Safety Science 144 (2021) 105472

Contents lists available at ScienceDirect

Safety Science

journal homepage: www.elsevier.com/locate/safety

Work ability of informal caregivers of patients treated by the public home care service of Brazil: A cross-sectional study

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ARTICLE INFO

Keywords:
Caregivers
Home Care Services
Work capacity evaluation
Cross-sectional study
Quality of life
Occupational Health

ABSTRACT

Informal caregivers are subject to a heavy work burden, which can have negative repercussions on their work ability. This cross-sectional study with 70 informal caregivers aims to evaluate the work ability of informal caregivers caring at home for patients followed by the Public Home Care Service in Bauru, Brazil, as well as to investigate its associated factors. The association between work ability and the variables under study was estimated using simple and multiple logistic regression models, including a hierarchical model. Work ability, care-related burden, sleep quality and quality of life were assessed through the Work Ability Index, the Zarit Burden Interview Scale, the Mini-sleep Questionnaire, and the 12-Item Short-Form Health Survey, respectively. Almost 36% of the informal caregivers had an inadequate work ability. The variables that increased the probability of an adequate work ability were quality of life (OR: 0.94; CI: 0.92–0.97) and self-perceived physical fitness (OR: 0.32; CI: 0.17–0.60), while those that reduced the likelihood of adequate work ability were age (OR: 1.06; CI: 1.02–1.13), burden (OR: 1.05; CI: 1.01–1.10) and poor sleep quality (OR: 1.07; CI: 1.01–1.12). It is necessary to develop public health policies aimed at informal caregivers who, due to their informality, are not seen as workers.

1. Introduction

More than 3.5 million Brazilians have an intense degree of physical limitation or are unable to perform their basic daily activities (Instituto Brasileiro de Geografia e Estatística, 2015). This number is increasing due to the aging population, the increased prevalence of chronic diseases (Duca et al., 2011) and, also, the high number of permanently disabled people resulting from violence and traffic accidents (Seguradora Líder-DPVAT, 2019).

For several reasons, such as reducing health care costs, the risks of hospital infection, and increasing the comfort and emotional support of terminally ill patients, Brazil and many countries currently recommend long-term home care for these patients (Karsch, 2003).

The Brazilian recommendation was turned into action in 2011, when the public national health system, known as Unified Health System (SUS), determined that home care service (SAD) would be integrated into its emergency care network (Brazil, 2011). In 2013, SAD was implemented as a substitute or complementary service to hospitalisation and outpatient care, with guaranteed care continuity, regularity and integrality in order to promote health, prevent diseases and provide treatment and rehabilitation (Brazil, 2013).

SAD is composed by a multi-professional healthcare team that works closely with the patients' family. In this way, SAD's professionals are responsible for: (1) identifying and training the patients' caregiver(s); (2) involving the caregiver(s) in the provision of care, making them aware that they are the main responsible for the day-to-day care activities, while respecting their limits and potential; and (3) meeting regularly with the caregiver(s) to resolve questions and complaints. According to patients' health conditions, their physical ability to reach a health facility, the frequency of care and the number of resources they need to be treated, SAD must balance the degree of family and professional care offered to its patients (Brazil, 2013).

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https://doi.org/10.1016/j.ssci.2021.105472
Received 30 July 2020; Received in revised form 8 July 2021; Accepted 27 August 2021
Available online 4 September 2021

Even though informal caring (i.e. taking care of relatives with health problems, without being a healthcare professional, having no contracts concerning caring activities, nor being paid for it) is the most common form of long-term care throughout the world, (Triantafillou et al., 2010) and it should become even more frequent due to the aging population, providing informal care has already been associated with social network problems (Zwaanswijk et al., 2013), psychological suffering (Gérain and Zech, 2021), physical complaints (Mendes et al., 2019) and work productivity loss (Mazanec et al., 2011).

Given this scenario, the aims of this study were to measure the work ability and to evaluate its associated factors in informal caregivers of patients accompanied by the SAD.

2. Theoretical background

With the increasing number of elderly people that require care and the substantial financial costs of hospitalization, long-term care in institutional settings and nursing home care, many western countries have implemented public home care services (Glomsås, et al., 2021). Home care is currently the main strategy to care for individuals who lack or have lost a significant degree of their physical, psychological or intellectual autonomy, and thus require substantial assistance or help to carry out their day-to-day activities (Silva et al., 2005; Julià, et al., 2021). Even though public home care services differ between and within countries (MacAdam, 2004; Glomsås, et al., 2021), a common element among these services is the goal to move away from the longstanding care strategy that is centered in hospitals and specialized outpatient facilities (Paixão et al., 2010). To achieve this goal, public home care services offer a comprehensive variety of caregiving modalities, including post-acute, supportive, and end-of-life home care (MacAdam, 2004; Glomsås, et al., 2021; Laukli et al., 2021).

