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Title: OVERESTIMATION OF HOURS DEDICATED TO FAMILY CAREGIVING OF PERSONS WITH HEART FAILURE.

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Keywords.

caregivers, nursing, heart failure, chronic disease, questionnaire.

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Abstract

Aims. The aim of this study is to profile the family caregivers of people living with heart failure, to determine the perceived and real time devoted to daily care and to identify the factors associated with caregivers' overestimation of time dedicated to care.

Background. The time spent by family caregivers on daily care is related to overload, but there are differences between real and perceived time spent. The reason for this difference is unknown, as is its impact on the caregiver.

Design. Multicentre, cross-sectional study.

Methods. This study forms part of a longitudinal, multicentre, ambispective cohort investigation. The study population was composed of 478 patient–family caregiver dyads and the data were collected over two years from 2014-2016.

Results. The average time perceived to be spent on daily care was 8.79 hours versus a real value of 4.41 hours. These values were positively correlated. A significant correlation was also found between the overestimation of hours spent and the age of the caregiver, the duration of the caregiving relationship and the number of people providing support and with the patient's level of dependence and self-care.

Conclusion.

The overestimation of time dedicated to care seems to be related to patients' and caregivers' characteristics, such as functional status, caregiver burden, age and cohabitation. These patterns should be considered by nurses when carrying out assessment and care planning with these patients and their caregivers.

Keywords.

caregivers, nursing, heart failure, chronic disease, questionnaire.

Summary statement

Why is this research needed?

- The presence of a family caregiver is associated with a good prognosis, but caring can affect the mental health of caregivers.
- The time devoted to care by the family caregiver is related to overload, but differences are observed between perceived and real time spent on care.

- This study highlights the importance of measuring the perception of time dedicated to family caregiving as a means of identifying caregivers with a high distortion of perceived time dedicated to care.

What are the key findings?

- Family caregivers of patients with heart failure overestimate the number of hours dedicated to daily care.
- This overestimation is related to caregiver characteristics, such as age and cohabitation with the patient and with patient characteristics, such as functional status and level of self-care.
- Measuring perceived and real time spent on daily care has allowed us to identify caregivers who overestimate hours dedicated to care.

How should the findings be used to influence policy/ practice/ research/ education?

- The measurement of real and perceived time spent on daily care would be an efficient means of identifying an overestimation of this time.
- In the assessment made of the family caregiver, the nurse could include this measurement of the time devoted to daily care to quantify the overestimation.
- This measurement could be included in the initial assessment of the family caregiver of people living with heart failure, thus helping to identify risk populations among family caregivers.

Introduction

The availability of a family caregiver is known to be of crucial importance in managing patients with chronic diseases, particularly those with heart failure (Clark et al., 2016; Pressler et al. 2013; Ponikowski et al., 2016). The presence of a family caregiver is associated with a positive prognosis for people living with heart failure and with a reduced use of hospital services. Moreover, caregiving affects carers' self-perceived qualities of life (Luttik et al., 2009) Self-perceived caregivers' health is influenced by sociodemographic factors as well as by care-related factors, such as family support, different styles of coping and overload (Chang et al., 2016). These factors can ultimately influence caregivers' perceived mental health (Duggleby et al., 2016; Pérez-Cruz et al., 2017) and physical health (Xie et al., 2016), especially as the age and dependence of the patient increases.

Background

Overload/ Burden and dependence

The effects of burden on family caregivers and their mental health, are related to the patient's age and functional status (Pérez-Cruz et al., 2017). Santini (2016) conducted a study in four European countries with family caregivers of patients with incontinence and concluded that the dependence of these patients, in the most advanced stages of their illnesses, was associated with the caregivers' progressive social isolation and physical exhaustion — in addition to psychological deterioration. The caregivers also complained of inadequate support and general silence on the problem, which further aggravated their situation (Santini et al., 2016).

