

# Sociodemographic profile and burden of informal caregivers of patients assisted in occupational therapy outpatient clinic

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**Abstract:** Introduction: Situations involving serious, degenerative diseases and/or functional disabilities (motor, sensory-perceptual or cognitive) affect the patient's daily life and all those involved, including the Informal Caregiver – IC that accompanies them, showing a burden that can be directly related to the care task. Objective: This study aimed to identify the sociodemographic profile and burden of ICs accompanying patients in the Occupational Therapy Outpatient Clinic. Method: This is an exploratory, descriptive, cross-sectional of quantitative and qualitative nature. We used two data collection instruments, the standardized scale, Zarit Burden Interview – ZBI assessing the burden of caregivers and a sociodemographic questionnaire that contained open and closed questions, which variables: gender, age, occupation, marital status, among others, were analyzed. Results: The results showed that caregivers were mostly women, mothers, married, Catholic, between 30 to 50 years. Furthermore, it was found that most (46.6%) rated as moderate burden presented, followed by 43.4% rated as moderate to a severe burden. Conclusion: Finally, the study allowed verifying the necessity and the importance of building more effective strategies that can be adopted to attend the Informal Caregivers fully. These results may contribute subsidizing the implementation of actions and training programs/support improving the quality of care for everyone involved.

**Keywords:** *Occupational Therapy, Caregivers, Family Relations.*

## Perfil sociodemográfico e sobrecarga de cuidadores informais de pacientes assistidos em ambulatório de terapia ocupacional

**Resumo:** Introdução: Situações que envolvem doenças graves, degenerativas e/ou incapacidades funcionais (motora, sensoriperceptiva ou cognitiva) trazem alterações na vida cotidiana, não somente do sujeito adoecido, mas também de todos os envolvidos, incluindo o Cuidador Informal – CI que o acompanha, evidenciando sobrecarga que pode estar diretamente relacionada à tarefa de cuidar. Objetivo: Assim, este estudo teve por objetivo identificar o perfil sociodemográfico e a sobrecarga dos CI que acompanham pacientes assistidos em Ambulatório de Terapia Ocupacional. Método: Trata-se de um estudo exploratório, descritivo, de corte transversal e de natureza quanti-qualitativa. Para seu desenvolvimento foram utilizados dois instrumentos de coleta de dados: a Escala padronizada Zarit Burden Interview – ZBI, que avalia sobrecarga em cuidadores, e um Questionário sociodemográfico que continha perguntas abertas e fechadas, cujas variáveis de gênero, idade, ocupação, estado civil e escolaridade foram analisadas. Resultados: Os resultados obtidos evidenciaram que os cuidadores eram, em sua maioria, mulheres, mães, casadas, católicas, cujas idades variavam de 30 a 50 anos. Além disso, constatou-se que a maioria (46,6%) apresentou sobrecarga avaliada como moderada, e 43,4% dos participantes apresentaram sobrecarga classificada como moderada a severa. Conclusão: Por fim, o estudo possibilitou constatar a necessidade e a importância da construção de estratégias mais efetivas que possam ser adotadas no sentido de assistirem integralmente os Cuidadores Informais. Entende-se que os resultados obtidos podem contribuir subsidiando a implantação de ações e programas de treinamento/suporte, melhorando a qualidade da atenção a todos os envolvidos.

**Palavras-chave:** *Terapia Ocupacional, Cuidadores, Relações Familiares.*

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## 1 Introduction

The term Informal Caregiver IC usually defines a family member or not who took over the task of caring, exercising all the necessary care to a person with any pathology or deficiency, including hygienic care, food, mobility, financial, medical, among others, without payment and without having specific training and/or technical training to perform the assistance activities characterized as leading figure in monitoring the patient with temporary or permanent disabilities.

Today, informal caregivers have been considered resources in the service of the ill person, but not necessarily they were the focus of attention of the health team. In this sense, it is necessary to emphasize the importance of their role, considering them also as a person who may be in need of help and support to carry out their caring role and, therefore, subject worthy of attention and care of professionals health (ARAÚJO et al., 2009).

Floriani and Schramm (2006) and Beck and Lopes (2007) pointed that the IC should receive support not only to learn how to care for the patient, but above all to meet, understand and share the disease situation and/or disability, so they can deal more appropriately with their problems, conflicts, fear and increasing responsibilities, mainly by observing that IC of patients having chronic alarming problems.

