Functional dependency of older individuals and caregiver burden

ABSTRACT
This study investigated the functional dependency of older individuals and caregiver burden. This epidemiological and cross-sectional study was conducted in 2009 with 574 older people and 124 caregivers in Ribeirão Preto, SP, Brazil, using the following instruments: Functional Independence Measure (FIM) and Zarit Burden Interview. Among the elderly, 67.8% were women with an average age of 76.6 years old; 54.7% had a low level of education and a monthly per capita income of R$942.20, and only 15.7% were identified as dependents. A total of 85.6% of the caregivers were women with an average age of 56.5 years; 90.3% were family caregivers (daughters, wives), and the average burden was 27.8 (±17.5). The older individuals' dependency was a risk factor for caregiver burden (p<0.05). Preventive actions and early intervention should be priorities for this population. Surveillance from a multidisciplinary health team is required, as well as the application of instruments to assess the extent to which functionality is compromised and interventions to prevent caregiver burden.

DESCRIPTORS
Aged
Activity of daily living
Caregivers
Stress, psychological

RESUMO
A finalidade deste estudo foi identificar a dependência funcional de idosos e a sobrecarga do cuidador. Trata-se de estudo epidemiológico e transversal realizado em 2009 com 574 idosos e 124 cuidadores em Ribeirão Preto-SP, por meio dos instrumentos MIF e Escala de Sobrecarga de Zarit. Entre os idosos, a maioria era do sexo feminino (67,8%), com média de 76,6 anos, baixa escolaridade (54,7%) e renda individual mensal de R$ 942,20. Apenas 15,7% foram identificados como dependentes. Dos cuidadores, 85,6% era do sexo feminino, com média de 56,5 anos e 90,3% eram familiares (filhas ou esposas). A média de sobrecarga dos cuidadores foi de 27,8 (±17,5). A dependência do idoso foi fator de risco para sobrecarga do cuidador (p<0,05). A abordagem preventiva e a intervenção precoce devem ser prioritárias para essa população. São necessárias a vigilância de uma equipe multidisciplinar de saúde, a aplicação de instrumentos de avaliação do comprometimento da funcionalidade e a intervenção para prevenção da sobrecarga dos cuidadores.

DESCRIPTORES
Idoso
Atividades cotidianas
Cuidadores
Estresse psicológico

RESUMEN
Se objetivó identificar la dependencia funcional de ancianos y la sobrecarga del cuidador. Estudio epidemiológico, transversal, realizado en 2009 con 574 ancianos y 124 cuidadores en Ribeirão Preto-SP, mediante los instrumentos MIF y Escala de Sobrecarga de Zarit. Entre los ancianos, hubo mayoría femenina (67,8%), media etaria de 76,6 años y baja escolarización (54,7%), renta mensual individual promedio de R$942,20. Sólo 15,7% fueron identificados como dependientes. Entre los cuidadores, 85,6% era de sexo femenino, media etaria de 56,5 años, 90,3% eran familiares (hijas o esposas). El promedio de sobrecarga fue de 27,8 (±17,5). La dependencia del anciano constituyó factor de riesgo para sobrecarga del cuidador (p<0,05). El abordaje preventivo y la intervención precoz deben priorizarse en este segmento. Son necesarios el apoyo de un equipo de salud multidisciplinar, la aplicación de instrumentos de evaluación del compromiso de la funcionalidad e intervención para prevenir la sobrecarga de los cuidadores.

DESCRIPTORES
Anciano
Actividades cotidianas
Cuidadores
Estrés psicológico
INTRODUCTION

One of humanity’s greatest triumphs has been to drastically increase life expectancy; however, this increased longevity has resulted in major challenges for healthcare workers.

In Brazil, the number of seniors aged 60 and over has risen from 14.8 million in 1999 to approximately 20.6 million in 2010 (11% of the population) according to the Brazilian Institute of Geography and Statistics (IBGE). The increase has been even greater among older age groups. In 1999, Brazil recorded 6.4 million people over the age of 70 (3.9% of the total population); however, by 2010, this age group had reached 9.3 million, accounting for 5.1% of all Brazilians(1).

