ORIGINAL ARTICLE

Who Cares? Sociodemographic and Health Characteristics of Carers of Older Persons in Jamaica

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ABSTRACT

Objective: *To describe the sociodemographic and health characteristics and implied needs of caregivers to older persons in Jamaica.*

Method: *This was a community-based, nationally representative study in which a sample of 180 caregivers to older persons was interviewed.*

Findings: *Caregivers were aged between 18 and 88 years (mean 50.5; s = 14.7) and most (77%) were informal compared to 23% who were paid to care. There were no differences between urban and rural caregivers with respect to gender, union status, residing with care recipients and holding a regular job while giving care. Urban caregivers were significantly more likely to report attaining secondary education than those in rural communities* (χ^2 *(2) = 7.40,* $p < 0.05$*). Over 90% reported they had not received any formal training in caregiving and those ≤ 45 years were more likely than those in age groups ≥ 46 years to say they want to get caregiver training* (χ^2 *(4) = 27.1,* $p < 0.001$*). Male caregivers were significantly more likely to report being the 'child/grandchild/in-law' of care recipients than female caregivers, among whom almost one in four reported their relationship as employee (Fisher's Exact test:* $p = 0.002$*). Most caregivers (51.7%) reported being diagnosed with one or more medical condition and 89% of those diagnosed reported being prescribed medications for their illnesses. Forty-five per cent of caregivers reported that they performed one or more activity of daily living (ADL) for their care recipients daily.*

Conclusion: *Carers of older persons in Jamaica are predominantly family members, most have not received caregiving training and most have been diagnosed with a medical condition.*

Keywords: Caregiver health, caregiving, older persons, Jamaica

¿Quién cuida? Características Sociodemográficas y de Salud de los Cuidadores de Personas Mayores en Jamaica

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RESUMEN

Objetivo: *Describir las características sociodemográficas y de salud, así como las necesidades implícitas de los cuidadores de las personas mayores en Jamaica.*

Método: *Se trata de un estudio comunitario representativo a nivel nacional, en el que se entrevista una muestra de 180 cuidadores de personas de edad.*

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Resultados: *Los cuidadores tenían entre 18 y 88 años (media 50.5; s.d. = 14.7) y la mayoría (77%) eran informales en comparación con el 23% que recibían pago por el cuidado. No hubo diferencias entre los cuidadores urbanos y rurales con respecto a género, estado civil, residir con las personas objeto del cuidado, y mantener un trabajo regular a la par con la atención a los ancianos. Los cuidadores urbanos presentaban una probabilidad significativamente mayor de haber alcanzado educación secundaria en comparación con aquellos de las comunidades rurales ($\chi 2$ (2) = 7.40, $p < 0.05$). Más del 90% reportó no haber recibido ninguna capacitación formal en cuidados, y aquellos con ≤ 45 años eran más propensos que los de los grupos de edad ≥ 46 años a decir que deseaban recibir entrenamiento como cuidadores ($\chi 2$ (4) = 27.1, $p < 0.001$). Los cuidadores hombres presentaban una probabilidad significativamente mayor de ser "hijo/nieto/yerno" de personas receptoras de cuidados, que las mujeres cuidadoras, entre las cuales casi una de cada cuatro reportó su relación como empleado (Prueba exacta de Fisher: $p = 0.002$). La mayoría de los cuidadores (51.7%) reportaron estar diagnosticados con una o más condiciones médicas, y el 89% de los diagnosticados reportaron recibir prescripciones de medicamentos para sus enfermedades. Cuarenta y cinco por ciento de los cuidadores informó realizar una o más actividades de la vida diaria (AVD) para las personas bajo su cuidado diariamente.*

Conclusión: *Los cuidadores de personas mayores en Jamaica son en su mayoría miembros de la familia; la mayor parte de ellos no ha recibido capacitación como cuidadores; y la mayoría han sido diagnosticados con alguna condición médica.*