Type of caregiving and time dedicated to it

Family caregivers spend a significant proportion of the day — sometimes eight hours or more — providing direct and indirect care (Jowsey et al., 2013). Among caregivers of patients with dementia, up to 55.7 hours per week may be needed (for example, by patients with Alzheimer's), although the dedication required of caregivers varies according to the type of dementia (Costa et al., 2013). Studies have measured the time employed by family caregivers of people living with chronic illness, such as diabetes, heart disease and chronic obstructive pulmonary disease (Jowsey et al., 2012; Delgado et al., 2014), but few have assessed the types of care provided to these people. Two main methods have been used to measure the time dedicated to informal care: the use of journals, which is considered the gold standard, or the use of recollection. The latter approach has been shown to offer sufficient validity for this purpose, although it tends to overestimate the real time employed and is subject to some long-term instability (Van-den-Berg & Spauwen 2006).

There is an interesting relationship between the time free of caregiver responsibilities and perceived overload. In this respect, a pattern of inverse correlation has been observed (Del-Pino-Casado & Ordóñez-Urbano 2016), which highlights the impact of the time spent caregiving on the caregiver's ability to cope. Despite this evidence, the extent of the difference between the time spent on family care and the time perceived to be spent by the caregivers, together with the factors that determine this difference — especially regarding people with chronic heart disease has yet to be established. Further knowledge of this phenomenon would facilitate the estimation of the total costs of care and also help identify the impact made by family caregiving, both on the patient's daily activities and on the caregiver's perceived quality of life.

The study Aims

The aims of this study are to identify the characteristics of the family caregivers of chronic heart failure patients, to determine the perceived and real time dedicated to daily care and to identify the factors associated with this perception.

Design

A multicentre, cross-sectional study was carried out in four hospitals in Andalusia (Spain): a first-level hospital in an urban area, a second-level hospital in the coastal area and two third-level hospitals in a rural areas with a total reference population of one million. The hospital level is an ascending classification determined by the number of beds, the degree of specialisation and the population attended. This study forms part of an ongoing longitudinal, multicentre, ambispective cohort investigation to analyse perceptions of quality of life among patients with heart failure and their family caregivers and the use made of health services.

Participants

The study population were patients with heart failure and their caregivers. The inclusion criteria were patients admitted to hospital with a main diagnosis of heart failure, with or without comorbidities and for whom a principal family caregiver was identified. The family caregiver could be any member of the family dedicated to this task. The exclusion criteria were: patients with a poor prognosis which prevented follow up; refusal to participate by the patient or by the caregiver; language difficulties that might limit understanding of the questionnaires used in the study; patients for whom no primary family caregiver could be identified or whose care was provided by various persons irregularly (patients with various family caregivers were eligible for inclusion, provided there was one primary caregiver who provided most hours of care).

The necessary sample size for this study was calculated to estimate the weekly time dedicated to caregiving prior to the patient's hospital admission. Assuming an accuracy of 3% and an alpha value of 0.05 for a population of 7,115 patients admitted to hospital with heart failure in Andalusia (Spain) (Data: Ministry of Health, Social Services and Equality - Statistical Portal

- Registry of Hospital Admissions of the National Health System) and assuming a weekly caregiving dedication of 44.93 hours (SD: 30.54) (Delgado et al., 2014), it was established that a total sample of 378 subjects was needed.

This sample size was achieved with the population recruited to the ongoing longitudinal study (Timonet et al., 2015). The sample size was then overestimated by 25% to cover potential losses

and therefore a total sample of 472 patient–caretaker caregiver dyads was required. The patient–caregiver dyad was selected either on admission to one of the participating hospitals or when patients attended for a follow-up visit after a previous hospital admission for heart failure (within the last year).

Data collection

Data were collected over two years, from 2014 - 2016. Baseline information was obtained during the admission or at the follow-up visit. Sociodemographic variables were recorded and the patient–caregiver dyad characterised in terms of age, sex, cohabitation and level of education. Variables specific to the family caregiver included the occupational status of the primary caregiver, the time spent as a family caregiver, the number of people in the family environment involved in caregiving and the presence of a paid caregiver (Act 39/2006, of December 14, on the Promotion of Personal Autonomy and Care for Dependent People) (Salvador-Piedrafita et al., 2017). The number of hours dedicated to care, both direct and indirect, was estimated in terms of the time perceived and the time employed to this end. The number of hours perceived to have been worked corresponded to those directly reported by the main family caregiver per day, collected by interview. The actual hours were estimated by interview, using a questionnaire/handbook to calculate the real hours based on an analysis of the tasks and activities involved in direct and indirect care (Table 1). The overestimation of hours dedicated to the tasks of direct and indirect care was calculated as the difference between the actual hours and those perceived by each caregiver.