In addition to this demographic transition, Brazil is also undergoing an epidemiological transition as a result of its aging population. This transition has led to a higher prevalence of chronic diseases, cognitive impairment, sensory decline, accidents and social isolation, all of which can result in functional dependence in the elderly(2).

Functional dependence is the inability to maintain the physical and mental skills necessary to live independently and autonomously(3). It is generally measured by the inability to perform the activities of daily living (ADLs), either basic activities (BADLs), which are often described as self-care activities, or instrumental activities (IADLs), which involve the organization of one’s daily routine.

A major challenge we face with regard to aging is to reach old age without suffering from one or more of the diseases or medical conditions that limit daily life and render us dependent on others. However, when a person is impaired for any reason, it is most often the family who assumes the task of daily care, often without adequate preparation or knowledge for such a role or the support necessary to perform it(4,5).

The complexity of the task often makes caregivers forget about themselves, their own needs and interests. Mixed feelings, psychological conflicts, grief, fear and insecurity are common throughout the caregiving experience(6). Such conflicts are often the result of continuous caregiving and are considered symptoms of the caregiver being overburdened by the task of assisting a senior in basic activities, such as bathing, dressing, oral hygiene, feeding or helping an elderly person to move around or be transferred or positioned. These activities are considered the most stressful tasks in the daily routine(7).

In this context, the role of the nurse is critical. As an educator, a nurse is in a position to suggest strategies and give advice that can transform the lives of both individuals and the wider community.

Further research on this topic is required because the challenge of how best to provide support for caregivers is a relatively new question for the Brazilian healthcare system. Analyzing the reasons why caregivers often fall ill themselves is particularly pertinent. Such data would help to improve the health care system’s ability to address the health needs of this population.

The loss of an elderly person’s functional independence is an important public health issue. Studies that address this issue are therefore essential because they can inform and guide public health policies for both the elderly and those who take care of them.

Although current literature has highlighted numerous characteristics of family caregivers in the home environment, a need to explore this issue further remains because such features take on different contours according to the country’s regional peculiarities.

With this in mind, we set out to answer the following question: Are the caregivers of functionally dependent seniors in Ribeirão Preto, SP, Brazil, feeling overburdened by their caregiving activities? The main objective of this study is thus twofold: to determine the level of functional dependence of the elderly living in the community and to evaluate whether their family caregivers were being overburdened by the job.

METHODS

We conducted an epidemiological study that was descriptive and cross-sectional in nature. The study was performed in the urban community of Ribeirão Preto, SP, Brazil.

Our target population comprised seniors aged 65 and older and their caregivers who lived in the local community (inclusion criteria). We used two-stage cluster sampling to arrive at the number of seniors in the sample. After a random selection of sectors, at least 110 households in each sector were visited. We went on to identify these sectors on the map of Ribeirão Preto and mark the neighborhoods and streets that were visited.

We registered 733 elderly people using this method but interviewed only 574. This 22% reduction was because of deaths, changes of address, and those who did not agree to participate in the study.

During each home visit, the elderly individuals and their caregivers were invited to participate in the study, and those who accepted and met the inclusion criteria were asked to sign a consent form in duplicate. The study was approved by the Ethics Research Committee at the University of São Paulo at Ribeirão Preto, College of Nursing.

Data were collected between January and July, 2009. We used an instrument that addressed the...
following variables and scales to obtain data on senior citizens in the area:

*Socio-demographic profiles:* These included the following variables: age, gender, marital status, personal and family income, source of income, years in retirement, education level and living arrangements.