Studies on the sociodemographic profile of informal caregivers show, most of the time, women, married, living with the patient in the household. Also, they are not employed and have a relationship with the patient they assist. They perform the function of caring for people with different health problems, such as chronic obstructive pulmonary disease, terminal cancer, Alzheimer's, cerebral palsy, among others. Most of the time, these health problems entail disabilities, making partially or totally dependent patients (ARAÚJO et al., 2009; BECK; LOPES, 2007; DOMINGUES; SANTOS; QUINTANS, 2009; YAMASHITA et al., 2010).

The daily care provided by informal caregivers to patients have numerous and extensive activities. Therefore, Floriani (2004) describes that caregivers are showing symptoms such as stress, depression, sleep disorders, among others, demonstrating overload.

Factors such as the severity of the disease, the level of disability, impairment in the ability to communicate, the number of drugs used, the presence of psychiatric, visual, auditory and/or cognitive disorders presented by patients are associated with the level of burden and the IC quality of life. Thus,

according to some authors, the more dependent and unfavorable the conditions of patients, the greater the impact and duties relating to the care act, performed by the IC (WASSERMAN, 1992; COMARU; MONTEIRO, 2008).

Overload of IC can cause physical, psychological, emotional, social and financial problems, which end up affecting both the well-being of the caregiver and the patient. Thus, it is clear that the assignments of the IC, relevant to the act of caring for their sick family member and/or dependent interfere with aspects of their own personal, family, work and social life, predisposing them to conflicts (ARAÚJO; PAUL; MARTINS, 2009; ARAÚJO et al., 2013).

Although the concept of overload is comprehensive and complex, it is often associated with negative senses, because the care actions and their impact on the lives of caregivers are described as a "burden", a term which etymologically is associated with the idea of "weight" or "what weighs on a person", "task" (RICARTE, 2009). The overload refers to the wear of the IC due to fatigue, resulting in significant stress factors and short time or prolonged exposure to minor stressors, but over time originating consequences (SEQUEIRA, 2010).

In general, it can be said that the overload includes the biopsychosocial sphere and results of the search for a balance between different variables, such as availability of time to perform the care, financial, psychological, physical and social conditions, assignments and distribution of roles (OLIVEIRA et al., 2012).

Based on the described aspects, this study sought to identify the sociodemographic profile and the burden of informal caregivers accompanying patients at the Occupational Therapy Clinic. It is understood that the results can subsidize the planning of actions that meet the health needs of informal caregivers and minimize the impact that caring function can result in their daily lives, improving the quality of care for everyone involved.

## 2 Method

This is a descriptive, exploratory, cross-sectional of quantitative and qualitative nature. The study included 30 informal caregivers accompanying patients (children and adults) treated at the Occupational Therapy Clinic. The inclusion criteria for the selection of research subjects have the fact that they are informal caregivers, aged over 18 years old, of both genders, who were performing the task of caring for a minimum period of six months, not

receiving compensation for the performance of the care task and agreed to participate in the study by signing the Consent and informed Form (TCLE). There were 06 caregivers excluded from the study, of which 04 have not agreed to participate, and 02 whose IC function could not be identified, because although they assume as informal caregivers, they occasionally accompanied their family member in service and, when asked about the care activities developed with their family member, they were not characterized as routine activities, that is not performed frequently.

To perform the data collection in the field, two instruments were used for research, the standardized scale Zarit Burden Interview – ZBI, which evaluates burden in caregivers, and a sociodemographic questionnaire containing open and closed questions, which focus turned to variables such as gender, age, marital status, education, religion, relationship with the service user, time of performance as a caregiver, what were the activities and daily tasks they performed for them and the necessary care to the family sick member.

The ZBI scale consists of 22 items that assess the caregiver-patient relationship, health status, psychological well-being, finances, and social life, encompassing objective and subjective aspects. The information includes four factors: the impact of the provision of care, interpersonal relationship, expectation towards the care and perception of self-efficacy. The range of responses comprises a score ranging from 0 to 4, according to the presence or intensity of an affirmative response (0 = never; 1 = rarely; 2 = sometimes; 3 = frequently; 4 = always), except for the last item scale (in which the respondent is asked if he is feeling overworked in the caring role). For this last item scale, the answers are scored considering (0 = not at all; 1 = a little, 2 = moderately; 3 = very; 4 = extremely). The total score ranges 0-88; the higher the score, the more overload they have (FERREIRA et al., 2010; SCAVUFCA, 2002). Thus, the burden of caregivers may be classified according to Table 1.