Instruments

For patients:

- The presence of comorbidities, according to the Charlson Comorbidity Index (O’Connell & Lim 2000). This system evaluates life expectancy at ten years, according to the patient’s age and comorbidities. It consists of 19 items in addition to the age of the patient (sensitivity 90.7%, specificity 69%).
- Functionality, according to the New York Heart Association Functional Classification. This method is used for the functional classification of patients with heart failure into four classes based on the limitations on physical activity caused by cardiac symptoms. In class I, there is no limitation to physical activity, whereas in class IV there is an inability to perform any physical activity (sensitivity 68%, specificity 77%).
- The level of dependence, according to the Barthel Index (Mahoney & Barthel, 1965), a ten-item questionnaire scored on a Likert scale with values ranging from 0 to 100

at five-point intervals, with lower scores corresponding to greater dependency and higher scores corresponding to greater independence (Cronbach's alpha: 0.94).

- The level of self-care, according to the European Heart Failure Self-care Behaviour Scale (Jaarsma, Riegel & Strömberg 2017). This scale consists of twelve items scored from 1 (completely agree/always) to 5 (completely disagree/never), with higher scores corresponding to lower levels of self-care (Cronbach's alpha: 0.85).

For caregivers:

- The presence of family caregiver overload, according to the Caregiver Strain Index (CSI) (Sullivan 2003), which consists of 13 true-false questionnaire items. Each affirmative answer is scored 1 and a total score equal to or greater than 7 reflects a high level of caregiver strain (Cronbach's alpha: 0.86).
- The presence of depressive symptoms, according to the Spanish version of the Patient Health Questionnaire (PHQ-9) (Diez-Quevedo et al., 2001). This instrument consists of nine items, scored from 0 (never) - 3 (almost every day), on how often the caregiver was affected by certain problems during the previous two weeks. A score greater than or equal to 15 would justify treatment for depression with antidepressants, psychotherapy, or a combination of treatments (Cronbach's alpha: 0.89).

Ethical considerations

The study was authorised by the Research and Ethics Committee of the Costa del Sol Health Area, under Decision No. ES-0980-OCT-2013. The norms of good clinical practice and ethical principles established for human research in the Declaration of Helsinki, revised in Brazil 2013, were followed at all times and all patients and caregivers were asked for informed consent before participating in the study.

Data analysis

IBM SPSS Statistics 20.0 software (SPSS / IBM, Chicago, IL, USA) was used for the statistical analyses. A descriptive analysis was also performed to obtain measures of central tendency and dispersion or percentages and the normality of the distribution was evaluated by the Kolmogorov-Smirnov test. A bivariate analysis was performed using Student t, chi square and Mann-Whitney U tests and the Pearson (r) and Spearman correlation coefficients were calculated depending on the normality of the distributions. In addition, ANOVA was applied, and the homogeneity of variances was estimated by the Levene test and by post-hoc analysis, using the Bonferroni and Games-Howell tests. Robust Brown-Forsythe statistics were obtained. Finally, a multivariate linear regression model was constructed to identify the factors associated

with divergences between real/perceived time spent on family caregiving. The level of statistical significance was set at $p < 0.05$. The cost of informal care was estimated using the proxy method (van den Berg, Brouwer, & Koopmanschap, 2004) at €14.20/hour on average, although according to official sources the rate in Andalusia was €13.00/hour (Imsero 2014 Annual Report on Aging).

Validity and reliability

The validity and reliability of all the research instruments used in this study have been established in previous studies except the questionnaire/handbook for calculating the actual hours worked, which was used during the interviews and was drafted by a group of experts and members of the research team. All the study variables were obtained by four nurses trained in collecting data through interviews and questionnaires.

Results

During the years 2014 - 2016, a total of 2,492 patients were discharged from the participating hospitals after having suffered heart failure (DRG 544-congestive heart failure and cardiac arrhythmia with major complications or comorbidity and 127-Heart failure and shock). From these, 478 patient-caregiver dyads were finally included in the study

Patients

The patients presented the following characteristics: mean age 74.9 (SD 11.4) years; 51.5% (N=246) of the patients were female; 64.6% (N=304) of the patients presented minimal levels of literacy or only primary education.

