


Health-Related Quality of Life and Use of Hospital Services by Patients with Heart Failure and Their Family Caregivers: A Multicenter Case-Control Study

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Key words

Heart failure, quality of life, patient readmission, caregivers, burnout, psychological

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Accepted January 27, 2020

doi:10.1111/jnu.12545

Abstract

Background: Heart failure (HF) causes high rates of hospital admissions. It is known that disease progression impacts the health-related quality of life (HRQoL) of both patients and caregivers, yet to date, this finding is based on cross-sectional studies with limited samples.

Objectives: The study aim is to analyze the relationship between HF patients' use of hospital services (a proxy for disease progression) and the HRQoL of their family caregivers.

Methods: This work is a multicenter nested case-control study on a population of patients admitted to hospitals in southern Spain due to heart failure. The sample comprised 530 patient-caregiver dyads. Hospital admission data were retrospectively collected for the 5 years prior to inclusion in the study. Bivariate analyses and multivariate logistic regression were used to determine associations between patient deterioration and caregivers' quality of life.

Results: Patients' use of hospital services was associated with worsened quality of life for family caregivers, with an overall OR of 1.48 (95% CI: 1.23-1.79). A positive correlation was found between patients' perceptions of their physical health and the perceived mental health of caregivers ($r = 0.127$, $p = 0.004$) and between the perceived mental health of both ($r = 0.291$; $p < 0.0001$).

Conclusions: Greater use of hospital services by patients with HF is an independent predictor of deterioration of family caregivers' HRQoL. The physical and mental components of patients' and their family caregivers' HRQoL interact and influence each other. Additional factors, such as the nature and intensity of care provided, also determine the worsening of a family caregiver's HRQoL.

Clinical Relevance: These results can be used to identify family caregivers of people with heart failure at risk of suffering a deterioration in their health-related quality of life. Increased use of hospital services is an independent predictor of the deterioration of the family caregivers' health-related quality of life. Since clinical nurses are the main provider who gives support and education to family caregivers, they should be alert to this situation and individualize interventions to prevent this deterioration.

Heart failure (HF) is one of the most serious health problems currently facing health services (Conrad et al., 2018). Though its impacts vary from one country to another (Blair, Huffman, & Shah, 2013; Ciapponi et al., 2016; Guha & McDonagh, 2013), in general, HF causes high rates of hospital admissions and readmissions and generates substantial costs to healthcare systems (Conrad et al., 2018). In Spain, it is estimated that over 1.3 million people have HF (Montes-Santiago, Arévalo Lorigo, & Cerqueiro González, 2014) and the mortality rate due to HF is 10.9% (Gómez-Martínez et al., 2018). It is the fourth highest cause of death, leads to 100,000 hospital admissions each year, and accounts for 2% of all emergency department visits. Half of all hospitalized HF patients are over 75 years old (Montes-Santiago et al., 2014) and have multiple comorbidities that require successive readmissions. These patients have a mortality rate of 16% at 1 year after discharge following hospital admission, and close to 60% at 10 years after discharge (Montes-Santiago et al., 2014).

Many initiatives and intervention models have been developed to improve these patients' clinical outcomes and their resulting quality of life (QoL; Van Spall et al., 2017). These models have been shown to improve HRQoL through interventions such as the detection of at-risk populations (Montes-Santiago et al., 2014), multidimensional assessments with psychological-educational support (Liljeroos, Ågren, Jaarsma, Årestedt, & Strömberg, 2017), education on self-care (Jaarsma, Riegel, & Strömberg, 2013; Jaarsma, et al., 2017), structured proactive monitoring, regulation of drug doses (Stamp et al., 2016), support for families and caregivers (Deek et al., 2017), community case management (Liljeroos et al., 2017), optimal and individual care planning, patient and caregiver engagement (King, Johnson, R., Cramer, H., Purdy, S., & Huntley, 2018), early home visits, and, lastly, the development of multilevel clinical pathways and incorporation of evidence-based recommendations (Jaarsma et al., 2017; Liljeroos et al., 2017). Nevertheless, social determinants, an element that is often omitted from these models, should also be taken into account due to their potential influence on health outcomes (Northwood, Ploeg, Markle-Reid, & Sherifali, 2018).