*Functional Independence Measure (FIM):* This instrument was developed to assess the level of dependency in patients with functional restrictions of various origins. Its primary objective is to quantitatively evaluate the burden of care required for a person to perform a series of everyday cognitive and motor tasks. The scale consists of two areas and six dimensions. The area of motor FIM (including the dimensions of self-care, sphincter control, mobility and locomotion) is assigned a score of 13-91 points. The area of cognitive FIM (including the dimensions of communication and social cognition) is scored between 5-35 points. Two or more activities are evaluated in each dimension for a total of 18 functional categories of which 13 are motor and five are cognitive. These categories are evaluated in terms of how independently they can be performed. For this evaluation, we used a seven-point scale wherein each category was given a score of one (total dependence) to seven (complete independence). This yields a minimum score of 18 and a maximum of 126. For data analysis, we considered the global average, motor and cognitive FIM scores. In Brazil, the scale was translated into Portuguese and validated in 2004.

To evaluate the caregivers, we used the following tools:

*Caregiver profiles:* These allowed us to create a picture of caregivers looking after seniors with cognitive deficits. The profiles included the following: gender, age, marital status, kinship, knowledge of the disease, degree of formal training in caregiving, number of hours devoted to care, types of caregiving tasks performed, and support they received.

*The Zarit burden scale:* This scale was translated and validated in 2002 for Brazil. It consists of 22 items and seeks to assess the extent to which the caregivers believe the activities of caring affect their physical and emotional health, social activities and financial situation. The responses to the 22 items should be on a five-point scale that describes how each statement affects the person. The total score is obtained by totaling all the items and can range from 0 to 88. The higher the score, the greater the perceived care burden.

### RESULTS

*Socio-demographic profiles and functional independence measures (FIM scores) of the elderly living in the community*

It is interesting to note that the most significant age range (33.4% of participants) was that of 80+ (minimum age of 65 and maximum of 103 years) and that the great majority of seniors who participated in the study were female (67.8%). The mean age of all participants was 76.6 years (± 7.6) with mean ages of 76.5 (+ 7.7 years) and 74.9 (± 7.3) for women and men, respectively. Of the 574 seniors, 326 (56.8%) reported not having a partner, being either widowed, single or divorced. Analyzing only those participants who had been widowed, we found that 54.5% of women were in this situation whereas only 15.7% of men categorized themselves as such. With regard to education, 314 (54.7%) participants had studied for between 1-4 years, followed by 116 (20.2%) who categorized themselves as illiterate.

Regarding the economic situation of the elderly, 363 (63.2%) were retired, and 188 (32.8%) were receiving alimony, most of whom were women (179 or 46%). Only a minority (62 or 10.8%) reported themselves as working. As for personal income, the average was R$947.20, with the men receiving approximately R$300.00 more than their female counterparts. The average total household income (including that of the elderly person) was R$1,460.00.

Table 1 shows the correlation between functionality levels (FIM scores) and the socio-demographic variables of age, education, personal income and family income. The positive correlation among global, cognitive and motor FIM scores and the participant’s age, although significant, was weak. However, we found a statistically significant negative correlation of moderate strength between functionality and education, i.e., in this population, participants with higher levels of education had lower levels of functional impairment.

Table 2 shows data on mean FIM scores related to the variable “with/without caregiver,” indicating whether they had help in their daily routines. Our data suggests that seniors who were assisted by a caregiver had lower than average FIM scores. In other words, we observed that those seniors were generally the most functionally dependent. The differences were statistically significant, revealing that the higher the functional dependence of the senior, the greater the need for caregiver support.

| Table 1 - Correlation coefficients of FIM scores with the socio-demographic variables of age, education, personal and family income - Ribeirão Preto, SP, Brazil 2009 |
|------------------|-----------|-----------|-----------|-----------|
|                  | Pearson   | Age       | Education | Personal income | Family income |
| Global FIM       | 0.184*    | -0.422*   | 0.070     | 0.031          |
| Motor FIM        | 0.162*    | -0.411*   | 0.061     | 0.026          |
| Cognitive FIM    | 0.208*    | -0.383*   | 0.081**   | 0.038          |

*p<0.001; **p<0.05
overburdened, i.e., the more dependent the senior, the more dependence is a possible risk factor for a caregiver’s becoming overburdened. These findings were reported in another study (16), in which women were shown to be more likely than men to experience widowhood. The same study (16) also showed higher average burdens: male (28.1, ± 16.3), females (40 or 37.4%) and males (7 or 41.25%), had studied a partner (71 or 66.4%), whereas among male caregivers, the majority did not have a partner (12 or 70.6%).

