. In order to test whether the scale was measuring more than one latent variable, a factor analysis was performed using the principal component method. The loading showed that all the questions loaded on factor one, and explained 83.9% of the variance in the scale. This indicates that the questions were adequate to measure the burden of caregiving. Further, a reliability test showed that the scale was reliable (Cronbach's alpha 0.98). After the reliability test, a composite score was developed. The possible range of scores was 10–45 points, with higher scores indicating a higher burden of caregiving.

Data analysis

Descriptive and analytical techniques were used to show the background characteristics of caregivers, the caregiving profile and level of the burden of caregiving. Correlation was used to show the association between age and the burden of caregiving. Independent sample t-test and analysis of variance were used to assess associations between caregiver characteristics and the burden of caregiving. In addition, linear regression was used to examine determinants of the burden of caregiving. The data were analysed using STATA Version 12. A kurtosis test was performed to check for normality of the distribution of the burden of caregiving. The kurtosis test showed that the burden of caregiving was not distributed significantly differently from a normal distribution at the 5% significance level ($P = 0.1420$). Hence, the assumption for normality was not violated.

Results

Characteristics of caregivers and non-caregivers

The sociodemographic characteristics of caregivers and non-caregivers are shown in Table 1. In total, 238 (4.3%) subjects were caregivers. Table 1 shows that the caregivers did not differ significantly from the non-caregivers in terms of age, sex, marital status, religion and employment status. However, significant differences in place of residence and level of education were found between caregivers and non-caregivers.

Table 1 – Characteristics of caregivers.

Characteristics	Caregivers		Non-caregivers		P-values
	n = 238	%	n = 4817	%	
Caregiver					
Family caregiver	238	4.3			
Age, mean (SD)	238	60.5 (14.5)	4817	60.2 (14.1)	
Sex					
Male	119	50.0	2584	53.6	0.271
Female	129	50.0	2233	46.4	
Place of residence					
Rural	128	52.1	3150	59.4	0.000
Urban	114	47.9	2150	40.6	
Marital status					
Not currently married	144	39.5	3214	39.3	0.949
Currently married	94	60.5	2080	60.7	
Level of education					
No education	111	46.6	2674	50.5	0.008
Primary	40	16.8	1240	23.4	
Secondary or above	87	36.6	1380	26.7	
Religion					
Non-Christian	73	30.7	1948	36.7	0.057
Christians	165	69.3	3354	63.3	
Employment status					
Currently not working	81	34.0	1819	34.3	0.931
Currently working	157	66.0	3483	65.7	
Type of caregiver					
Not primary caregiver	68	28.6			
Primary caregiver	170	71.4			

SD, standard deviation.

Specifically, the mean age of the caregivers and non-caregivers was 60.5 [standard deviation (SD) 14.53] years and 60.2 (SD 14.1) years, respectively. Approximately half of the caregivers and non-caregivers were female (50.0% and 53.6% respectively). A higher proportion of the caregivers lived in urban areas compared with the non-caregivers (47.9% and 40.6%, respectively). With regards to level of education, approximately half of the caregivers (46.6%) had no education and one-third (36.5%) had secondary education or more. Conversely, more than half of the non-caregivers (50.5%) had no education and 27% had secondary education or more. More than 60% of caregivers and non-caregivers were currently married. Sixty-six percent of the caregivers were currently employed (vs 65.7% of non-caregivers), and 69.3% of the caregivers were Christians (vs 63.3% of non-caregivers).

Caregiver profiles

The number of individuals that needed care in a household ranged from one to eleven, and the majority of caregivers (74%) provided care for one person. In terms of the conditions for which care was provided, 1.3% of caregivers provided care for human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS)-related reasons; 66.0% provided care for other health-related reasons; and 35% provided care for reasons such as violence, migration, disability, work-related, school-related, old age and young age (Table 2).

Table 2 – Caregiving profile.

	Yes (%)	No (%)
Conditions for which care was provided		
HIV/AIDS related	1.3	98.7
Other health related	66.0	34.0
Other	34.9	65.1
Don't know	3.0	97.0
Type of care provided		
Financial	63.5	36.5
Social	41.2	58.8
Health	37.4	62.6
Physical	36.5	63.5
Personal	16.8	83.2
Type of support received		
Financial	20.2	79.8
Emotional	2.9	97.1
Health	2.9	97.1
Physical	3.8	96.2
Personal care	1.7	98.3

HIV/AIDS, human immunodeficiency virus/acquired immunodeficiency syndrome.

With regard to the types of care provided by caregivers, more than 60% provided financial care. The proportions of caregivers who provided social, health, physical and personal support were 41.2%, 37.4%, 36.5% and 16.8%, respectively. Generally, the support received by caregivers was low (Table 2). Approximately 20% of caregivers received financial support and less than 5% received emotional, health, physical and personal care support (2.9%, 2.9%, 3.8% and 1.7%, respectively) (Table 2).