Palabras clave: Salud del cuidador, cuidados, personas mayores, Jamaica

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INTRODUCTION

As the older population increases, there is a growing demand to provide long-term care for dependent older persons. Worldwide, informal caregivers, constituting family members and friends caring without compensation, seem to bear the brunt of such care (1–4). The Caribbean region and, in particular, Jamaica, is experiencing rapid population ageing and face similar challenges with increased demand for caregiving as other nations worldwide. Jamaica has a population of 2.7 million with 13% being 60 years and older (5). It is projected that by the year 2050, this proportion of older persons will increase to 29% (6). A national survey among older persons in 2012 (7) shows that 75.3% of Jamaica's older population have been diagnosed with one or more chronic non-communicable disease (CNCD). Consequently, there will be increased need for caregiving services over-time especially in cases where self-management is inadequate and complications are likely. The report further shows that 7.3% of older persons are dependent in one or more Activity of Daily Living (ADL) and almost 1% are dependent in all ADLs, highlighting the need for care. Like other countries, family members of older persons in Jamaica were also reported to be the most common source of care (7).

Local studies have drawn attention to the ageing of the population especially in relation to demographic changes, social and health issues of older persons but without focus on caring for older persons (7–9). This paper seeks to characterize carers and the caregiving context in Jamaica. It highlights the implications for intervention especially in light of global concerns about the well-being of caregivers of older persons (1–3).

SUBJECT AND METHOD

Study population

A cross-sectional nationally representative study was conducted in 2016 to characterize caregivers and the caregiving context as well as estimate caregiver burden. The population of interest was all persons engaged in providing day to day non-institutionalized care for community dwelling older persons 60 years and older. Persons providing care for older people were included if they had been doing so for a month or more whether on a part-time or full-time basis. Caregivers who were engaged in caring for two older persons at the time of the interview were excluded since it would be difficult to (a) determine which care recipient was the source of any detected burden and (b) separate needs and attributes based on specific care management profile.

Sample size sampling strategy

Caregiver burden was a primary outcome of the study and this is commonly measured using the Zarit Burden Interview instrument (10). To our knowledge, caregiver burden has not been previously assessed among

caregivers to older persons in Jamaica. One study done in 2013 on caregiver burden among caregivers of older persons with Dementia in the developing country of Malaysia found the mean burden score to be 46 [SD ± 17] (11). Assuming such score and standard deviation and applying the usual 95% confidence interval and a desired precision of 2.5 units, a minimum sample of 178 persons was needed and later rounded to 180, (See http://www.raosoft.com/samplesize.html online sample calculator used). Multistage sampling was employed involving selection of parishes within health regions, selection of enumeration districts (communities) within parishes, selection of households within the enumeration districts (identified communities) and identification of eligible subjects for the study.

The required sample size was first distributed according to the population size of older persons in each of the four regions in the Ministry of Health's (Jamaica) jurisdiction. Table 1 outlines the distribution of the sample across these regions based on the population size.

Table 1: Population aged 60 years and older by Health Region

Region	Population size (age 60 years and over)	Percentage (%) of total national population age 60 years and over	Number needed from region for sample
South-East	181027	44.8	80
North-East	59650	14.8	26
Western	67715	16.8	30
Southern	95775	23.7	42
TOTAL	**404167**	**100.0**	**178**

Selection of communities within the selected parishes for each region

A list of communities in Jamaica is maintained by the Social Development Commission and further disaggregated by parish into enumeration districts (EDs) of size 80 households in urban areas and 150 households in rural areas. For each of the parishes selected, the list was used as the sampling frame and the enumeration districts as clusters. The selection of the clusters from which participants were to be obtained was done by standard probability proportional to population size technique. Once a cluster was selected, the community corresponding to that cluster or ED was identified by name and scheduled to be visited. Twenty-seven communities were selected for the recruitment of caregivers.

Trained interviewers visited the enumeration districts selected (the identified communities) and under the supervision of a field supervisor, a random starting point in each community was determined using GIS technology. From this random starting point house to house visits were made and participants recruited based on the inclusion criteria until the required sample was obtained.

Two main instruments were utilized in the study. The first is a structured questionnaire consisting of 44 questions including forced choices, matching responses and open-ended options. Questions were categorized across four themes capturing information regarding demographics, the health profile of caregiver, the health profile of care recipients and the context and circumstances surrounding the provision of care. The other instrument was the ZBI (10) which assesses caregiver burden with scores ranging from 0–88; higher scores indicating greater burden. Both the structured questionnaire and the ZBI instrument were interviewer-administered in a face-to-face paper-based interview. Interviewers were trained for this purpose and the instrument was pretested in a parish not included in the sample.