However, even in the presence of these services, research shows that the largest component of home care services is delivered by informal caregivers, especially among individuals who have a higher level of dependency, with approximately seven hours of informal care for every two hours of professional care (Seow et al., 2010; Allin et al., 2020). Informal caregivers are usually family members or people who are close (such as neighbors or close friends), their role is fundamental in keeping those under their care with a level of autonomy and involvement when connecting with family, friends and society (Brazil, 2012). Informal caregivers may perform a wide variety of activities ranging from healthcare (arranging and attending health appointments and assisting with medications, treatments or therapies) to routine daily living activities (such as personal hygiene, dressing, feeding and ambulating) and also household work (shopping, cooking and cleaning) (Triantafillou et al., 2010; Martsolf et al., 2020).

Taking on the informal caregiver role is usually driven by family and friendship relations, but also by social and cultural norms. It is not unusual that one becomes a caregiver without any planning or intentionality. Meaning that many informal caregivers are not able to make the arrangements needed to become a certified caregiver (Detaille et al., 2020). Thus, many informal caregivers have to combine their informal caregiving activities with paid employment, resulting in heavy workloads (Dorant and Boumans, 2016; Martsolf et al., 2020).

Even though positive consequences may arise from caregiving, as it has already been shown in the literature (Carbonneau et al., 2010), informal caregiving can be a serious burden. A growing number of studies have shown that informal caregivers present a higher frequency of poor mental and physical health (Halpern et al., 2017; Mendes et al., 2019; Gérain and Zech, 2021). Their heavy workloads may also lead to inadequate rest breaks during their day of work and consequently to exhaustion, reducing social contact and opportunities to adopt or maintain a healthy lifestyle (Detaille et al., 2020).

Health problems and intense workloads may result in an imbalance between the individuals' physical and intellectual resources and the emotional, cognitive, and physical demands and characteristics of their work, thus leading to a decline in their work ability (Ilmarinen and Ilmarinen, 2015). Work ability (WA) is an important concept in occupational health research and practice. Findings from previous research have shown that WA is associated with sickness absences, early retirement, intention to leave and work stress (Camerino et al., 2006; Kujala et al., 2006; Sell et al., 2009; Knezevic et al., 2011).

In this study, we adopted the concept proposed by Tuomi et al. (2005) which says that WA can be understood as an answer to the question: "how good is the worker at present, in the near future, and how able is he or she to do his or her work in respect to work demands, health, and physical and mental resources". However, it should be noted that, since the concept and the conceptual models of WA have evolved throughout time, it is difficult to come up with a definite definition for WA.

In 1983, the balance model of work ability was proposed. Based on a stress-strain model, the balance model of WA states that occupational stress creates strain which must be regulated by the resources of the individual. This model acknowledges that work strain differs from individual to individual. It also recognizes the need to find a balance between the strain created by work and the workers' resources to deal with it, since, when these factors are in balance, the strain can be positive, maintaining and developing workers' abilities and well-being (Ilmarinen et al., 2008).

Later, as a consequence of extensive research in the area, multidimensional models have been proposed to explain WA. These models broaden the scope and extent of previous WA models, on the grounds that they include not only workers' resources and work demands but also factors outside work life, which are in constant interaction and changing over time. One of the most known multidimensional models is the WA model developed by the Finnish Institute of Occupational Health. This model portrays WA as a house with four floors, its staircase, and the surrounding environment. The first three floors of the house are workers' resources: (1st) health and functional capacities, (2nd) professional expertise, and (3rd) values, attitudes and motivation. The fourth floor represents work-related aspects (work conditions, work content and demands, work community and organization, supervisory work and management). The staircase indicates that all floors of the house interact, while the surrounding environment (family, immediate social environment and society) can be looked at from a balcony located on the third floor. If the workers' resources are in balance with the fourth floor, the WA will be preserved (Ilmarinen et al., 2008; Ilmarinen and Ilmarinen, 2015).

WA is influenced by individual (e.g., age, weight and musculoskeletal capacity), job-related (e.g., physical workload, mental work demands, physical work environment, decision authority, skill discretion, supervisor support, social support and meaning of work), and lifestyle factors (e.g., leisure-time physical activity, diet, smoking and sleep) (van den Berg et al., 2009; Lian et al., 2015; Converso et al., 2018; Oellingrath et al., 2019). Therefore, interventions aimed to maintain or increase WA should consider all of these factors.

Aging is an individual factor that is intrinsically related to WA. Due to the cognitive and physiological decline related to aging, WA inevitably decreases in older individuals, even if workers' competence and experience partially compensate for these changes (Almeida et al., 2018; Converso et al., 2018). Considering this relation between age and WA, and that informal caregivers are mostly older individuals (Wolff and Kasper, 2006; Wolff et al., 2016; Ornstein et al., 2017) it is extremely important to understand and monitor WA amongst these workers. However, even though WA has been extensively studied for the past few decades because of the impacts of aging in the working population (Ilmarinen, 2019), WA studies concerning informal caregivers are scarce, in Brazil, for example, most WA studies focus on nurses and manufacture workers (Cordeiro and Araújo, 2016).

