Socio-economic effects on informal caregivers of long-term hospitalized adult patients: A cross-sectional study

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(Index words: socio-economic, informal caregivers, caretaker, hospitalized patients, caregiver burnout)

Abstract

Introduction: A significant proportion of patients are being treated at hospitals in the government sector in Sri Lanka. Informal caregivers play a major role in taking care of hospitalized surgical patients while facing physical, social, and psychological challenges.

Objective: To describe the socio-economic effects on informal caregivers of long-term hospitalized adult patients.

Methods: A cross-sectional descriptive study was conducted among 202 informal caregivers of long-term hospitalized patients in a tertiary care hospital in Sri Lanka, using an interviewer-administered questionnaire. Sociodemographic assessment of both caregiver and care recipient, the health status of the care recipient, effects on social life, and economic aspect of informal caregiver were assessed.

Results: Most of the caregivers were married (n=164, 81.2%), first degree relative of the care receiver (n=139, 68.8%), employed (n=115, 56.9%) and sole caregivers (n=130, 64.4%). Four out of 5 caregivers (n=181, 89.6%) showed moderate to severe socio-economic maladaptation. Increasing age (p=0.00), marital status (p=0.00) and sole caregiving (p=0.01) are significantly associated with the level of maladaptation.

Conclusion: Moderate to severe levels of maladaptation is present among a substantial number of informal caregivers of long-term hospitalized patients. Sole caregiving is one of the contributing factors and can be addressed by adequate formal caregivers appointed by health care authorities or from voluntary services to minimize informal caregiver burnout.

Introduction

In Sri Lanka, over seven million hospitalizations occurred in 2018 in the government sector which comprises 643 curative care hospitals [1]. A significant proportion of hospitalized patients face physical and cognitive challenges that affect their daily activities. Changing disease patterns from infectious diseases to non-communicable diseases over time and the exponential rise of the elderly population further contribute to the matter. The importance of the role of the caregiver is emphasized more and more for this reason.

A caregiver is defined as a person who aids with the activities of daily living of another person with an illness or disability [2]. They also provide emotional support to the patient, interact with the medical staff, and communicate with family members about the care decisions. Caregivers are either "formal" or "informal". Ward attendants are the formal caregivers appointed to a ward with training in patient care. In addition, a limited number of paid formal caregivers from private firms are available. However, their service generally fails to meet the demand of a large number of hospitalized patients in the public health sector.

An informal caregiver is an unpaid person from the patient's social network (e.g. a relative or a friend) who lacks education and training pertaining to patient care. Informal caregiving has rewarding components including psychological satisfaction of helping a helpless and feeling useful and developing competence in patient care. In addition, the presence of family caregivers during patient-clinician interaction leads to improved provision of biomedical information [3]. However, there are well-studied

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negative effects on the quality of life of the caregivers in terms of physical and psychological health [4-8].

However, socioeconomic effects on informal caregivers are limited in the literature. The available evidence shows a reduction in social interactions (e.g. reduced number of friends) and declines in income with a high level of caregiving burden [9]. These studies were mainly conducted on outpatient caregivers who provide care for elderly patients with chronic illnesses including dementia in Western countries. Data on the socio-economic effects on informal caregivers of hospitalized patients are scarce in Sri Lankan setting to the best of our knowledge.

The purpose of this study was to address the shortcomings of socioeconomic impact on informal caregivers of long-term hospitalized surgical patients.

Methods

A cross-sectional descriptive study was conducted from March 2021 to March 2022 at the Professorial Surgical Unit of Colombo South Teaching Hospital (tertiary care referral centre), Sri Lanka. The informal caregiver is defined as an unpaid person from the patient's social network (e.g. a relative, a friend) who lacks education and training pertaining to patient care.

Sample

Informal caregivers who provide care for more than one week duration for the hospitalized patients were enrolled in the study. Informal caregivers of paediatric patients (age 12 years) and paid caregivers were excluded from the study. The minimum sample size required to estimate a 50% proportion of moderate to severe socio-economic burden on inward informal caregivers with 95% confidence intervals within +/- 7% precision was 196.

Data collection

Ethical clearance was obtained from the Ethics Review Committee, Colombo South Teaching Hospital. An interviewer-administered questionnaire was used to collect data from informal caregivers. The interviews were carried out by trained members of the study group who were conversant in Sinhala, Tamil, and English. Each interview lasted approximately 20 minutes and consisted of a sociodemographic assessment of both caregiver and care recipient, the health status of care recipient including the illness and level of disability, effects on social life and economic aspect of the informal caregiver.

The level of disability of the care receiver was assessed using Katz index of independence in activities of daily living which indicates the performance in six functions, namely, bathing, dressing, going to the toilet, transferring, continence, and feeding [10].