Regarding the degree of kinship to the senior, most caregivers fell into the category of daughter/son or son-in-law/daughter-in-law (69 or 55.6%), followed by spouses (22 or 17.7%). For female caregivers, 62 (57.95%) were daughters or daughters-in-law, and 18 (16.8%) were spouses. The great majority of caregivers reported living with the senior (99 or 79.8%) and having knowledge of how to provide care (115 or 92.7%).

Table 3 shows the socio-demographic aspects of seniors with caregivers and how they affect caregiver burden scores. The average score of our participants on the caregiver burden scale was 27.8 (± 17.5), with caregivers who assisted seniors aged between 65 and 69 years reporting a higher average burden than those of other age groups. Similarly, caregivers of seniors with the following profiles also showed higher than average burdens: male (28.1, ± 16.3), divorced/separated (39; ± 19.9) and those who had studied for between five and eight years (38.8; ± 13.9). These results, however, were not statistically significant.

We analyzed the data using linear regression with the total score on the Zarit burden scale as the outcome and the global FIM as the explanatory variable and found a statistically significant correlation (r = -0.179, p = 0.046). These findings indicate that the level of a senior’s dependence is a possible risk factor for a caregiver’s becoming overburdened, i.e., the more dependent the senior, the greater the chance of caregiver burden.

**DISCUSSION**

**Socio-demographic profiles and burden levels of caregivers assisting seniors living in the community**

We interviewed 124 caregivers, of whom 107 (85.6%) were female and 17 (14.4%) were male. The average age of the caregivers was 56.6 (± 13.4), with male caregivers having a higher average age (61.8, ± 18) than their female counterparts (55.7, 55.7 ± ). This difference is statistically significant (p <0.05).

For the variable having a partner, we included caregivers who were either married or in a stable civil union. Single, widowed, separated or divorced caregivers were categorized as not having a partner. Most female caregivers reported having a partner (71 or 66.4%), whereas among male caregivers, the majority did not have a partner (12 or 70.6%).

With regard to education, most of the caregivers, both females (40 or 37.4%) and males (7 or 41.25%), had studied for between one and four years. Few were illiterate, and few had studied for more than 13 years.

Regarding the degree of kinship to the senior, most caregivers fell into the category of daughter/son or son-in-law/daughter-in-law (69 or 55.6%), followed by spouses (22 or 17.7%). For female caregivers, 62 (57.95%) were daughters or daughters-in-law, and 18 (16.8%) were spouses. A similar trend was evident for male caregivers, of whom seven (41.2%) were sons or sons-in-law and four (22 or 17.7%) were spouses. The majority of caregivers reported living with the senior (99 or 79.8%) and having knowledge of how to provide care (115 or 92.7%).

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**Table 2 - Distribution of means and standard deviations of the FIM and MMSE related to the variable of without/with caregiver - Ribeirão Preto, SP, Brazil. 2009**

<table>
<thead>
<tr>
<th>Profile of senior</th>
<th>With caregiver Mean (SD)</th>
<th>Without caregiver Mean (SD)</th>
<th>Total Mean (SD)</th>
<th>t test p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>MIF Global</strong></td>
<td>89.1(30.6)</td>
<td>120.8(8.3)</td>
<td>113.9(20.6)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td><strong>MIF Motoria</strong></td>
<td>65.2(23.4)</td>
<td>87.5(6.3)</td>
<td>82.7(15.3)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td><strong>MIF Cognitiva</strong></td>
<td>23.9(9.5)</td>
<td>33.32(2.8)</td>
<td>31.3(6.4)</td>
<td>&lt;0.001</td>
</tr>
</tbody>
</table>

Based on 574 seniors and 124 caregivers.