Prevalence of the burden of caregiving

Table 3 shows the prevalence of the burden of caregiving. Each of the 10 items has a score ranging from none (1) to extreme (5). The overall mean score for the burden of caregiving was 18.5 (SD 8.4). The general pattern shows that caregivers experienced a mild-to-moderate burden of caregiving. The

Table 3 – Prevalence of burden of caregiving.

Burden of caregiving	Mean	95% CI
1. Difficulty getting enough sleep	1.8	1.7–2.0
2. Problem getting enough food to eat	1.7	1.5–1.8
3. Not enough energy for extra work	1.8	1.7–1.9
4. Cannot take care of health, ailment/chronic condition	1.7	1.6–1.9
5. Unable to pay for medication/treatment for ailment/chronic condition alone	1.9	1.8–2.1
6. Cannot visit friends and relatives as much as before	1.9	1.7–2.0
7. Cannot share feelings about caregiving responsibility with others	1.7	1.6–1.8
8. Experienced financial problems due to loss of income	2.5	2.3–2.7
9. Do not know the correct care to provide for health problems of care recipients	1.8	1.6–1.9
10. Experienced stigma or problems as a result of the care recipient's illness or death	1.7	1.5–1.8

CI, confidence interval.

main reported burden of caregiving was financial problems and loss of income due to caregiving duties.

Factors associated with the burden of caregiving

Table 4 shows the associations between caregiver demographic characteristics, other caregiving-related factors and the burden of caregiving. A significant positive correlation was found between age and the burden of caregiving ($r = 13\%$, $P < 0.05$). Urban residents, Christians and employed individuals experienced a lower burden of caregiving compared with their respective counterparts. One-way analysis of variance showed that the burden of caregiving differed significantly across the levels of education [$F(2,235) = 11.38$, $P < 0.001$]. The burden of caregiving was lower among those with primary and secondary/higher education compared with those with no education. While caregivers who provided financial support had a lower burden of caregiving, those who provided health, physical and personal support had a higher burden of caregiving. In addition, the burden of caregiving was lower for caregivers who received financial support than those who did not receive financial support. With regards to the number of people cared for, the burden of caregiving decreased with increasing number of care recipients.

Determinants of the burden of caregiving

Table 5 presents determinants of the burden of caregiving. Place of residence; provision of financial, health and physical support to care recipients; and receipt of financial, physical and health support were significant determinants of the burden of caregiving. These variables explained 21.7% of the variation in the burden of caregiving [$F(20,217) = 4.28$, $P < 0.001$]. Specifically, the burden of caregiving score was 4.3 points lower in caregivers living in urban areas compared with those living in rural areas (Table 5). While caregivers who provided financial support had a lower burden of caregiving, those who provided health and physical support had a higher burden of caregiving than their respective counterparts. Further, caregivers who received financial and physical support experienced a lower burden of caregiving, while those who received health support had a higher burden of caregiving.

Discussion

This study examined caregiver profiles and determinants of the burden of caregiving in Ghana. The mean age of caregivers in this study was 61 years. Most caregivers had no formal education, and the male:female ratio was approximately equal. Specifically, the age distribution of caregivers indicates that the aged are caring for the aged. This could be explained by the increasing rural–urban migration of young people into cities and overseas.²⁹

The findings from this study show that place of residence, types of care provided and social support received were significant determinants of the burden of caregiving in Ghana. This study confirms the stress process model which emphasizes the multidimensional nature of predictors of caregiver

Table 4 – Factors associated with burden of caregiving.

Variables	Mean	95% CI
Age r^c	0.13	
Sex		
Male	18.4	17.0–20.0
Female	18.5	16.9–19.9
Place of residence ^a		
Rural	20.9	19.3–22.5
Urban	15.8	14.5–17.1
Marital status		
Currently not married	19.4	17.6–21.2
Currently married	17.9	16.5–19.2
Religion ^a		
Christian	17.3	16.1–18.6
Non-Christian	21.0	19.0–23.0
Employment status ^b		
Employed	17.4	16.1–18.7
Unemployed	20.6	18.7–22.6
Level of education ^a		
No education	21.4	19.7–23.0
Primary	17.6	15.2–20.1
Secondary or more	15.1	13.6–16.5
Type of caregiver		
Primary caregiver	18.5	17.2–19.7
Not primary caregiver	18.2	16.3–20.5
Types of care provided by caregivers		
Financial ^b		
Yes	17.4	16.2–18.7
No	20.9	18.9–22.9
Social		
Yes	19.0	17.3–20.6
No	18.0	16.6–19.4
Health ^b		
Yes	20.8	19.0–20.6
No	16.8	15.5–18.0
Physical ^b		
Yes	20.3	18.6–22.0
No	17.1	15.8–18.5
Personal ^c		
Yes	20.7	18.2–23.2
No	17.8	16.6–19.0
Types of support received by caregivers		
Financial ^c		
Yes	16.5	14.5–18.5
No	19.0	17.7–20.2
Emotional		
Yes	17.6	11.1–24.1
No	18.5	17.4–19.6
Physical		
Yes	14.3	9.1–19.6
No	18.6	17.5–19.7
Personal		
Yes	15.8	2.5–29.0
No	18.5	17.4–19.6
Health		
Yes	18.3	9.9–26.6
No	18.5	17.4–19.6
Number cared for ^c		
1	19.1	17.8–20.3
2	18.4	15.0–21.7
3	17.7	13.5–21.8
4	12.5	10.0–14.9

CI, confidence interval.