Data pertaining to caregivers' characteristics and the caregiving context (but not including caregiver burden) were analysed for this paper assisted by the Statistical Package for the Social Sciences Version 21. Descriptive statistics, including frequencies and measures of central tendency were used to describe participants' profile. Inferential statistics such as Chi square test of association, *t*-tests and ANOVA were used to better understand the relationship between variables. The study was approved by The University of the West Indies, Faculty of Medical Sciences, Ethics Committee, Mona, Jamaica, and informed consent was obtained from all study participants.

RESULTS

The participation rate was 100%.

Demographic profile of caregivers

Caregivers ranged in age from 18 to 88 years (mean 50.5; s = 14.7). There were no differences between urban and rural caregivers with respect to gender, union status, residing with care recipients and holding a regular job while giving care. Urban caregivers were significantly more likely to report attaining secondary education than those in rural communities (χ^2 (2) =7.40, $p < 0.05$). Table 1 gives the details.

Most (91.6%) had not received formal caregiver training. Only 15 (8.4%) persons reported doing short courses at schools of practical nursing including the National Training Agency, HEART Trust (Human Education And Resource Training Trust). Of those not

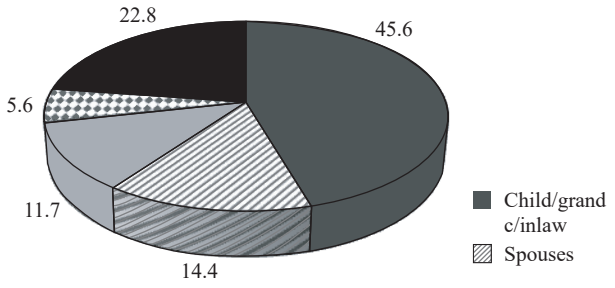
reporting formal training, 19 (11%) persons said they had informally received on the job experience and information from a variety of sources including doctors and pharmacists. While the majority of those without formal training (66.7%) was not interested in being trained, the others (33.3%) said they would like to be trained as nurses and in various specialties. Younger caregivers (age ≤ 45 years) were more likely to say that they want to get further training (χ^2 (4) = 27.1, $p < 0.001$) compared to those in age groups ≥ 46 years.

The majority (77%) of caregivers was informal and the others (23%) were employed to provide caregiving services. Male caregivers were significantly more likely to report being the 'child/grandchild/in-law' of care recipients than female caregivers, among whom almost one in four reported their relationship as employee (Fisher's Exact test: $p = 0.002$, Figure 1).

Table 2: Sociodemographic profile of caregivers based on location

Characteristics	Urban n = 113 % (n)	Rural n = 67 % (n)	χ^2 *p*-value
Gender			0.145
Male	50.0 (13)	50.0 (13)	
Female	64.9 (100)	35.1 (54)	
Marital status			0.209
Single	66.7 (68)	33.3 (34)	
Married/common-law	60.9 (39)	39.1(25)	
Separated/divorced/widowed	42.9 (6)	57.1 (8)	
Living arrangements			0.547
Reside with care recipient	61.8 (89)	38.2 (55)	
Live ≤ 0.5 miles away Live	60.9 (14)	39.1 (9)	
> 0.5 miles and travel	76.9 (10)	23.1 (3)	
Have regular job and give care			0.976
Yes	62.5 (15)	37.5 (9)	
No	62.8 (98)	37.2 (58)	
Level of education			0.025
Primary/all-age	50.8 (33)	49.2 (32)	
Secondary	66.7(56)	33.3 (28)	
Tertiary	77.4 (24)	22.6 (7)	

Figure 1: Relationship of caregiver to care recipient.



Most caregivers (80%) shared living accommodation with their care recipients; 12.8 % lived next door or within walking distance (≤ half mile) and few (7.2%) lived at a distance that requires them to travel by vehicle daily. The hours spent providing care varied from 10 to 91 hours weekly, with a mean of 41.3 (s = 15.4). No statistically significant difference was found in the hours spent providing care between formal (paid) caregivers who typically spent 42.6 hours weekly and informal caregivers who spent 40.9 hours [t(84.3) = 0.721, p = 0.473]. Time off was flexible for half of caregivers (51.1%) but for 25%, there was no scheduled time off and only 10.6% of caregivers got weekends off.