**Table 3 - Distribution of socio-demographic profiles of seniors who had caregivers related to mean caregiver burden - Ribeirão Preto, SP, Brazil 2009**

<table>
<thead>
<tr>
<th>Senior’s profile</th>
<th>Mean caregiver burden (SD)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregivers</td>
<td>27.8 (±17.5)</td>
<td></td>
</tr>
<tr>
<td><strong>Age group</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>65 – 69</td>
<td></td>
<td>&lt;0.001*</td>
</tr>
<tr>
<td>70 – 74</td>
<td>30.0(16.6)</td>
<td></td>
</tr>
<tr>
<td>75 – 79</td>
<td>21.3(11.6)</td>
<td></td>
</tr>
<tr>
<td>80 or over</td>
<td>26.6(17.2)</td>
<td></td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td>0.876*</td>
</tr>
<tr>
<td>Female</td>
<td>27.5(18)</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>28.1(16.3)</td>
<td></td>
</tr>
<tr>
<td><strong>Marital status</strong></td>
<td></td>
<td>0.692**</td>
</tr>
<tr>
<td>Married</td>
<td>27.1(16.9)</td>
<td></td>
</tr>
<tr>
<td>Widowed</td>
<td>28.1(18.2)</td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>24.5(15.5)</td>
<td></td>
</tr>
<tr>
<td>Divorced/separated</td>
<td>39.0(19.9)</td>
<td></td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td>&lt;0.001*</td>
</tr>
<tr>
<td>Illiterate</td>
<td>27.1(15.6)</td>
<td></td>
</tr>
<tr>
<td>1 to 4 years</td>
<td>27.7(18.9)</td>
<td></td>
</tr>
<tr>
<td>5 to 8 years</td>
<td>36.8(13.9)</td>
<td></td>
</tr>
<tr>
<td>9 to 11 years</td>
<td>17.8(22.1)</td>
<td></td>
</tr>
<tr>
<td>12 years or more</td>
<td>27.7(12.3)</td>
<td></td>
</tr>
</tbody>
</table>

*t = test de Student; **ANOVA a 1 fator.

**Socio-demographic profiles and functional independence measures (FIM scores) of the elderly living in the community**

We found a predominance of women and older seniors in the local community. The overall mean age of the seniors in our study was 76.6 years, which is similar to the average life expectancy data reported by some Brazilian and international studies[12-15].

The seniors in our study were classified according to marital status, as having or not having a partner. Those who had a partner were either married or lived with a partner, whereas those classified as having no companion were widowed, divorced or single. It is noteworthy that the majority of women were widowed, whereas the majority of men were married. The difference between these variables was statistically significant.

Similar findings were reported in another study[16], in which women were shown to be more likely than men to remain unmarried after widowhood. The same study[16]...
showed that social isolation is a risk factor for disabilities because unmarried people are significantly more likely to need a caregiver than those with a partner.

When considering the per capita income of the senior, the vast majority reported receiving a pension or alimony, whereas only a small minority categorized themselves as working. The overall average personal monthly income, in Brazilian reais, was R$947.20, approximately 2.1 times the minimum wage (in 2009, the minimum wage was R$450.00). This figure was higher than that reported by other Brazilian studies[13,17-18].

With regard to education, the data show that the population we chose to study had little access to education; most of the studied seniors were either illiterate or had studied for between one and four years. A lack of access to education was a strong variable and was negatively and independently correlated with the need for a caregiver. Conversely, higher educational levels were associated with both a higher functional status and a lower risk of cognitive impairment among the elderly[19].

In the distribution of living arrangements, most respondents reported living only with a spouse. Another study[20] showed that only a minority of older people lived alone, whereas the vast majority cohabited in multigenerational households (two or three generations).

In assessing the population aged 80 or over in the city of Ribeirão Preto, SP, Brazil, a study[17] showed that many older participants (26.5%) lived only with a spouse, especially those aged between 80 and 84 years old, a percentage that decreased with age. This difference can be explained by the interval of seven years between the surveys because, during this time, the Brazilian family structure has been migrating from multigenerational extended families to predominantly nuclear families.