The effects on the socio-economic aspect of the informal caregivers were assessed by the scale of quality of life of caregivers (SQLC) introduced by Glozman *et al* (1998) [11]. Even though this has been originally described for the caregivers of Parkinson's disease, subsequent studies have shown the applicability to other disabling conditions [12]. SQLC has comprised of 16 questions under 3 subcategories namely, the impact on professional activities, the impact on leisure activities, and the responsibilities of the caregiver to help the patient for everyday living. Assessment allows categorization of the level of social maladaptation both qualitatively and quantitatively into 3 groups.

Mild	100-140 points
Moderate	86-99 points
Severe	<85 points

An additional set of questions was formulated on the effects on education and the availability of basic facilities for caregivers at hospitals as they were not being addressed in the SQLC. A member of the research group will enter the collected data into a password-protected computer.

Statistical analysis

The data was analyzed by a standardized data analyzing tool (SPSS version 26). The socio-demographic characteristics of the patients and the care-givers were described by frequency distribution. Descriptive statistics were used to describe the socio-economic effects. Association between the socio-demographic variables of caregiver and the level of maladaptation was carried out using Chi-square test and one-way ANOVA test. A p value of <0.05 was considered statistically significant.

Results

Out of 220 invited caregivers of long-term inward patients, 18 did not participate in the study giving a response rate of 91.8%.

Majority of the patients were females (n=111, 55%) and the mean age was 50.9 years (range: 16-80) (Table 1). The commonest surgical ailment among the patients was lower limb ulcers (n=42, 20.8%) followed by pyelonephritis (n=21, 10.4%). The mean duration of hospital stay was 12.8 days (range 7-44). Assessment of Independence in Activities of Daily Living (Katz Index) revealed a severe impairment in 14.4% (n=29), moderate impairment in 42.1% (n=85) and mild/no impairment in 43.6% (n=88).

Table 2 demonstrates the socio-demographic data of the informal caregivers. The majority were females (n=111, 55%) and mean age was 45.1 years (range: 16-69), with 12.4% being over the age of 65 years. Regarding relationship of the caregiver to the patient, 68.8% (n=139) were first degree relatives, 17.8% (n=36) were second degree relatives, 18% and 9% were third degree relatives

and friends respectively. Most of the patients (n=130, 64.4%) had sole caregivers. The majority of the caregivers were married (164, 81.2%) and employed (n=115, 56.9%). Among those who had jobs, most were labourers (n=44, 21.8%) and self-employed (n=23, 11.4%). Fifty three caregivers (26.2%) were involved in educational schemes including schooling (8.7%), attending university (2.5%) or occupation related programme (15.3%). Of them, 6 (11.3%) claimed that they could not engage in educational activities at all during the caregiving period and 38 (71.7%) were able to attend the activities partly. Considering the basic facilities, a proper place to shower was not available for 31.7% and proper place to sleep was not available for 93.6%.

Table 1. Sociodemographic data and Katz index of independence in activities of daily living of patients

	Characteristics	*Study population*
Sex	Male	91 (45%)
	Female	111 (55%)
Age	12-25 years	12 (5.9%)
	26-45 years	60 (29.7%)
	46-65 years	97 (48%)
	>65 years	33 (16.3%)
Marital status	Married	153 (75.7%)
	Single	49 (24.3%)
Katz index	No/mild impairment	88 (43.6%)
	Moderate impairment	85 (42.1%)
	Severe impairment	29 (14.4%)

Table 2. Sociodemographic data of the informal caregivers

	Characteristics	*Study population*
Sex	Male	91 (45%)
	Female	111 (55%)
Age	12-25 years	24 (11.9%)
	26-45 years	74 (36.6%)
	46-65 years	79 (39.1%)
	>65 years	25 (12.4%)
Marital status	Married	164 (81.2%)
	Single	38 (18.8%)
Employment status	Employed	115 (56.9%)
	Unemployed/retired	87 (43.1%)
Relationship to the patient	First degree relative	139 (68.8%)
	Second degree relative	36 (17.8%)
	Third degree relative	18 (8.9%)
	Friend	9 (4.5%)
Number of caregivers	Sole caregiver	130 (64.4%)
	Multiple caregivers	72 (35.6%)

Approximately two-thirds of caregivers (n=124, 61.4%) demonstrated severe socio-economic maladaptation. A moderate level of maladaptation was observed in 28.2% (n=57) and mild maladaptation was observed in 10.4% (n=21) (Table 3). The increasing age of the caregiver was significantly associated with a greater level of maladaptation (p=0). Post hoc analysis further revealed that the age of the caregiver was statistically higher in severe maladaptation (46.9±10.7 years, p=0) and moderate maladaptation (45.6±18.1 years, p=0) groups compared to the mild maladaptation group (32.3±9.1 years). There was no statistically significant difference between the severe and moderate maladaptation groups (p=0.8).

Moderate to severe maladaptation was significantly higher among married caregivers (p=0) and sole caregivers (p=0.01). However, there was no significant association between the level of maladaptation and gender (p=1.01) or employment status (p=0.66) of the caregivers and the level of activities of daily living (Katz index) of care receivers (p=0.56) (Table 4).