3. Material and methods

3.1. Design

This is a cross-sectional study carried out with informal caregivers responsible for the home care of patients (including bedridden patients) who were under follow-up by the SAD in Bauru, a medium-sized city (with a population of about 340 thousand) located in the midwestern region of the State of São Paulo, Brazil.

3.2. Inclusion and exclusion criteria

The inclusion criteria for the informal caregivers were: being 18 years of age or older, not being paid for this activity, and identifying themselves as the primary caregiver for the patient. Caregivers who were trained health providers and/or who performed the informal care activities for less than three months were not included. During data collection, the SAD followed 90 patients (and their 90 respective caregivers). Since there was one single refusal to participate in the study and 19 caregivers met the exclusion criteria (7 were trained health providers and 12 had been caregivers for less than three months), the universe of cases consisted of 70 informal caregivers.

3.3. Data collection

Data collection took place from October 2018 to March 2019. The following variables related to the caregivers were evaluated: sociodemographic characteristics, caring activities, self-perceived physical fitness, burden of care, sleep disturbances, quality of life, and WA. While the variables related to the care recipients were: estimated weight and functional independence level.

3.4. Research instruments

To assess WA, the Brazilian Portuguese version of the Work Capacity Index (WAI) was used. The WAI has already been translated to Brazilian Portuguese (Tuomi et al., 2005) and validated (Martinez et al., 2009). It is composed of ten items divided into seven dimensions: current work ability compared with best work ability throughout life; work ability in relation to the demands of the job; number of current diseases diagnosed by a physician; estimated work impairment due to diseases; sick leave during the past year (12 months) (this dimension was modified from the original questionnaire, sick leave was replaced by "inability to provide care to the patient due to illness"); own prognosis of work ability 2 years from now; and mental resources (Tuomi et al., 2005). Each question is scored individually, resulting in a score ranging from 7 to 49. WA scores greater than or equal to 37 points were considered adequate (Golubic et al., 2009; El Fassi et al., 2013).

Care-related burden was assessed using the Zarit Burden Interview Scale, which was translated and validated to Brazilian Portuguese by Scazufca (2002). This scale consists of 22 items that assess the perceived impact of care on physical and emotional health, social activities, and financial conditions. Each item receives a score ranging from "never" (zero points) to "always" (four points), while in question 22, answers range from "not at all" (zero points) to "extremely" (four points). The final score obtained can vary from 0 to 88 and the higher the score, the greater the burden.

Caregivers' sleep-related disorders and disturbances were assessed using the Mini-Sleep Questionnaire, which has also been translated and validated into Brazilian Portuguese (Falavigna et al., 2011). The instrument consists of 10 questions on a Likert scale, ranging from never (one point) to always (seven points). The final score, therefore, varies from 10 to 70, and the higher the score, the greater the level of sleep disturbance. The study that validated the instrument characterizes a score greater than or equal to 25 points as designating poor sleep quality (Falavigna et al., 2011), in this study, however, this variable was analyzed as a continuous one.

The informal caregivers' quality of life (QoL) was assessed using the Brazilian Portuguese version of the 12-Item Short-Form Health Survey (SF12) scale. It consists of 12 items regarding the individual's perception of aspects of his or her life in the last four weeks, which are grouped into eight functional health subdomains: physical functioning, physical role, bodily pain, general health, vitality, social functioning, emotional role, and mental health. Each of the 12 items has a set of possible responses distributed on a Likert-type scale, where the attribution of scores is summarized in two domains, the physical and the mental. The scores obtained are transformed into a scale from 0 to 100, and a higher value portrays a better QoL (Camelier, 2004).

Self-perceived physical fitness was evaluated with the following question: "How do you rate your physical fitness?" Answers were based on a six-point ordinal scale, with explanatory verbal qualifiers in the extremities: the words "precarious" (0) and "excellent" (5). Another study that used the same means of assessing physical fitness defined a score as "good" when it was greater than three (Mascarenhas & Fernandes, 2014). In the present study, this variable was treated as a continuous one.