Regarding their functional level, 56.3% (N=269) of the patients were limited to moderate (level II) activity, while another 30.8% (N=147) were limited to mild (level III) activity. The mean level of dependency was mild (71.4; SD 30). The mean comorbidity score was 4.7 (SD 2.1) and that of self-care was 32.2 (SD 9.8, range 12-60). Additional information about the clinical features of the patients by gender is detailed in Table 2.

With respect to social support, only 15.9% (N=76) of the patients had a non-family caregiver, while 16.5% (N=79) had home help, attended a day-care centre or received assistance according to legislation to promote personal autonomy and care for persons in a situation of dependence.

Caregivers

The mean age of the caregivers was 56.4 years (SD: 14.1) and they were predominantly female (77.9%, of the sample [n] of 372). More than half of the caregivers had minimal levels of literacy or only primary education (56.3%, N=269), while (23.4%, N=112) had secondary or high school education or vocational training.

The largest group of family caregivers were the patients' children (52.1%, N=249), followed by their spouses (37.4%, N=179). A significant proportion of these family caregivers were

homemakers and had no paid employment (40.4%, N=193) or were retired (27.4%, N=131). On average, assistance with caring duties was provided by 1.50 family members (SD 1.6) and 58.4% (N=279) lived in the same home as the patient.

In general, family caregivers presented a low level of overload (mean CSI 4.5, range 0-13, SD 3.4) and a mild-moderate level of depression (mean PHQ-9 6.2, SD 5.8).

By genders, significant differences were observed. Thus, a greater number of male family caregivers had assistance or support from another family caregiver (chi-square: 3.425; $p=0.047$); moreover, in terms of occupational status, men were less likely to be homemakers or retired (chi square: 47.824; $p<0.001$). On the other hand, male caregivers presented greater overload ($p=0.046$) and higher levels of depression ($p<0.001$). Detailed results of these differences are shown in Table 3.

With respect to the time devoted to care — the daily hours perceived by the caregiver and those estimated empirically — the mean values obtained were 8.8 hours (SD 8.6) and 4.4 hours (SD 2.8), respectively, with a positive Spearman's rho correlation between the perceived and the actual hours ($\rho=0.64$, $p<0.001$). Application of the proxy method to estimate cost produced an average difference between real and perceived cost of €56.99 per caregiver, which for the total sample would amount to €27,241.

Evaluation of the differences between perceived and real hours dedicated to care with respect to patient characteristics and type of care (Fig. 1) revealed a moderate and statistically significant correlation between the family caregiver's age and the overestimation of caregiving time ($\rho=0.211$, $p<0.001$), but the same was not true with regard to the patient's age ($\rho=0.07$; $p=0.132$). Regarding the time spent as a family caregiver, a weak but significant correlation was also detected ($\rho=0.168$, $p<0.001$). The number of people in the family environment who contributed to the provision of care inversely correlated with the overestimation of the time spent on care, although with low values ($\rho= -0.152$, $p=0.001$). The functional dependency level of the patient presented a similar inverse correlation ($\rho= -0.190$, $p<0.001$), as did the patient's level of self-care ($\rho= -0.146$, $p=0.001$). There was a weak and significant positive correlation between the level of depression among family caregivers and the overestimation of the time spent on care ($\rho= 0.178$, $p<0.001$). Caregiver burden showed a moderate and significant positive correlation with overestimation of the time spent providing care ($\rho=0.246$, $p<0.0001$).

In this study, moreover, sociodemographic factors were analysed to determine whether the caregivers' occupational situation modified perceptions of the time devoted to care. Important differences in this respect were observed between homemakers through ANOVA (average overestimation 5.2 hours, SD 7.9), the retired (6.5 hours, SD 8.3), the unemployed (4.3 hours, SD 6.7) and those in employment (2 hours, SD 5.5) ($F(3,470): 10.28$; $p<0.001$). The largest mean differences were obtained between retired and employed persons (-4.57 , 95% CI -6.77 to -2.37 , $p<0.001$) and between homemakers and the employed (-3.24 , 95% CI -5.40 to -1.09 , $p=0.001$).