In our study, the majority of seniors who had a caregiver lived in multigenerational households with their spouses, their children and their daughters and sons-in-law. These findings are consistent with those of another study that showed that this type of arrangement is more than a sociocultural choice; it is a means of survival. This is because living alone is independently and negatively correlated with a person’s need to have a caregiver[16]. This trend may reflect the relatively better conditions of those who are able to live alone compared with those who cohabit with other generations.

According to the values found in our study, our participants presented an average FIM of 113.9 (± 20.6). Our findings are similar to those of another study[20] that evaluated 125 elderly people in a city in the state of São Paulo to verify the relation between subjective well-being, independence and the functional performance of the lower limbs (muscle strength, speed of gait and balance) of elderly outpatients. This study found average global FIM scores of 112.9 (± 12.86), motor FIM scores of 82.07 (± 9.69) and cognitive FIM scores of 30.87 (± 4.81).

By analyzing FIM scores against socio-demographic variables, such as age, gender, education and income, we observed that education was positively correlated with the functional performance of the elderly. Seniors with lower levels of education were five times more likely to be dependent on others in their daily routine[18]. In contrast to other studies[16,21], we found no significant correlations between functionality and the variables of personal or family income.

We found a negative correlation between age and functional performance, which suggests that the older the participants, the lower their FIM scores will be. In other words, older seniors tend to have lower functional independence. This correlation was, however, not considered to be statistically significant. Two large studies of the elderly community in São Paulo found that the difficulty in performing the basic activities of daily living is associated with both advancing age and gender[20].

The independence of the elderly is directly related to maintaining their ability to carry out the activities of daily living without assistance and the autonomy and freedom to make their own decisions and to manage their own lives. Seniors may be dependent, requiring help for self-care, but nevertheless preserve their autonomy. Functional capacity indicates not only the ability to perform everyday tasks but also the preservation of mental activities and the ability to integrate socially[21].

Studies on the functionality of the elderly show that the basic activities of daily living are the last to be compromised as a result of aging or health problems. In a hierarchy of complexity, it is initially the ability to perform the advanced activities of daily living that is compromised, followed by the instrumental and, finally, the basic activities of daily living. These basic activities are those that are closely related to self-care[21].

Thus, it is important to associate FIM with other instruments that assess the different levels of complexity of activities, particularly those related to instrumental and advanced activities of daily living. This analysis is vital because early intervention is necessary to prevent dependency and promote the recovery of functional independence in the elderly.

When a senior’s independence and autonomy are impaired, the need for a caregiver arises. In the present study, caregivers were associated with lower average FIM scores. This correlation is consistent with the findings of other Brazilian and international studies[12-15].

Researchers in this line of study are often motivated by the recognition that caregivers play an essential role in public health care, especially when chronic physical disabilities are present.
Socio-demographic profiles and burden levels of caregivers assisting seniors living in the community

Our data show that 86.4% of caregivers surveyed were female, which is consistent with extensive Brazilian and international literature. These findings reinforce the historical role of women, which attributes to them the social function of caring for the house, the children and the spouse. Moreover, the historical fact that women did not perform duties outside the home meant that they were more apt than men to undertake this role.

The mean age of the caregivers in our study was 56.6 (± 13.4), which is similar to Brazilian studies but lower than other international studies. In developed countries, life expectancy is higher than in developing countries, perhaps explaining the higher mean age of caregivers in developed countries when compared with Brazilian data.

A survey of caregivers in the Programa de Assistência ao Idoso no Domicilio [Assistance for the Elderly at Home Program] (USP) found that 24.1% of caregivers were spouses and 39.8% were their children, many of whom were over 60 years of age themselves. In contrast, some international studies on caregivers report that a majority of caregivers are spouses. Social and cultural norms in developed countries often result in an elderly spouse assuming the role of caregiver because most families are nuclear with few or no children. In developing countries, however, the elderly generally have more than one child, making it more likely that children take responsibility for the care of their elderly parents.

The majority of caregivers in our study reported living with the person they care for. This finding is in keeping with the majority of Brazilian and international studies. This situation can be perceived as favorable to the senior who is receiving care because their care demands can be met promptly. However, it can be negative for the caregiver, whose constant exposure to the task of caregiving can generate high levels of stress.