To assess caregivers' sociodemographic characteristics a questionnaire was developed containing the following self-reported variables: continuous variables - age (years of life), Body Mass Index (kg/m^2), education (years), income (number of minimum wages, this means the total income of the informal caregiver - thus, not earned from the act of caring -; nowadays, in Brazil, the minimum wage is about U$ 200.00 monthly), length of time as caregiver (months), total time dedicated to patient care (hours per day) and frequency of care (days); dichotomous variables - sex, residing with partner, stopped working, children, children residing with the caregiver, smoking, abusive alcohol consumption, help to provide care, sleep interruption to provide care, not providing full-time care, and adapted home; categorical variables - caregiver's relationship to the patient (marital, relative and non-relative). To determine which daily caring activities the caregivers performed, the questionnaire included questions regarding bathing, toileting, (un)dressing, feeding, transferring, walking assistance, cooking, laundry and cleaning, with answers on a five-point Likert scale ranging from "never" to "always". For statistical analysis purposes responses to these questions were coded as a dichotomous variable (yes/no).

Regarding the care recipients the following variables were evaluated: estimated weight (kg) as reported by the caregivers (since there was no adequate scale for bedridden patients); and functional independence level. Functional independence was assessed using the Functional Independence Measure (FIM), a scale translated and validated to Brazilian Portuguese that assesses the burden of care demanded by a person to perform a series of motor and cognitive tasks of daily life (Riberto et al., 2004). Each item receives a score between 1 (total dependence) to 7 (complete independence) and the total score ranges from 18 (high dependence) to 126 (complete independence).

3.5. Data analysis

Data analysis was performed using the IBM SPSS Statistics software v.26.0. (IBM, Armonk, NY, USA). The descriptive analysis was carried out based on measures of central tendency and dispersion for continuous variables and simple frequencies for categorical variables.

Two logistic regression models were adjusted to analyze factors associated with the caregivers' WA. The first, a hierarchical model, evaluated the association between WA and the caregiver's sociodemographic characteristics, self-perception of physical fitness, caring daily activities, and those related to the care recipients. The second model evaluated the association of caregiver burden, sleep disturbances, and QoL with WA.

The decision to use two different regression models was made due to the choice of using a hierarchical conceptual model for the multiple

analysis. In the hierarchical model, the variables of the distal level were related to the caregiver and the proximal level consisted of variables related to care. Since the Zarit Burden Interview, the Mini-sleep Questionnaire, and SF12 addressed variables at both levels, it was decided not to include them in the hierarchical model, because they could produce confounding effects due to multicollinearity in the analysis.

The hierarchical model was preceded by a bivariate analysis in which the association of independent variables with WA (dichotomous outcome) was analyzed using Student's *t*-test for continuous variables and chi-square test for categorical ones.

Subsequently, the independent variables were grouped according to a two-level hierarchical model (Fig. 1), and the analysis took place sequentially from the distal level (factors related to the caregiver) to the proximal level (factors related to care).

Thus, the variables of the first level were adjusted to each other through a logistic regression analysis with a stepwise forward procedure, in which the independent variables related to the caregiver (distal level) that reached at least $p \leq 0.25$ in the analysis were maintained in the model. Variables related to care (proximal level) were adjusted to each other plus those of the distal level that were maintained in the model, following the same procedure and with the same cut-off p-value used in the distal level. Therefore, proximal level variables were adjusted both by the variables of their level and by those of the previous level. Finally, variables that attained a significance level of $p \leq 0.25$ in the previous step were included in the final multiple hierarchical model, in this final model variables that reached a (two-tailed) level of statistical significance below 5% were considered to be associated with the outcome.

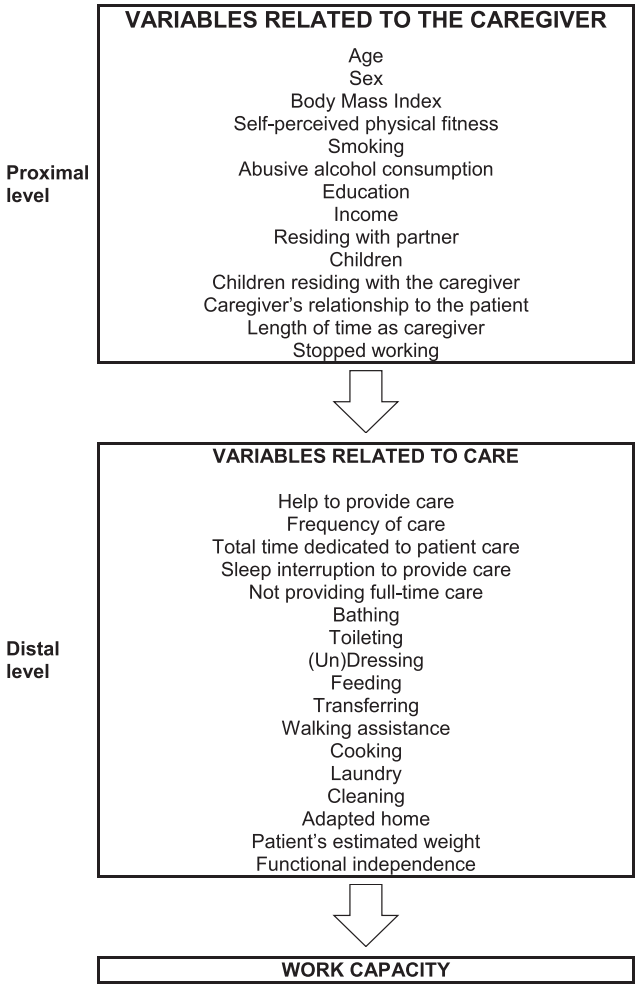

Fig. 1. Theoretical hierarchical model of the studied variables, according to the established levels.