Finally, a multivariate linear regression model was constructed to consider which factors were associated with overestimations in the perception of time dedicated to care. These factors were selected according to the literature review performed (caregiver burden, functional status) and the results of bivariate analyses (age, cohabitation, self-care). This model showed, with a coefficient of determination of 0.233, that the more functionally impaired the patient, the greater the caregiver's age, the greater the probability of cohabitation with the patient and the greater the overestimation of hours dedicated to family caregiving. Similarly, the lower the patient's self-care score, according to the European Heart Failure Self-Care Behaviour Scale (i.e., the better the self-care), the lower overestimation of time dedicated to care (Table 4).

Discussion

The findings presented contribute to our understanding of the profile of caregivers of people living with heart failure and may lead to improved clinical practice in the identification of populations at risk. In our study, the typical caregiver of people with heart failure is a 56-year-old woman, usually the patient's daughter or wife, who is a housewife or retired, with primary or secondary education and is cohabiting with them. Housewives or unemployed women assume the role of caregiver because they usually cohabit with the people living with heart failure and have more time available, which, in turn, are triggering conditions for developing caring activities and support.

This typical caregiver looks after people living with heart failure who are about 75-years-old, male or female, with mild dependence but markedly affected by dyspnoea, who take ten medications a day, presents some comorbidity, has poor knowledge of his/her disease and has a below-average level of self-care (Jaarsma et al., 2017).

Scant financial support is received under legislation on dependency (Salvador-Piedrafita et al., 2017), although assistance is provided by other relatives, a finding that agrees with a previous study published in Spain on caregivers of the elderly (Vara, 2014). An average of four hours is spent each day on caregiving duties, although the perceived time is twice this. The caregiver is well-adapted to her role and effectively provides both direct and indirect care. There is no overload, but depressive symptoms are present, as observed in other studies of a Spanish population and dependent patients (Navarro-Sandoval et al., 2017).

The caregiver profile obtained is very similar to those previously reported elsewhere (Salvador-Piedrafita et al., 2017; Pérez-Cruz et al., 2017, Pressler et al., 2013) but not regarding the average age, which has been reported as being somewhat higher (Vara, 2014; Kricheldorff & Brijoux, 2016; Van-den-Heuvel et al., 2016; Santini et al., 2016). The reason for this might be that when a patient is hospitalised, the daughter invited to participate in a research study describes herself as the primary caregiver, even if it is the spouse who performs this role.

There was considerable variability in the responses to how long the family caregiver had been providing assistance, ranging from days to many years or even, as one patient reported, 'all of my life'. For the purposes of the study, this time was taken as having elapsed since the first day the

patient was routinely admitted following symptoms and/or diagnosis of heart failure. However, it is difficult to know exactly how long the family member has exercised the role of caregiver and the effect that this may have produced on him/her. The situation is further complicated by the fact that in a traditional Spanish family, the wife or daughter usually helps in activities of daily family life (food, hygiene) if any illness is present (Salvador-Piedrafita et al., 2017).

No differences were observed in the types of direct and indirect care provided, since all patients required similar forms of indirect care associated with tasks of accompaniment, monitoring, or counselling (Mitrani et al., 2006).

The functional profile of people living with heart failure with mild dependence, NYHA II/III, may account for the slight differences in the impact made by different types of care. Much of the care received involves accompaniment and monitoring, but as the disease and the patient's dependence advance, assistance with more basic tasks is needed. Therefore, it would be interesting to measure the caregiver's capacity to continue patient care over time by conducting long-term longitudinal studies to ascertain the caregiver's health during this process (Parveen et al. 2013; Salvador-Piedrafita et al., 2017).

People living with heart failure and their caregivers mainly receive support from the family environment (one or two persons) and only a minority of patients have a paid caregiver to assist with daily activities (Vara, 2014). This family support is expected to have a positive impact on the prognosis (Saunders, 2008; Luttik et al., 2009), as heart failure patients living alone or in a situation of social isolation are more vulnerable and tend to have poor self-care (Pressler et al., 2013; Dunbar et al., 2008).

The main challenge facing public administration in this regard is to maintain, promote and support informal resources and to provide services to ease the burdens imposed on caregivers (Lüdecke et al., 2012).

Most of these people living with heart failure do not receive financial assistance under the legislation on dependency. People living with heart failure with a lower social status are known to be at a higher risk of adverse outcome, above and beyond their clinical characteristics and in general low socioeconomic levels are associated with poorer health status. Follow-up studies of populations with acute myocardial infarction and a low socioeconomic status have shown these patients to present with a higher risk of short-term mortality (Wang et al., 2014) and that people from this demographic living with cardiovascular disease are less likely to receive treatment (Kitzmilller et al., 2013).