Table 3. Distribution of socio-economic effects according to scale of quality of life of caregivers

SQLC score	*Frequency*	*Percent*
Mild maladaptation 140-100	21	10.4%
Moderate maladaptation 99-86	57	28.2%
Severe maladaptation <85	124	61.4%

Table 4. Association between socio-demographic and patient factors and level of socio-economic maladaptation

Characteristics	*P value*
Sociodemographic characteristics of caregiver:	
Age	0.0
Gender	1.01
Marital status	0.0
Sole/multiple caregivers	0.01
Employment status	0.66
Characteristic of patient:	
Katz index	0.56

Discussion

To our knowledge, this is the first study to assess the quality of life in terms of socio-economic effects on informal caregivers of long-term hospitalized patients. Owing to that fact, the findings of our study were compared

with the studies performed on caregiving for elderly patients or patients with cognitive impairment in the outpatient settings. The findings of this study provide new information on several aspects of caregiving for hospitalized patients in the government hospital settings in Sri Lanka. First, the socio-demographic characteristics of the long-term hospitalized patients are different from the general health statistics of Sri Lanka. Our data shows that most of the long-term surgical patients were females (55%) with the commonest surgical ailment being lower limb ulcers. Although, Annual health statistics (2019) state that most of the patients were males with the commonest ailment being traumatic injuries [1]. Short-term hospital stay and transferring for specialized orthopedic care in most trauma cases may be the reason for observed difference.

Second, we compared the socio-demographic trends of informal caregivers with the local and global studies performed on caregiving for patients. In agreement with previous studies, most of the caregivers are married and they are either spouses or first-degree relatives of the patients [4,5,13]. Since the spouses are not allowed for inward care because of the gender policy of the hospital, most of the caregivers were first degree relatives in our study. Although, the female gender has been shown to take up the caregiver role more, we could not assess that fact because of the hospital policy of having an inward caregiver of the same gender [14].

Third, 4 out of 5 patients (89.6%) show moderate to severe socio-economic maladaptation in this study. This magnitude of care burden in terms of socio-economic factors is higher compared to previous studies which show approximately 26 - 56% of moderate to severe care burden [8,13,15]. This discordance may be because existing studies assess the caregiving for elders or cognitively impaired patients in-home care settings. Therefore, caregivers may have adequate time to adapt their lifestyle more compared to our study population who provide care to surgical patients in a ward setting. Substandard infrastructure with a suboptimal level of basic facilities (e.g. sleep, shower, meal, etc.) for caregivers may significantly contribute to a higher level of maladaptation in inward care compared to home care. Furthermore, 26.2% of caregivers were involved with some sort of educational scheme which may be an additional factor that hinders the level of adaptation.

We have observed several factors that may have contributed to the high level of socio-economic maladaptation concordant with previous studies. Increasing age is significantly associated with a higher level of maladaptation. Most of the caregivers being in the middle age group (mean=45.1 years, SD=13.7) with 12.4% of caregivers over 65 years, raise the susceptibility to higher care burden. Older age in caregiving further increases the vulnerability to poor physical wellbeing, worsening of existing medical conditions and poor psychological health according to the literature [8]. Furthermore, being a sole caregiver without adequate support from the social network is significantly associated with a higher level of maladaptation similar to existing studies [4]. We have observed a significantly higher level of maladaptation in married caregivers unlikely in the previous studies [16]. As opposed to inward care, home-based caregiving assessed in literature may have a lesser impact on the responsibilities of marital life.

The gender of the caregiver did not show any significant association with the level of maladaptation. Some western studies show that the female gender has a higher care burden, while others claim that gender is not a contributing factor to a higher care burden [14,17-19]. Surprisingly, we did not observe significantly higher maladaptation among employed caregivers. Mixed finding are available in the literature for employment status as a contributing factor [20-22]. The level of disability of the care receiver is not significantly associated with the level of maladaptation contrary to previous studies [18].

Finally, based on the results of this study we emphasize that a moderate to severe level of maladaptation is present among a substantial number of informal caregivers of long-term hospitalized patients. Among the factors (age, marital status, and sole caregiving) that are significantly associated with a higher level of maladaptation, sole caregiving due to lack of support can be addressed by appointing formal caregivers by health care authorities or from other sources (e.g. voluntary services). Moreover, caregiving needs to be recognized more as integral to health care and recruiting an adequate number of properly trained caregivers should be considered to minimize informal caregiver burnout.

There are limitations to this study. The analysis was based on a sample of caregivers selected from a single surgical unit. This may affect the generalizability of the results. Causal inferences of this study must be used with caution considering the cross-sectional nature of the study. We have not assessed the physical and psychological impact on caregivers since our emphasis is on the socio-economic effects. Strengths of this study include the adequate sample size to describe the proportion of maladaptation of caregivers. We used a caregiver assessment questionnaire including a broad range of factors to capture socio-economic effects and possible contributing factors in the local government hospital setup ensuring accurate analysis.

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Conflict of interests

There are no conflict of interests.

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