For the adjustment of the second model, simple logistic regression models were estimated using the results of the Zarit Burden Interview, Mini-sleep Questionnaire, and SF12 as independent variables, and WA as the dependent variable. Then, the variables that presented $p \leq 0.25$ in the simple models were included in the adjustment of the multiple logistic regression model. Again, variables that reached a (two-tailed) level of statistical significance below 5% were considered to be associated with the outcome.

Ethical approval

The research followed Resolution 466/12, which regulates ethical aspects of research involving human beings, and was carried out after approval by the Research Ethics Committee of the UNESP - Botucatu Medical School (protocol 2,878,639) and the Committee of Ethics in Studies and Research of the Municipal Health Department of Bauru. All participants were informed about the study and its objectives and provided written informed consent prior to any study procedure or activity.

4. Results

In total, 70 informal caregivers were included in the study. Most of them were female (80%) and 35.7% had an inadequate WA. Table 1 shows the characteristics of the participants stratified into two groups, adequate and inadequate WA (WAI $\geq$ 37 and $<$ 37, respectively). The group with inadequate WA were older, had higher burden, and worse quality of sleep, while the group with adequate WA had better self-perceived physical fitness and QoL.

Table 2 shows the results of each item on the WAI. It deserves to be highlighted that, only 38.6% of the caregivers estimated their work ability with respect to the physical demands of work to be between very good and rather good and half of the participants felt that it was unlikely that they would be able to do their current job in a period of two years. The mean score of the WAI was 37.2 ($\pm$6.6) points.

Table 3 shows the results of the simple logistic regression models, grouped at the two hierarchical levels, and the variables that were associated with the outcome in the multiple hierarchical logistic regression model.

Table 4 shows the OR estimates and respective 95% CI for the scales that achieved p-values $<$ 0.05 in the multiple logistic regression model. It shows that work overload and poor sleep quality are factors that reduce WA, while a higher QoL increases WA.

5. Discussion

The results of our study show that 35.7% of informal caregivers had inadequate WA. Similar results can be found in studies with formal caregivers (Simões, 2012) and nursing professionals (Lindegard et al., 2014; Martinez et al., 2017) who perform similar activities to those performed by informal caregivers. Chua et al. (2016) evaluated WA among 16 informal caregivers, using the Work Productivity and Activity Impairment Questionnaire (WPAI), and showed a more severe situation, seeing that 57% of these caregivers had inadequate WA. However, one should not infer that the informal caregivers in this study were better able to cope with caring demands than those evaluated by Chua et al. (2016), since the WAI measures a worker's perceptions of their current and future work ability while the WPAI measures absenteeism, presenteeism, and daily activity impairments. In this regard, Gardner et al. (2016) have found only moderate correlations between the WAI and the WPAI, corroborating the existence of conceptual divergences among them. Therefore, it is difficult to compare the results from both studies.

The results also revealed a high frequency (50%) of informal caregivers who did not believe that they would be able to do their current job in a period of two years. This is extremely concerning from a public

Table 1
Characteristics of study participants stratified into groups: Adequate work ability (WA) and inadequate WA.