A low socioeconomic level may be a marker of decreased ability to access and pay for treatment, to communicate with the health system and/or to understand the recommended treatment (Benderly et al., 2013). These people may not receive dependency assistance, either because of ignorance or because they are not highly dependent, but it is very significant that the families who request and are granted financial assistance often turn to a paid caregiver. This highlights

the scale of the task facing family caregivers and the importance of their receiving help to alleviate the burden of care (Molloy et al., 2005).

Most caregivers report dedicating considerable time to daily care, in relation to the slight degree of dependence that may be present. Much of this time seems to be measured with respect to the indirect care provided, but longitudinal studies have shown there is a

relationship between the number of hours dedicated to care and the caregiver having a poorer perception of quality of life (Pressler et al., 2013).

The generalised overestimation of the number of daily hours dedicated to care seems to indicate the presence of subjective overload (Pérez-Cruz et al., 2017). Thus, we highlight the existence of family caregivers who have no objective burden, as defined in the Caregiver Strain Index, but who are exposed to a subjective burden, which is reflected in exaggerated perceptions of the amount of time dedicated to care. This finding corroborates previous authors who have referred to the presence of subjective overload experienced by the caregiver — even when the patient does not present significantly impaired health (Schulz & Sherwood, 2008).

The relationships observed between the overestimation of hours spent on care, on the one hand and people living with heart failure and type-of-care characteristics, on the other, show that older caregivers who are not employed or who are retired, or who do not receive support from other relatives or who present depressive symptoms tend to overestimate the hours dedicated to care responsibilities (Pérez-Cruz et al., 2007). This is also the case for those who have been providing long-term care and when the patient is more dependent or has a lower level of self-care. This overestimation might be explained by the real perceived burden, which interferes with carers' perception of time. Alternatively, carers may consider that they need support from public administration to relieve their burden and that without an overestimation of care duties, this support might be denied (Lüdecke et al., 2012).

Our results show there is an inverse relationship between the patient's level of self-care and the carer's overestimation of time dedicated to caregiving. This could be related to the fact that self-care is more difficult in the presence of poor functional status (Ponikowski et al., 2016), a situation that we found to be associated with a greater perception of time dedicated to care.

Limitations / Strengths

Many of the people living with heart failure included in the study were characterised by mild limitations to functionality, with dyspnoea and a relatively low degree of dependence. The inclusion of a more dependent population could have influenced the results, especially among the caregivers, as the degree of dependence affected the time and effort employed in fulfilling the role of caregiver.

Both people living with heart failure and caregivers presented a medium-low sociocultural profile and therefore the external validity of these results could be compromised if they were

extrapolated to populations with a different distribution of cultural levels. However, the population studied is heterogeneous and derived from different areas (rural, coastal and urban).

Another possible limitation to this study is that in primary care areas or health centres where specific resources are available for the integrated care of people living with heart failure, the results obtained for levels of self-care and level of knowledge may differ from those reported here and so comparative studies should be undertaken to clarify this question, taking into account the types of educational interventions, monitoring, follow-up and inter-level coordination provided.

Future Lines of Research

Longitudinal studies are needed of caregivers for people living with heart failure to better identify the population at risk over a longer time and to detect changes in coping ability or in mental-physical overload. It would also be interesting to obtain efficient indicators with which to measure these variables so that a nursing assessment may quickly identify a population at risk.

Conclusions

The overestimation of time dedicated to care seems to be related to people living with heart failure and caregivers' characteristics, such as functional status, caregiver burden, age and cohabitation. These patterns should be taken into account by nurses when carrying out assessments and care planning with these types of patients and their caregivers.

Moreover, objective measures to determine the real amount of time dedicated to caregiving should be developed to facilitate a comprehensive assessment of the caregiver's situation. If this were done, specific interventions could be designed for caregivers with a strongly distorted perception of the time dedicated to care to detect underlying clinical or social circumstances that could be producing this misconception. This issue could then be addressed by means of educational or behavioural interventions.

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Table 1: Estimated time of activities performed by the family caregiver.