**Table 1.** Classification of burden level - ZBI Score Scale.

Score	Burden level
< 21	Little or no burden
21 and 40	Mild to moderate burden
41 a 60	Moderate to severe burden
61 an 88	Sever burden

After the study was approved by the Research Ethics Committee (Protocol 0489/11), data collection proceeded was carried out in the field between August 2013 and March 2014. Initially, informal caregivers were contacted at the Occupational Therapy Clinic service linked to the School of Occupational Therapy at the University of the State of São Paulo that provides care to insured patients of the Unified Health System – SUS. Its goal is to recover, enable and restore people who have different problems that end up compromising, functionality and/or performance of daily activities on some level. In this initial contact, the potential research subject (informal caregiver) was informed about the research objectives and invited to participate. With the voluntary agreement of the IC, two subsequent meetings were scheduled to conduct the data collection.

It is emphasized that the data collected supported the development of a database constructed from a spreadsheet in Excel and later received simple descriptive statistical analysis. As for the qualitative data resulting from open questions contained in the questionnaire, they were analyzed based on theoretical assumptions concerning the Discourse Analysis – DA.

The analysis is properly carried out by the exhaustive reading of the material, to explore it and build the processing and interpretation of data. At this point, the researcher identifies the context of the production of discourse to encode it, identify its units records and the categories that emerge from it (MACEDO et al., 2008, p. 652).

The data processing required a pre-analysis stage of the material, followed by the data selection, considering their articulation with the established objectives and the theoretical reference underlying this study.

### 3 Results and Discussion

The results obtained showed diversity in both the sociodemographic profile and the activities performed and the level of burden on informal caregivers investigated.

#### 3.1 Socio-demographic profile and the routine activities of informal caregivers

From the sample studied, it was observed that caregivers were predominantly women (77%), with ages ranging from 30 to 50 years old

(mean age 44.5 years old), married (63%) and mothers of children assisted in that service (67%), data supporting the studies of Silva et al. (2006) and Araújo, Paul and Martins (2009). Moreover, most caregivers lived in the same house that the family member (89%) and did not share the care task with someone else (72.5%).

Regarding the education of caregivers, it was observed that 26% had not completed the elementary school, 33% had completed the high school, and only 3.3% had higher education, data that confirm those described by Nakatani et al. (2003). Although in this study the correlation between the level of education and the level of caregiver burden has not been reviewed, it is emphasized that this correlation has been described in the divergent literature. Araújo et al. (2013) reported that caregivers with higher education are affected by the same problems that caregivers with lower education levels. For Tabeleão, Tomasi and Quevedo (2014), the low educational level of the IC may be difficult for the caregiver to assimilate information and knowledge about the disease, a factor that directly affects their overload.

As for the routine activities and tasks that they develop, it was found that 70% was dedicated to the activities of their home, like cleaning the house, prepare breakfast, wash clothes, go to the supermarket, in addition to care activities, such as giving medication, monitor family health services, take care of food and hygiene, transfer to the toilet and bed. It was observed that most of the caregivers (66%) had been off their jobs to devote fully to the care of their family members because their routines had tasks carried out under different circumstances than usual. The tasks required more time to be done than normal and required different management systems, such as feeding by tube; locomotion assisted pushing a wheelchair, care about the position change, maintenance devices and orthotics, performing bath in bed, etc. It is noteworthy that most of the family member accompanied by caregivers investigated had Cerebral Palsy – CP pictures (33.4%), Spinal Cord Injury – SCI (16.6%) and Traumatic brain injury – TBI (13.4%), most dependent or partially dependent on the performance of Activities of Daily Living – ADL.

The described results show that, in fact, historically women have assumed the role of provider of general care of the family member while the man has the function of material support. These data reaffirm aspects related to gender and kinship because they are mostly women and mothers, they cannot have other functions outside the home and end up leaving the job. Thus, they have full-time care, so that only

the father or the partner is the main support provider (OLIVEIRA; PEREIRA; FREITAS, 2010).

Gonçalves et al. (2006) and Milbrath et al. (2008) states that the daily life and self-esteem of these mothers are the most affected aspects arising from this financial dependence. Culturally mothers have assignments on which rests their responsibility of caring, the belief that there is another person able to meet the child's needs (overprotection) and blood and emotional bonds (BECK; LOPES, 2007; CAMARGOS et al., 2009; MARTINS; SOLER, 2008; OLIVEIRA; PEREIRA; FREITAS, 2010). Thus, emotional support, affection, and care are the responsibility of women. However, it is important to note that, currently, these roles have been changing (CAMARANO; PASINATO; LEMOS, 2007; PIMENTA et al., 2009).

It was also found that 77% of caregivers reported having left their lives, often neglecting self-care, leisure and/or social activities, a result similar with those obtained by Fonseca, Penna, and Soares (2008). Therefore, it is evident that the increase in responsibilities assumed by informal caregivers interfere in their lives because their daily actions are now turning to the care of the family member.