With regard to the educational level of the caregivers, most had studied for between one and four years. Their relative lack of education may contribute to the likelihood of their becoming a caregiver because society increasingly demands higher levels of education in the formal labor market, making it more difficult for individuals with less education. Consequently, it is more likely that these people will devote themselves to housework and the task of caregiving.

When considering the age of the caregivers, 31.8% were over 60 years of age and had therefore had been brought up when access to schools in Brazil was particularly difficult. Moreover, at that time, families often gave their children responsibility for many household activities, especially in rural environments. Nevertheless, 68.2% of caregivers were less than 60 years old. Despite these caregivers’ being younger and, therefore, products of a different era, low education levels were also prevalent among them, revealing an underlying social issue.

The data showed a positive correlation between educational levels and the income of the caregivers surveyed. The average household income (including that of the senior) was R$1,460.00, which is 3.2 times the minimum wage (the minimum wage in 2009 was R$450.00), indicating that 66.7% had a monthly family income equivalent to one to three times the minimum wage. 20% received four to six times the minimum wage and 13.3% were earning more than six times the minimum wage. These findings are consistent with those of other Brazilian studies. It is noteworthy that when caregiving occurs under economically difficult conditions, the caregiver tends to see caregiving as a duty or does not see any alternative to the arrangement, making the task even more stressful.

In analyzing the profiles of the seniors being cared for in terms of caregiver burden, we found that caregivers who assist seniors aged between 65 and 69 showed higher levels of burden than those caring for older seniors, although this relation cannot be considered statistically significant. Some research suggests that burden levels decrease over time, possibly as a result of the caregivers’ adapting to their new role. In one study, caregivers reported increased confidence as the years went by as a result of their experience and subsequently reported decreased feelings of burden.

In the current study, which was conducted in Ribeirão Preto / SP, the functional capacity of the senior was the only variable that proved to be statistically significant in relation to caregiver burden with inversely proportional averages, i.e., the lower the average FIM, the higher the average burden. These findings suggest that the greater the dependence of the elderly, the higher the level of caregiver burden, supporting the conclusions of other Brazilian studies.

Support groups play an important role in helping caregivers develop coping mechanisms and in decreasing caregiver burden. As a global and multidimensional phenomenon, caregiver burden requires coordinated interventions rather than the isolated and random actions that are most commonly the case.

Nursing has a vital role to play, and action should be taken in the area of health education to improve geriatric care and caregiver support, especially in situations of functional dependence. This action should include providing guidance on positioning the bed, bathing, feeding, and transfer, among other daily necessities. Counseling and psychoeducation can prepare caregivers and families for the feelings of guilt, frustration, anger, sadness, depression, etc., that come with the responsibility of caring for a sick family member at home, even with the help of health professionals.

To provide such support, it is essential that caregivers receive planned interventions, such as regular home visits from health professionals (nurses, doctors, psychologists, etc.), as well as other forms of supervision and training. This type of support should be considered a basic and essential requirement to meet the needs of caregivers and the elderly.

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CONCLUSION

Caregiving, when associated with a senior’s lack of ability to perform the basic activities of daily living, results in caregiver burden. The level of dependence of the senior was an important predictor of elevated burden levels.

In most cases, a senior is already incapable of many self-care activities when a caregiver begins the task of assisting him or her. Often, caregivers take on this role without any prior training and are urged to learn from experience. They often lack the information and guidance on the specifics of geriatric care that should be supplied by health professionals. Where there is evidence of caregiver burden, which is often accompanied by psychosomatic symptoms, it is even more important to take specific measures to prevent caregiver burden, provide counseling and even treat informal caregivers.

We suggest further studies to address this issue, as well as the development of public policies targeting the elderly and their caregivers residing in the community. The use of assessment tools that address functional capacity in terms of the instrumental and advanced activities of daily living are particularly important because research in this area has mainly been focused on the evaluation of the basic activities of daily living of the elderly. Such a change in focus would lead to results that would benefit not only the elderly in preventing dependency but also their caregivers in lowering their level of burden.

REFERENCES