One social determinant that affects outcomes is the availability of a spouse or other family caregiver to take care of a patient, a factor which has been associated with the patient's health status, self-care, and prognosis (Graven & Grant, 2014; Heo, Lennie, Moser, & Kennedy, 2014; Stamp et al., 2016). Patients with HF who live alone or in a situation of social isolation are more vulnerable and tend to have a lower level of self-care (Maunder, Nolan, Park, James,

& Newton, 2015). Moreover, the lack of family support for patients with HF is associated with greater perceived severity and higher rates of hospitalization (Saunders, 2008).

Family caregivers may also experience variations in their perceived QoL (Luttik, Jaarsma, Lesman, Sanderman, & Hagedoorn, 2009; Prazeres & Santiago, 2016), with responses such as strain or feeling excessive responsibility (Saunders, 2008). There may be a negative impact on their perceived mental health (Baumstarck et al., 2017; Duggleby et al., 2016; Timonet Andreu et al., 2015) and physical health (Xie et al., 2016), especially among caregivers of older patients and dependents (Pérez-Cruz, Muñoz-Martínez, Parra-Anguita, & Del-Pino-Casado, 2017). These impacts vary according to sociodemographic factors such as gender, age, and cultural and economic level (Chang et al., 2016) in addition to other care-related factors such as the type of care provided, time dedicated to care, and cohabitation, that is an independent variable that has been related to an overestimation of time dedicated to care (the difference between the actual hours dedicated to care, and those perceived; Timonet-Andreu et al., 2018).

Those acting as caregivers may also experience positive effects (Poulin et al., 2010; Brown et al., 2009). The underlying causes of the different responses to the role of family caregiver, whether positive or negative, have yet to be clarified (Maunder et al., 2015; Mroz et al., 2018). The quality of the relationship and communication also seem to be important for the health and well-being of patients with HF and their family caregivers (Hooker, Grigsby, Riegel, & Bekelman, 2015). In summary, issues such as availability, sociodemographic characteristics, the type of care provided, health-related quality of life, the quality of the relationship and communication, and patients' hospital admissions are important factors that must be analyzed in order to determine their influence on the patient-family caregiver dyad (Maunder et al., 2015; (Hooker et al., 2015; Bidwell, Lyons, & Lee, 2017).

Though previous studies have partially addressed these factors, in most cases, cross-sectional designs and limited study populations were used. With respect to quality of life and events such as readmission, the published results are even more limited (Bidwell et al., 2017). Due to these limitations, the directionality and strengths of the associations between the factors remain largely unknown. If patients' progressive worsening is determined to be a risk factor for the deterioration of caregivers' QoL, specific interventions could be planned as part of health services in both hospital and primary care as preventative measures. These

strategies would not be limited to the traditional approach focused on patient self-care, but rather would include a health promotion approach for family caregivers, who play a major role in HF patient care and whose relationship should be taken into account (Dunbar et al., 2013).

Study Aims

The broad aims of this study are firstly, to determine the profile of family caregivers of patients with HF and its relationship with these patients' use of hospital services and secondly, to examine the effects of this care on the caregivers' own health and QoL. The specific study aim is to analyze the relationship between the use of hospital services by patients with HF and the QoL of their family caregivers and to evaluate the associations between other factors related to the family caregiver (sociodemographic data, QoL, strain, and level of depression) and to the patient (sociodemographic data, QoL, level of self-care, and functionality).

Methods

This work is a multicenter nested case-control study retrospective in regard to data on use of hospital services. In this study, the null hypothesis examined was that there was no association between patients' use of hospital services and the caregiver's perceived QoL.

Patient inclusion criteria included a hospital admission with a principal diagnosis of HF or a follow-up consultation in an outpatient clinic following an admission for HF during the previous year and the identification of a family caregiver. Patient exclusion criteria included prognosis of imminent death, language or cognitive difficulties that impeded understanding of the study questionnaire, or if no main family caregiver was identified. The family caregiver inclusion criterion was identification as the main provider of care and support at home (regardless if the patient also had a paid home healthcare aide). The family caregiver exclusion criterion was any language or cognitive difficulties that impeded understanding of the study questionnaires. The patient-caregiver dyads were selected at the time the patient consulted at or was admitted to the hospital for HF.