	Duration		
	(Hours per activity)	Times/day	Total (hours)
Direct care			
Preparing, serving and help for breakfast, lunch, snacks and dinner	0.5h per meal	0-4	0-2
Dressing/undressing	0.25h each time	0-1	0-0.5
WC	0.25 h	0-2	0-0.5
Help for bath-shower-grooming	0.5 h	0-2	0-1
Mobility / wheel-chair assistance	1h	0-1	0-1
Help for transfers	0.25 h	0-1	0-0.25
Repositioning	0.25 h	0-1	0-0.25
Indirect care			
Shopping	0.5 h	0-2	0-1
Housework – repairs – cost control	0.5 h	0-2	0-1
Washing	0.5 h	1	0-0.5
Transport	0.5 h	1	0-0.5
Medication management	0.25 h	1	0-0.25

Table 2: Clinical and functional characteristic of patients, by gender

	Male	Female	
	(n=232) n (%)	(n=246) n (%)	p
Myocardial infarction	48 (20.7)	22 (8.9)	<0.001*
Coronary disease	96 (41.4)	71 (28.9)	0.004*
NYHA Functional Class			
Class I	6(2.6)	3(1.2)	0.036*
Class II	76(32.8)	71(29.0)	
Class III	134(57.8)	135(55.1)	
Class IV	16(6.9)	36(14.7)	
Peripheral vascular disease			
	24 (10.3)	21(8.5)	0.533*
Stroke	30 (12.9)	33(13.4)	0.546*
Arterial hypertension	164(70.7)	199(80.9)	0.013*
Alcoholism	27(11.6)	0(0)	<0.001*
Thromboembolic disease			
	10(4.3)	9(3.7)	0.816*
Arrhythmia	118(50.9)	132(53.7)	0.583*
Dementia	3(1.3)	6(2.4)	0.506*
COPD	67(28.9)	26(10.6)	<0.001*
Diabetes	114(49.1)	120(48.8)	0.514*
Kidney disease	54(23.2)	76(30.9)	0.08*
Oncologic disease	26(11.2)	14(5.6)	0.03*
	Mean (SD)	Mean (SD)	p
Age	72.86(11.94)	76.82(10.57)	<0.001**
Barthel Index	69.12(26.13)	74.09(31.64)	<0.001**
Charlson Index	4.97 (2.08)	4.97 (2.05)	0.009**

*Chi-square test

**Student's t

Table 3: Principal characteristics of caregivers, by gender.

	Male (n=106, 22.2%)	Female (n=372, 77.9%)	p
Partner or spouse	42 (39.6)	137 (36.8)	0.876*
Son or daughter	53 (50.1)	196 (52.7)	
Cohabiting with the patient	64 (60.4)	215 (58.6)	0.823*
Paid support from a formal caregiver	23 (21.7)	53 (14.2)	0.047*
Primary education	51 (48.1)	218 (59.1)	
Secondary education	31 (29.2)	81 (22.0)	0.239*
University education	16 (15.1)	45 (12.2)	
Homemaker or unemployed	24 (22.8)	169 (45.4)	
Paid employment	32 (30.2)	118 (32.2)	<0.001*
Retired	50 (47.2)	81 (22.2)	
	Mean (SD)	Mean (SD)	p
Age of principal family caregiver	57.92 (15.3)	55.94 (13.71)	0.287**
Time spent to date as caregiver (months)	51.18 (80.79)	39.9 (55.3)	0.512**
CSI	3.96 (3.43)	4.61 (3.39)	0.046**
PHQ-9	4.00 (4.33)	6.94 (5.95)	<0.001**
Perceived time spent caregiving	9.01 (9.15)	8.73 (8.39)	0.702**

*Chi square test

**Student's t / Mann-Whitney's U

Table 4. Multivariate linear regression model for factors associated with overestimation in the perception of hours dedicated to family caregiving.

	B	p	95%CI	
			Lower	Upper
(Constant)	-4.69	0.025	-8.80	-0.59
NYHA	1.14	0.02	0.18	2.10
CSI	0.46	0.001	0.27	0.65
EHFSC	-0.10	0.002	-0.16	-0.04
Age of family caregiver	0.08	0.001	0.04	0.13
Cohabitation with patient	4.30	0.001	3.00	5.61

NYHA: New York Heart Association Functional Classification CSI: Caregiver Strain Index