	Adequate WA (N = 45)		Inadequate WA (N = 25)		
	n (%)	Mean (sd*)	n (%)	Mean (sd)	p-value**
Age	–	49.7 (12.0)	–	58.9 (9.4)	0.001
Sex (Female)	33 (73.3)	–	23 (92.0)	–	0.061
Body Mass Index	–	28.6 (6.5)	–	29.7 (6.5)	0.492
Self-perceived physical fitness		3.8 (1.0)		2.3 (1.2)	<0.001
Smoking (yes)	5 (11.1)	–	5 (20.0)	–	0.309
Education	–	9.4 (3.4)	–	8.0 (4.1)	0.146
Income	–	2.2 (1.1)	–	2.3 (1.6)	0.775
Residing with partner (yes)	30 (66.7)	–	15 (60.0)	–	0.577
Children (yes)	34 (75.6)	–	23 (92.0)	–	0.090
Children residing with the caregiver (yes)	22 (48.9)	–	10 (40.0)	–	0.474
Caregiver's relationship to the patient					
Relative	34 (75.6)	–	15 (70.0)	–	0.069
Not related	5 (11.1)	–	1 (8.6)	–	
Spouse	6 (13.3)	–	9 (21.4)	–	
Length of time as caregiver	–	29.7 (36.6)	–	27.5 (26.7)	0.790
Stopped working (yes)	13 (33.3)	–	6 (33.3)	–	0.999
Help to provide care (yes)	37 (82.2)	–	19 (76.0)	–	0.533
Frequency of care	–	4.7 (2.8)	–	4.0 (3.0)	0.318
Total time dedicated to patient care		14.6 (2.6)		15.6 (1.1)	0.077
Sleep interruption to provide care (yes)	21 (46.7)	–	20 (80.0)	–	0.007
Not providing full-time care (yes)	12 (26.7)	–	4 (16.0)	–	0.309
Bathing (yes)	39 (86.7)	–	23 (92.0)	–	0.502
Toileting (yes)	39 (86.7)	–	23 (92.0)	–	0.502
(Un)Dressing (yes)	42 (93.3)	–	23 (92.0)	–	0.836
Feeding (yes)	41 (91.1)	–	24 (96.0)	–	0.447
Transferring (yes)	42 (93.3)	–	21 (84.0)	–	0.212
Walking assistance (yes)	10 (22.2)	–	6 (24.0)	–	0.865
Cooking (yes)	39 (86.7)	–	24 (96.0)	–	0.212
Laundry (yes)	35 (77.8)	–	22 (88.0)	–	0.292
Cleaning (yes)	40 (88.9)	–	22 (88.0)	–	0.911
Adapted home (yes)	29 (64.4)	–	12 (48.0)	–	0.181
Patient's estimated weight	–	63.8 (15.9)	–	59.3 (13.3)	0.236
Functional independence	–	42.3 (27.6)	–	39.1 (26.7)	0.639
Caregiver burden	–	27.2 (12.5)	–	43.0 (16.9)	<0.001
Sleep disturbances	–	26.2 (10.1)	–	39.0 (13.8)	<0.001
Quality of life	–	93.5 (8.7)	–	75.0 (12.1)	<0.001

*Standard deviation.
**Student's *t*-test for continuous variables and chi-square test for categorical variables.
†Abusive alcohol consumption was removed from the analysis because it was not mentioned by any caregiver.

health perspective since the World Health Organization (WHO) has already warned about the imbalance between the rapidly increasing number of older people requiring long-term home care and the reducing number of people who might be able to provide it (World Health Organization, 2017).

According to the WHO, an important aspect of this problem, for multiple reasons, is the fact that many of the informal caregivers are, themselves, older people (World Health Organization, 2017). Our results endorse this view since the inadequate WA group had a higher mean age. The multiple hierarchical logistic regression confirmed a statistically significant inverse association between age and WA - that is, the older the caregiver, the lower the WA. Similar results have been demonstrated in several studies (Tuomi et al., 1997; Monteiro et al., 2011; Simões, 2012; Roja et al., 2014). According to Tuomi et al. (1997), individuals over 45 have a WA decrease of 1.5% per year.

Over time, the human body presents changes and signs of aging through memory loss, decreased information processing speed and reduction of motor abilities, sensory abilities, vision, hearing, and motivation. All of these changes make it difficult to perform work activities and can compromise WA. Furthermore, WA tends to decrease with aging due to comorbidities that can further compromise physical and mental functional ability (Almeida et al., 2018).

Self-perceived physical fitness was positively associated with WA, a result that is corroborated by other studies (Tuomi et al., 1997; Norheim et al., 2019). Thus, informal caregivers' physical fitness also needs to be evaluated and acted upon by healthcare professionals.

Being physically active is not only directly related to physical fitness but is also a predictor of an adequate WA (due to the reduced risk of cardiovascular diseases, maintenance of aerobic capacity, endurance and muscle strength, improvement of physical performance, perception of health status and self-esteem) (Tuomi et al., 1997). Therefore, healthcare professionals should propose and develop strategies to engage informal caregivers in home exercise programs, which are effective in improving physical fitness (Souza-Filho et al., 2019), or physically active leisure activities, to prevent reductions in informal caregivers' WA and improve their health.

The inadequate WA group also showed a greater level of burden, corroborating the results found by Chua et al. (2016). Workloads that are disproportionate to individual resources compromise WA (Ilmarinen et al., 2008). In this sense, the burden of caregiving activities is capable of compromising not only social and economic aspects but also leading to mental health impairments, which can also impact on WA (Diniz et al., 2018).

Ilmarinen and Tuomi (2004) demonstrated that WA is not a one-dimensional construct and that it can be affected by different aspects of the worker's life related to their work environment, family, or society. For these authors, aspects related to the work environment such as conditions, content, and demands are the ones that have the most effect on WA.

In addition to the emotional, mental and social burden inherently associated with care, informal caregivers also face an accumulation of caregiving activities, which may be associated with a lack of judgment

Table 2
Descriptive results of the WAI.