HRQoL was evaluated with the Spanish version of the SF12 instrument (Vilagut et al., 2008). The resulting physical component summary (PCS) and mental component summary (MCS) of this instrument were used in the analyses. To analyze caregivers' QoL and patients' use of hospital services in this case-control study, caregiver cases were defined as those whose perceived

mental health (measured using the SF-12 questionnaire) was below the cut-off point estimated by Schmidt et al. for the general Spanish population with an age and gender profile similar to that of the caregivers (around 50 years of age and female gender; (Schmidt et al., 2012). The controls were all caregivers whose SF-12 value was above this cut-off point. For the patients, the cases were those whose perceived physical and mental health (measured using the SF-12 questionnaire) was below the mean values detected in the Spanish population with more than five chronic diseases. The controls were patients whose value was above this cut-off point (Schmidt et al., 2012). To analyze caregivers' HRQoL, the following criteria were established: Cases: caregiver mental health score < 48. Controls: caregiver mental health score > 48. To analyze patients' HRQoL and use of hospital services, the following criteria were established: Cases: patient perceived physical and mental health score < 33.93 Controls: patient perceived physical and mental health score > 33.93.

Sample

Data collection

The sample population for this study was a cohort of patients with HF who were admitted to the Costa del Sol Hospital (Marbella), the Serranía de Ronda Hospital (Ronda), the Virgen de la Victoria University Hospital (Málaga), or the Alto Guadalquivir Hospital (Andújar), all in southern Spain. Data were collected in 2 years, from May 2014 to May 2016. The patient-caregiver dyads were selected at the time of hospital admission with a primary diagnosis of Heart Failure or at the time of a follow-up appointment in an outpatient clinic within a year following hospitalization for HF. Following their inclusion, the patient and main family caregiver were interviewed and the patient's medical record was reviewed to obtain the following baseline variables: the patient's sociodemographic data, HRQoL, level of self-care, and functionality and the main family caregiver's sociodemographic data, HRQoL, strain, and level of depression. The patient's hospital use in the 5 years prior to inclusion in the cohort was retrospectively collected and the number of hospitalizations was collected by review of records, through hospital data sources. Six months later, a follow-up telephone call was held with all patients and family caregivers in which the questionnaire items were read and responded to in order to calculate their HRQoL values. To detect an OR of 2.5 between the presence of risk factors in the main family caregiver (HRQoL, mental health, strain, and sociodemographic factors) and the outcome of hospital admission

(to the emergency department or hospitalization) for patients with HF with an alpha of 0.05, a statistical power of 80%, and assuming a readmission rate of 17% (calculated from previous years' data obtained from hospital information systems), we established that a minimum sample size of 448 patients would be needed. These patients would be distributed as 176 cases and 272 controls in order to have a 1:1.5 ratio of cases to controls. To compensate for possible losses, the minimum sample size was increased by 15%; therefore, 70 additional patients were needed.

Data Analysis

An analysis was performed to obtain descriptive statistics of the variables, including measures of central tendency and dispersion (or percentages). The Kolmogorov-Smirnov test was conducted to evaluate the normality of the distribution of the variables. Bivariate analysis was carried out according to the characteristics of the variables: Student's *t* test was used for independent groups and paired groups and the chi-square test was used when the distribution was normal. When there was no normal distribution, nonparametric tests, such as the Mann-Whitney *U* test and the Kruskal-Wallis test, were used along with the Wilcoxon signed-rank test for paired samples. To evaluate the association between cases' and controls' hospital use and HRQoL, bivariate chi-square analyses were carried out followed by multivariate analyses. The HRQoL of the main family caregiver adjusted for age and sex was the dependent variable and the number of hospital admissions and other factors relevant to the patient and caregiver were predictors. All calculations were performed with an alpha of 0.05. The statistical program used was IBM SPSS Statistics 25.0 (SPSS/IBM, Chicago, IL, USA).

Instruments

The following sociodemographic data on the patient-caregiver dyad were measured: age; sex; living situation; education level; family caregiver's occupational status; time spent per day providing care; length of time the caregiver has provided care; number of people at home who share care responsibilities, existence of social support (such as a paid home healthcare aide); and availability of other types of assistance, such as financial support or the provision of a paid healthcare aide, for example.

For patients, the presence of comorbidities was measured using the Charlson Comorbidity Index (O'Connell & Lim, 2000). This system evaluates life expectancy at

10 years according to the patient's age and comorbidities. It consists of 19 items (0-37 points), in addition to the patient's age. It has a sensitivity of 90.7% and a specificity of 69%.