As for religion, it was found that 57% were Catholic and 40% Protestant, data corroborated with other studies. According to Santos and Cunha (2013) and Simonetti and Ferreira (2008), religious beliefs are facilitators for acceptance of resignation and conformism of the pathological picture of the family member, and intermediate facing the daily and comprehensive care. De Nardi et al. (2011) and Vilela et al. (2006) reported that caregivers who have no religious support have higher sickness rates, as experiencing excessively overloaded routines.

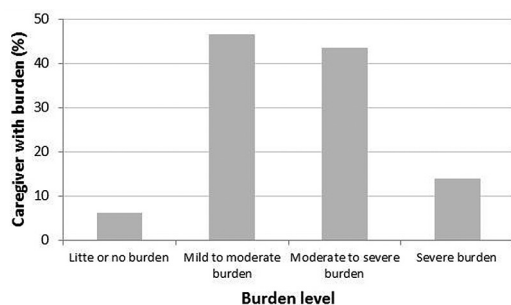
Regarding the time were carrying out the caring role, it was found that 53% had this feature for three or four years. The correlation between the performance time of care function and the overload has been addressed in some studies (SANTOS; CUNHA, 2013; VALENTE et al., 2013; ZAMBRANO-DOMINGUEZ; GUERRA-MARTIN, 2012), although in this study, this correlation has not been analyzed.

### 3.2 Informal caregivers burden

It was found that the caregivers in this study had varying levels of burden, as shown in Figure 1.

The results showed that most of the caregivers researched (46.6%) showed moderate overload, followed by 43.4% of moderate to severe overload.





**Figure 1.** Percentage distribution of burden level of caregivers researched.

The total average of the final scores of ZBI in this group of caregivers was 41.2 (0-88), indicating moderate to severe overload. These results are similar with those described in other studies that also aimed to evaluate the burden of caregivers of children and adults from the ZBI Scale (AMENDOLA, 2007; AMENDOLA; OLIVEIRA; ALVARENGA, 2008; CAMARGOS et al., 2009; MASLACH; SCHAUFELI; LEITER, 2001; WACHHOLZ; SANTOS; WOLF, 2013).

It was found that 73% of caregivers had the feeling they were the only people from whom the sick family member could depend on, and 66% said they felt stressed by caring for their family members and at the same time they carry out other responsibilities of the family. Also, 63% felt that their social life was affected due to the involvement in the care of the dependent family member, and 59% had the feeling of not having enough money to take care of them and the daily expenses, data confirmed by Amendola (2007).

It was also found that when the caregivers were asked about their perception of the level of burden, 53% said they feel overworked, 23% just a little, 12% moderately overworked, 6% very overworked and 6% extremely overworked. Although most caregivers (53%) refers not to feel overwhelmed by observing overload in the ZBI, it appears that 90% had levels classified between moderate and moderate to severe, showing the distance between the perceived overload and measured overload. The difficulty of the caregiver to realize and assume direct overload experience was shown in the studies by Santos et al. (2010) and Amaral et al. (2011), who attributed this gap to interference from things like fear, and feelings of shame by the IC to answer about their relationship with the care task.

As it can be seen, the analysis of the results of this study is relevant to the assessment of overload,

indicative of both objectives as a subjective burden. The overhead related to care is a risk factor to which family members are exposed daily when playing the role of caregivers. It is fundamental to planning and implementing health actions in the service in which they accompany their family members/patients, thus, they can be guided and receive the appropriate support needed to carry out the daily activities related to care, to minimize the burden they experienced (GREENWOOD et al., 2008).

## 4 Final considerations

The study developed showed that most informal researched caregivers presented overload assessed as moderate and moderate to severe, showing that they are exposed to risk and illness factors. Such results should be analyzed with caution since the limitations of the study should be considered, as the sample had reduced caregivers of a single health service. Nevertheless, the study shows some aspects that permeate the routine and the activities performed by caregivers and may be related to their increased burden.

Thus, it is important to develop more detailed studies on the subject, and the expansion of health actions that take the caregiver as the subject target of intervention. In this sense, the study points to the need for the service professionals team to implement and offer support actions, training and guidance to caregivers to assist them in carrying out care activities. Thus, this would minimize the burden experienced by them and contributing to a caring relationship, characterized by concern for the integrity and the uniqueness of the human being and the appreciation of the relationship and respect between each other.

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## Author's Contributions

Maria Luisa Gazabim Simões Ballarin: elaboration and guidance of the project, data analysis and writing of the article. Aline Cristina Benedito, Catherine Amorim Kröne Daniela Christovam, data collection and analysis and final writing of the article. All the authors approved the final version of the text.