^a $P < 0.001$.

^b $P < 0.01$.

^c $P < 0.05$.

Table 5 – Determinants of burden of caregiving.

Characteristics	B	95% CI
Age r	-0.025	-0.105 to 0.054
Sex		
Female	1.198	-1.304 to 3.700
Place of residence		
Urban ^a	-4.250	-6.455 to -2.046
Marital status		
Currently not married	1.610	-0.822 to 4.041
Religion		
Christian	-1.880	-4.403 to 0.706
Employment status		
Employed	-2.320	-4.696 to 0.056
Level of education		
No education		
Primary	-0.781	-3.820 to 2.258
Secondary or more	-0.745	-3.418 to 1.928
Type of caregiver		
Primary caregiver	1.673	-0.574 to 3.920
Types of care provided by caregivers		
Financial ^c	-3.063	-5.413 to -0.712
Social	-0.795	-3.144 to 1.553
Health ^b	3.058	0.782 to 5.334
Physical ^c	2.683	0.374 to 4.991
Personal	0.950	-1.774 to 3.676
Types of support received by caregivers		
Financial ^b	-3.938	-6.781 to -1.094
Emotional	-1.153	-7.510 to 5.205
Physical ^c	-8.987	-15.967 to -2.007
Personal	-3.822	-12.448 to 4.804
Health ^b	11.142	3.318 to 18.967
Number cared for	0.097	-1.105 to 1.300
CI, confidence interval.		
^a P < 0.001.		
^b P < 0.01.		
^c P < 0.05.		

burden.³ The findings showed that urban residents had a lower burden of caregiving compared with rural residents. This may be because caregivers who reside in urban areas have more access to resources than caregivers in rural areas. In addition, there is less demand for care in urban areas compared with rural areas.²⁹ Research has also shown that the proportion of elderly people has risen significantly in rural Ghana, and there is no evidence to suggest a corresponding increase in social care for the aged.⁷

Caregivers who provided financial support experienced a lower burden of caregiving. One plausible reason why those who provided financial support had a lower burden may be because they were not the primary caregiver. They may be secondary caregivers who only contribute financially without participating in other caregiving activities. On the other hand, those who provided health and physical support experienced a higher burden of caregiving. Provision of health care such as administration of medicines, changing bandages and arranging healthcare providers places a huge strain on caregivers. In addition, the findings from this study confirmed the results from other studies that caregiving activities can result in physical strain such as fatigue, tiredness or exhaustion.⁵ These physical effects can be huge, particularly if the caregivers are old and unemployed.⁵

Generally, caregivers who received financial and physical support experienced a lower burden of caregiving. Studies have shown that caregiving duties result in loss of income due to reducing hours of work or stopping work completely.⁵ In addition, caregivers often incur many financial costs when providing care. This produces a situation of double financial burden, as the caregivers may no longer be productive while spending a lot of money on providing care. Hence, receiving financial support increases caregivers' resources for care provision and may reduce the burden that could have emanated from inadequate funds. Further, as caregiving results in physical strain such as exhaustion, weakness and fatigue, receipt of support in this area may help to reduce the burden of caregiving.

On the other hand, caregivers who received health support experienced a higher burden of caregiving. A plausible explanation for this may be that those who received health support may be caring for individuals with greater disabilities. Hence, the burden of caregiving will remain high regardless of the type of health support received. For instance, those who provided care for people living with dementia or stroke may experience a higher burden of caregiving than those who provided care for people living with health conditions such as malaria or HIV/AIDS. This is because care recipients with dementia or stroke are more likely to be more impaired in terms of the activities of daily living. Other studies have also alluded to this in the sense that greater impairment of care recipients in terms of daily living is associated with a higher burden of caregiving.^{3,22,30,31}

One limitation of this study is that it was not possible to determine the specific disease for which caregivers were providing care. This could have helped to determine the contribution of each disease on the burden of caregiving. Also, the number of caregivers in this study was small, which may have reduced the predictive power of the sociodemographic factors. Also, the small sample size makes it difficult to generalize the findings to all caregivers in Ghana.

In summary, this study shows that the majority of caregivers were old. The number of people in need of care was higher than the number of caregivers, and most caregivers experienced a financial burden. Place of residence, types of care provided and types of support received were significant determinants of the burden of caregiving in Ghana. As the elderly (usually after retirement) are the main care providers in Ghana, there is a need for government policies to reduce the burden of caregiving. Government, non-governmental organizations and family can help with the provision of financial and social support, and develop programmes to enable caregivers to have a break from their caregiving activities. Reducing the burden of caregiving will improve the health of caregivers and care recipients in Ghana.

Author statements

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Ethical approval

Not required because the data used were collected by WHO, and permission was granted to use the data.

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Competing interests

None declared.

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