Functionality was evaluated using the New York Heart Association (NYHA) Functional Classification. This method is used for the functional classification of patients with HF, separating them into four classes based on the limitations on physical activity caused by cardiac symptoms. Functional level I, Functional level II, Functional level III and Functional level IV. In level or class I, there is no limitation to physical activity, whereas in class IV there is inability to perform any physical activity (Sensitivity 68%, Specificity 77%; Dolgin & New York Heart Association, 1994).

Level of dependence was measured using the Barthel Index, a 10-item questionnaire scored on a Likert scale, with values ranging from 0 to 100 at five-point intervals (0-20 *total dependence*, 21-60 *severe dependence*, 61-90 *moderate dependence*, 91-99 *low dependence*, 100 *independence*). Lower scores correspond to greater dependency and higher scores to greater independence (Cronbach's alpha = 0.94; Mahoney & Barthel, 1965).

Finally, patient's self-care was assessed with the European Heart Failure Self-care Behaviour Scale. This scale consists of twelve items, scored from 1 - 5 (12-60), with higher scores corresponding to lower level of self-care (Cronbach's alpha = 0.85; Jaarsma et al., 2017).

For caregivers, the presence of family caregiver burden was measured according to the Caregiver Strain Index (CSI), 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; Sullivan, 2003). Additionally, the presence of symptoms of depression was evaluated using the Spanish version of the Patient Health Questionnaire (PHQ-9). This instrument consists of nine items, scored from 0 (*never*) to 3 (*almost every day*), which measure 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 (0-27), *mild* <4, *moderate* >5, *severe* >15, (Cronbach's alpha: 0.89; Diez-Quevedo, Rangil, T., Sanchez-Planell, L., Kroenke, K., & Spitzer, 2001).

All data for these variables were obtained by means of interviews and questionnaires conducted by four nurses trained in data collection. They were instructed on interviewing and administering questionnaires with verbal and written instructions both face-to-face and via telephone.

Ethical Considerations

The study was authorized by the Ethics and Research Committee of the Costa del Sol Medical Area with Registration No. ES-0980-OCT-2013. The provisions of the Declaration of Helsinki (revised in Brazil, 2013) regarding good clinical practices and ethical principles for research on human subjects were upheld at all times. All patients and caregivers were informed in writing and orally of the project's objectives and methodology and gave informed consent prior to participating in the study.

Results

The final study sample comprised 530 patient-caregiver dyads (206 cases and 324 controls). Figure 1 shows a flow chart illustrating the patients' and caregivers' participation throughout the different phases of the study.

The mean age of patients was 74.8 (*SD* 11.4) years. There were slightly more female patients (51.5%; *n* = 273). In 89.6% (*n* = 475) of the cases, the patients had no educational qualifications (they had an incomplete elementary school grade). The most common functional level as measured on the NYHA scale was level III (54.8%, *n* = 290). The mean level of dependence was 72.3 (*SD* 29.6, range 0-100). The mean level of comorbidity, according to the Charlson comorbidity index, was 4.7 (*SD* 2.1 range 0-37). The mean level of self-care, measured on the European self-care scale, was 32.10 (*SD* 9.9, range 12-60).

The average age of the caregivers was 56.3 years (*SD* 14.3) and the majority were female (77.4%, *n* = 410). More than half only had a primary school education or no educational qualifications (62.6%, *n* = 332). The most common patient-caregiver relationship was that of parent-child (50.9%, *n* = 270), followed by spouses (37.9%, *n* = 201). A significant proportion of the family caregivers had no paid employment (41.4%, *n* = 218) or were retired (27.9%, *n* = 147). Sixty percent (*n* = 315) of caregivers lived with the patient and the mean number of other family members who provided help to the main family caregiver was 1.47 (*SD* 1.57). Only a small percentage of caregivers received help from a paid home healthcare aide (15.7%, *n* = 83) and 16.5% (*n* = 87) had access to in-home assistance services, adult daycare centers, or other types of assistance. No significant differences were found in the caregivers' strain according to the availability of paid home health care support (4.30, *SD*: 3.42 vs 4.97; *SD*: 3.25; *p* = 0.105).

The level of caregiver strain for the whole sample was low (mean CSI 4.41, *SD* 3.40, median 4, IQR 5) and the level of depression was mild-moderate (mean PHQ-9 6.18, *SD* 5.81, median 4, IQR 8). When analyzed by gender, female caregivers presented a significantly higher level of strain and suffered higher levels of depression (Table S1).