Employed caregivers earned approximately, $5778 Jamaican weekly from providing care. This translates to a rate of $145 (US $1.11) per hour. Disaggregated by urban-rural location, the corresponding weekly figures were $6081 and $4319, respectively, equivalent to a rate of $152 and $107 (US $1.17 and $0.82) per hour.

Informal caregivers commonly identified themselves as their source of financial support (51%) while 43% named a family member. Pension and the Programme for Advancement Through Health & Education (PATH) were identified by 4.5% of respondents as their sources of financial support. The other 1.5% identified being assisted by friends and church. On the issue of emotional support, almost 70% of caregivers identified their families or that of their care recipients as their source, 23% said friends and faith based sources while approximately 7% reported dependence on themselves or no one.

Ninety-three (51.7%) of caregivers reported that they had been told by a doctor that they have one or more medical conditions and most (89%) of these persons reported being on medications for their illnesses. The majority (71%, n = 59) had been prescribed 1–2 medications and 19 (23%) prescribed 3–4 medications. Medical conditions reported by 62% were, chronic non-communicable diseases including hypertension or diabetes singly or in combination with other conditions.

Care recipients were aged between 60 and 104 years (median - 83, inter-quartile range -15) and most (60%) were females. Most (81%) were reported to have ≥ 1 chronic condition including hypertension, diabetes and cancers. Almost equal proportions were either restricted in mobility or ambulant at 43.3% and 41.7%, respectively, while the remainder (15%) was confined to bed. Forty-five per cent of caregivers reported that they performed one or more ADL for their care recipients daily.

DISCUSSION

This is the first known local study highlighting the profile of those who care for older persons in Jamaica. We have found that in community dwelling settings locally, older persons are primarily cared for by informal carers. These findings mirror studies in the literature (2, 12, 13).

Desire for relevant training, even among those employed to care, is however, not an expressed need for most and may be a reflection of several factors. Culturally, it could be an acceptance of caregiving as a natural function of families. Conversely, substantial proportions of those who have been trained or who desire further training might have chosen to work in other settings like nursing homes and not in community dwelling settings from which this sample was drawn. It may also be due to a perception that successfully providing care over-time makes one competent. Older caregivers were less likely to desire training and this could be influenced by several factors including satisfaction with life, perceived caregiving accomplishments, inaccessible training opportunities due to distance and cost or hours of delivery of such courses. Forging partnerships with community organizations to do short competency based training especially in rural areas where there is less access to such training may be warranted. The literature shows that caregiving can negatively impact caregiver well-being especially when there is lack of understanding about what to do (2).

Consistent with the public health approach to de-emphasize institutional care for many health conditions, home based care is the desired approach for most families and this should be encouraged. James *et al* (14) have noted that ageing in place is desired by most older persons and the preference is to remain in one's home. If this is to be realized, however, community respite services for caregivers are warranted especially in light of the report that some caregivers provide over 80 hours of care weekly. In keeping with the policy mandates of the National Council for Senior Citizens (15), collaboration for recruitment and training of volunteers could strengthen respite services for caregivers.

One could very well ask who will care for the caregivers however, since almost 4 in 10 reported being diagnosed with a CNCD. This is worrying in light of previous study showing that nearly eight of ten older persons had a CNCD (7). Our findings also show that almost 32% of caregivers fall within the age group of older persons, ≥ 60 years, based on the United Nations classification of old age (6). Concerns about the quality of life of caregivers including the burden of caregiving arise, especially when they already suffer from a chronic disease.

CONCLUSION

Carers of older persons in community dwelling settings in Jamaica are predominantly family members. Most report one or more illness for which medications have been prescribed and most have received no formal caregiving training.

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AUTHORS' NOTES

This study was conceptualized by the first author, Kenneth James designed the methodology and all other authors read and commented on several drafts of this paper and approved the final draft. We declare no conflict of interest.

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