	Mean (SD)	n (%)
Current work ability compared with best work ability throughout life (in a 0 to 10 scale, where 0 means completely unable to work)	7.89 (2.09)	
Work ability in relation to the physical demands of work		
Very good		4 (5.7)
Rather good		23 (32.9)
Moderate		31 (44.3)
Rather poor		8 (11.4)
Very poor		4 (5.7)
Work ability in relation to the mental demands of work		
Very good		17 (24.4)
Rather good		28 (40.0)
Moderate		19 (27.1)
Rather poor		5 (7.1)
Very poor		1 (1.4)
Number of current diseases diagnosed by a physician		
None		17 (24.4)
1		15 (21.4)
2		14 (20.0)
3		12 (17.1)
4		7 (10.0)
5+		5 (7.1)
Estimated work impairment due to diseases		
No hindrance/No diseases		23 (32.9)
Able to do the job, but it causes some symptoms		18 (25.7)
Must sometimes slow down work pace or change work methods		16 (22.9)
Must often slow down work pace or change work methods		11 (15.6)
Able to do only part-time work		2 (2.9)
Entirely unable to work		0 (0.0)
Inability to provide care during the past 12 months		
None at all		57 (81.4)
9 days at the most		10 (14.3)
10–24 days		3 (4.3)
25–99 days		0 (0.0)
100–365 days		0 (0.0)
Own prognosis of work ability two years from now		
Unlikely		35 (50.0)
Not certain		28 (40.0)
Relatively certain		7 (10.0)
Able to enjoy regular daily activities		
Often		30 (42.9)
Rather often		9 (12.8)
Sometimes		15 (21.4)
Rather seldom		16 (22.9)
Never		0 (0.0)
Active and alert recently		
Often		36 (51.4)
Rather often		15 (21.4)
Sometimes		13 (18.6)
Seldom		6 (8.6)
Never		0(0.0)
Full of hope for the future recently?		
Continuously		39 (55.9)
Rather often		11 (15.6)
Sometimes		12 (17.1)
Seldom		8 (11.4)
Never		0 (0.0)

Table 3
Odds ratio (OR), 95% confidence interval (CI) and p-values obtained in the simple hierarchical logistic regression model and in the multiple hierarchical logistic regression model.

		OR	95% CI OR	p-value
Simple hierarchical logistic regression model				
Caregiver	Age	1.077	1.017–1.139	0.011
	Self-perceived physical fitness	0.175	0.068–0.445	<0.001
	Education	1.114	0.909–1.365	0.299
	Children			
	No	1		–
	Yes	1.789	0.199–16.052	0.603
	Caregiver's relation to the patient			
	Spouse	1		–
	Not related	1.984	0.233–16.892	0.531
	Relative	0.175	0.009–3.484	0.254
Care	Total time dedicated to patient care	1.188	0.932–1.515	0.164
	Transferring			
	No	1		–
	Yes	0.111	0.013–0.958	0.046
	Cooking			
	No	1		–
	Yes	1.345	0.153–11.842	0.789
	Sleep interruption to provide care			
	No	1		–
	Yes	6.437	1.666–24.875	0.007
	Adapted home			
	No	1		–
	Yes	0.315	0.094–1.056	0.061
	Patient's estimated weight	0.967	0.933–1.003	0.072
Multiple hierarchical logistic regression model				
Age		1.066	1.021–1.113	0.004
Self-perceived physical fitness		0.324	0.175–0.602	<0.001

Table 4
Odds Ratio (OR), 95% confidence interval (CI) and p-value of the multiple logistic regression model of the scales evaluated in the study.

	OR	95% CI OR	p-value
Caregiver burden	1.054	1.010–1.100	0.016
Sleep disturbances	1.070	1.017–1.127	0.011
Quality of life	0.948	0.925–0.971	<0.001

regarding the level of assistance needed by the care recipient to perform certain tasks. Often, care recipients are able to perform a certain activity, but the lack of knowledge, fear, and the feeling of neglect means that the caregiver provides help even if it is not needed or wanted (Pereira et al.,

2013).

Concerning sleep quality, both groups showed poor sleep quality. However, it was significantly worse in the inadequate WA group, corroborating Costa's (2009) results. Sleep disorders are recognized as a relevant public health problem, due to the numerous consequences they can cause to physical and mental well-being, such as tiredness, irritability, fatigue, and attention, concentration, and memory impairment (Buysse, 2014). Changes in sleep quality among informal caregivers may be associated with frequent changes in their nighttime sleep routines in order to provide care. Resuming sleep can be difficult after being awake, especially when these nocturnal interactions are prolonged or emotionally intense (McCurry et al., 2007). According to Buysse (2014), sleep health is a multidimensional pattern that promotes the physical and mental well-being of individuals, and changes in its quality can increase the risk of adverse effects such as those mentioned above, which could explain the decrease in WA among informal caregivers. In addition to the potential impact on the caregiver's life, the lack of quality sleep affects very important functions in providing adequate care, regardless of training.