No differences were found in patients' NYHA functional class between cases and controls, although patients belonging to the control group had a statistically

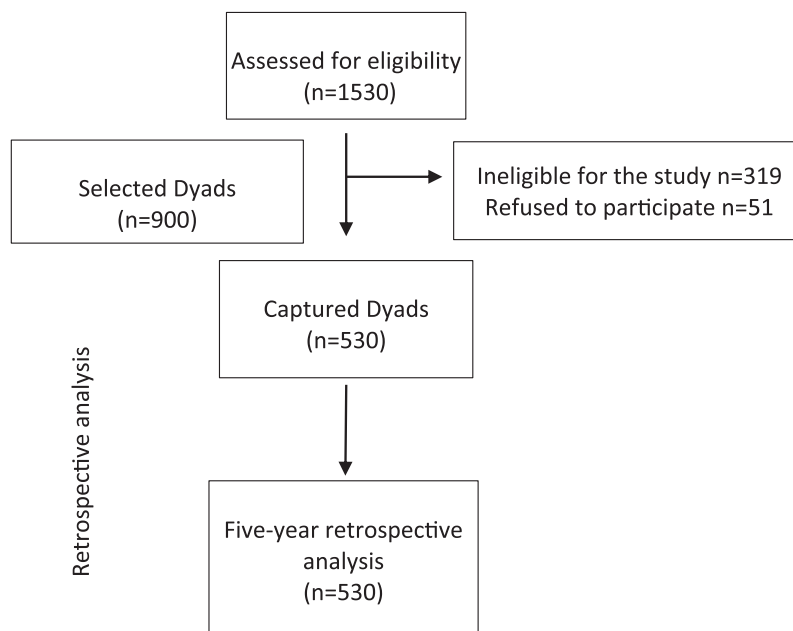


Figure 1. Patients flow-chart.

significant lower level of dependence (77.9 vs 68.6; $p < 0.001$). Caregivers in the control group spent fewer hours providing care and had lower CSI and PHQ9 scores. Detailed results on these parameters for the cases and controls are shown in Table S2.

A slight yet statistically significant positive correlation was found between patients' physical health and caregivers' mental health ($r = 0.13$, $p = 0.004$) and between patients' perceived mental health and caregivers' perceived mental health ($r = 0.30$; $p < 0.0001$).

During the 5 years that were retrospectively evaluated, 19.1% of patients required hospital admission or readmission following examination in the emergency department for Heart Failure. There was a pattern of an increasing number of admissions over the 5-year period. The mean number of hospital admissions was 0.12 (0.53) for the first year of follow-up, 0.26 (0.83) for the second, 0.29 (0.88) for the third, 0.35 (0.9) for the fourth, and 1.24 (2.02) for the fifth. No association was found between the number of hospital admissions and level of self-care ($r = 0.05$; $p = 0.234$ for the first year, $r = 0.03$; $p = 0.501$ for the second; $r = 0.01$; $p = 0.823$ for the third; $r = 0.03$; $p = 0.482$ for the fourth; and $r = -0.08$; $p = 0.067$ for the fifth).

The study hypotheses were tested as follows: patients' use of hospital services with a primary diagnosis of Heart Failure at admission in the previous 5 years was analyzed as a risk factor for low perceived mental QoL among caregivers. Caregivers whose score on the SF-12 MCS was higher than the mean value for the Spanish population were designated as controls whereas those whose score on the SF-12 MCS was lower than the mean value were designated as cases. Significant differences were found between the caregiver cases and controls in regard to the patients' total number of hospital admissions due to HF: mean patient hospital admissions per caregiver in the case group was 1.00 (2.35) versus 0.66 (1.62) for controls ($p < 0.001$). Likewise, significant differences were found between

the patient cases and controls regarding patient admissions for both PCS and MCS (Table 1).

This analysis revealed a significant association between use of hospital services by patients and a poorer QoL of their family caregiver at the end of the 5-year period, with an overall OR of 1.48 (95% CI%: 1.23 to 1.79), though in some years the OR was greater than 2. A statistically significant association was also identified between increased use of hospital services and patients' HRQoL at 5 years (Figure 2).