Regarding the QoL of caregivers, the results show that the adequate WA group presented a better QoL, a result similar to those found in Paula et al (2015), which evaluated 47 community health agents. Studies that evaluated factors that would improve QoL among caregivers (Argimon et al., 2005; Vellone et al., 2008) showed that good financial conditions, good physical health, greater independence of the person being cared for, and the presence of someone to assist in caregiving activities improve QoL. The results presented here corroborate these findings, since those in the group with adequate WA and better QoL received more help to provide care and received it more frequently, in addition to having better self-perceived physical fitness when compared to the inadequate WA group. Another factor that may have contributed to a higher QoL among caregivers was the functional dependence of care recipients, which was lower in the group with adequate WA, although this difference was not statistically significant in the present study.

QoL refers to the individual's perception of their own life and involves physical, mental, social, material, cultural, and behavioral factors. As demonstrated in the multidimensional WA model (Ilmarinen & Tuomi, 2004), several factors can affect WA, personal resources, including physical, mental, and social aspects, and health are, for these authors, the most important factors for maintaining WA throughout life, which could explain the reason why QoL has a positive association with WA.

When interpreting the results of this study, some limitations should be considered. The cross-sectional design does not allow for inferences of causality in the observed associations (except for age), given the bidirectional relationship that the variables can present with WA. Although reverse causality is a possible general limitation of cross-sectional studies, these studies nevertheless generate subsidies for the development of health interventions. Thus, the results of the present study may provide information to support initiatives aimed at informal caregivers, with the goal of maintaining and, perhaps, improving WA among them.

The self-reported data collection method can lead to socially acceptable responses. Due to the intimate and subjective nature of some of the questions of the scale used to assess the caregiver's burden, the authors believe that the values found may have been lower than the real ones, which could, in turn, lead to an underestimation of the strength of association of the work burden variable with WA.

The assessment of self-perceived physical fitness has the advantage of incorporating all possible aspects that allow the individual to record their perception of their physical state. However, like any self-assessment, this way of measuring physical fitness can generate differences regarding reliability and validity compared to direct measures, which also have their limits regarding validity and reliability (Stock et al., 2005).

The fact that data collection took place in the autumn and summer seasons, which in Bauru, at the time, had average maximum temperatures of 29 °C and 32 °C, respectively (Emidio, 2019), may have influenced WA results, since the heat may cause drowsiness, decreased blood pressure and concentration, exhaustion, and fatigue, among other physical and psychological symptoms (Roncoleta et al., 2019).

Finally, the study's results are limited to a small group of informal caregivers from a city in the midwestern region of the state of São Paulo, and it is not appropriate to generalize these results to different contexts. Although it had few participants, the study comprised all informal caregivers who were under follow-up by the SAD and that met inclusion and exclusion criteria. There is a need for further studies, with a higher number of participants, with data collection during all seasons and an evaluation of other variables that may be associated with WA.

Despite the limitations described above, it is important to highlight that those aspects related to informal caregivers' WA, which have already been recognized as a commonly neglected and invisible worker population (Ar and Karanci, 2019; Dintrans, 2019; Tranberg et al., 2019), are poorly studied not only in Brazil but also worldwide. In this context, the present study made it possible to evaluate the WA of informal caregivers and verify the factors associated with it, thus providing the elements to bring into light the need for discussion and implementation of public health policies aimed at preserving their WA.

Thus, informal caregiver burden also deserves special attention by healthcare professionals. Alternatives to ease the burden and adapt caregiving activities to the caregivers' WA include providing access to the resources, training, information and the advice they need to perform their role, evaluating the care recipient needs and developing individual therapeutic projects and identifying other caregivers that may also be able to provide care. Since aging is inevitable, encouraging changes in informal caregivers' lifestyles, such as healthy eating, regular exercise and smoking cessation, must be addressed and encouraged by services like SAD and the healthcare professionals that accompany the caregivers or the care recipients, as a way to potentially decrease the negative effects of aging and, consequently, changes in WA, after all, in most cases, caregivers are in a position where they have no alternative but to be the ones to provide care.

6. Conclusion

WA was inadequate for 35.7% of informal caregivers. Although informal caregivers are important not only for their care recipients but also for society, the burden imposed on them demands greater attention from health professionals and public health policy makers and advisers. This evaluation of informal caregivers' WA allowed the identification of associated variables and thus brought to light important elements that must be taken into account in the development of public health policies and interventions for the prevention, promotion, and restoration of informal caregivers' WA.

Funding

No funding has been perceived.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Acknowledgements

To the Universidad de Huelva / CBUA for the funding for open access charge.

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