This unadjusted association was evaluated using a multivariate model, which showed that increasing use of hospital services in previous years was independently associated with the perceived mental health of family caregivers, which was below the average level of their peers within the general Spanish population (goodness-of-fit: Hosmer-Lemeshow: 11.29; 8; $p = 0.140$). For women who spent the most time caring for dependent family members, especially those who were older, the impact on perceived mental health was even greater (Table 1). The same evaluation was performed for the patients. Patients whose score on the SF-12 MCS was higher than the mean value for the Spanish population were designated as controls those whose score on the SF-12 MCS was lower than the mean value were designated as cases. With respect to perceived physical function, the only associated predictors were comorbidities (OR: 1.6, range 1.13 - 2.27) and dependency as measured using the Barthel index (0.98, range 0.96 - 1). For patients' MCS scores, no models able to fit the data were identified.

Discussion

Profile of Patients and Caregivers

Our patient profile matches previously-published descriptions (Montes-Santiago et al., 2014; Sayago-Silva, García-López, & Segovia-Cubero, 2013), with mild

Table 1. Differences in Patient Total Hospital Admission for Patients' Cases and Controls

| | Physical component score | | |
|--------------------|--------------------------|-----------------------|--------|
| | Cases Mean (SD) | Controls Mean (SD) | P |
| Patient admissions | 1.14 (2.59) | 0.61 (1.48) | <0.001 |
| | Mental component score | | |
| | Cases Mean (SD) | Controls Mean (SD) | P |
| Patient admissions | 0.96 (2.07) | 0.82 (2.13) | 0.002 |

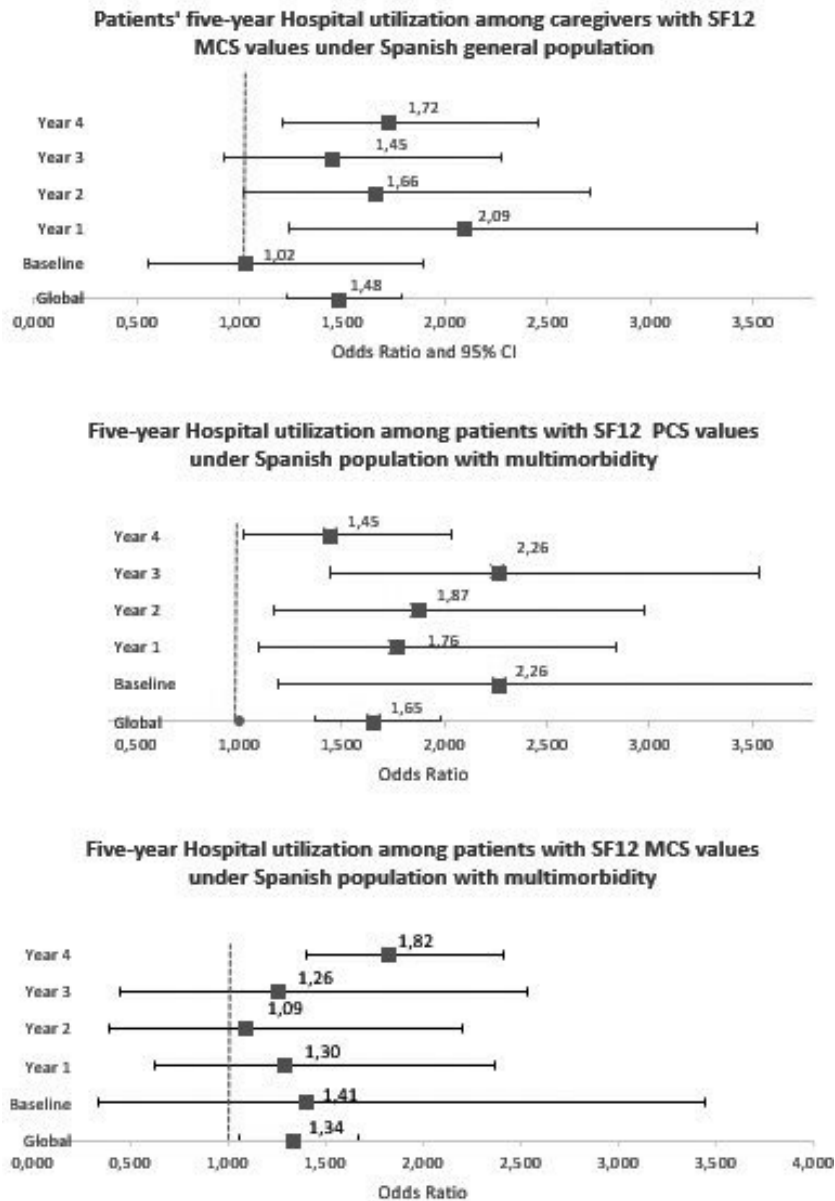


Figure 2. 5-year hospital utilization and SF-12 values for patients and caregivers.

dependence (measured on the Barthel scale) but significant limitations on physical activity, which causes fatigue, palpitations, dyspnea, or chest pain upon mild exertion. Although patients had a moderate level of dependence, they needed direct and indirect care from their family caregiver because of dyspnea, their limitations upon moderate effort, and a considerable degree of comorbidity (Jowsey, McRae, Gillespie, Banfield, M., & Yen, 2013). In addition, patients in our study had low levels of self-care. It should be noted that we did not find an association between hospital use and level of self-care, possibly because regardless of

self-care, disease progression along with a low educational level and patients' age were more influential factors for hospital use.

The typical caregiver is female, about 56 years old, usually the patient's daughter or wife, does not work outside the home, has a primary or secondary education level, and lives with the patient. These caregivers receive little or no financial assistance under Spanish legislation on caregivers (Salvador-Piedrafita et al., 2017), but they are helped by other relatives. These findings are in line with those obtained in an earlier study conducted in Spain on family caregivers of the elderly

(Vara, 2014). These caregivers did not present strain, but they did have symptoms of depression. Indeed, the scores obtained indicate the need for medical surveillance to determine whether medication might be needed should their mental health deteriorate, as has been reported by a recent study based on a Spanish population of patients with greater levels of dependence (Navarro-Sandoval, Uriostegui-Espíritu, Delgado-Quiñones, & Sahagún-Cuevas, 2017). This profile of family caregivers of chronic patients with HF also reported that family caregivers tended to overestimate the number of hours of care provided. A positive association was recorded between this overestimation and the caregiver's age, living with the patient, and a lower functional degree and level of self-care in the patient. By taking this profile into account, we would be able to identify family caregivers of chronic patients who are at risk of deteriorating health at relatively early stages of patient care and thus would be able to prepare and take preventative action (Timonet-Andreu et al., 2018).

Relationship Between the Use of Hospital Services and HRQoL

This study highlights the existence of a relationship between the use of hospital services (as a proxy indicator of disease acceleration) and a worse perceived HRQoL of both patients and their family caregivers. In addition, our analysis included additional factors such as the nature and intensity of the care provided, finding that the family caregiver's HRQoL worsens when more time is spent providing care and care is needed for a longer period of time. Hence, healthcare and social welfare systems should incorporate interventions that seek to mitigate the intensity of the family caregiver's patient care responsibilities, especially for those caregivers who have higher levels of strain or for those heart failure patients with palliative care needs, because family members report higher strain, and feeling unprepared to provide needed care (Cagle et al., 2017). Interventions such as respite care, improved communication with providers and better coordination of care among different providers, or having the option for hospice or palliative care, have been suggested for this purpose (Cagle et al., 2017). Nevertheless, we did not find differences in caregivers' strain depending on the availability of paid home healthcare support, but it is noticeable that the levels of strain in our sample were not excessively high. Furthermore, patients' comorbidity, poorer cardiac functioning, and female gender are all inversely associated with the patient's HRQoL and positively associated with the number

of hours per day and the length of time the family caregiver must provide care. In short, certain care-related factors, in addition to well-known sociodemographic factors (such as age, gender, and sociocultural level), negatively influence caregivers' QoL (Timonet-Andreu et al., 2018).

Physical and Mental Components of Patients' and Caregivers' HRQoL

The results obtained in this study show that both physical and mental components of patients' and their family caregivers' HRQoL are clearly associated, as previous research has reported (Saunders, 2008) (Brown et al., 2009; Poulin et al., 2010). Patient-caregiver dyads are not entirely heterogeneous in nature, but rather may have many aspects in common. Nevertheless, variations in HRQoL can be observed among caregivers with similar sociodemographic factors who care for patients with a similar functional level. It is very plausible that other aspects of their relationship could explain these variations, such as the quality of their relationship or communication (Hooker et al., 2015). Finally, the results presented in this paper highlights the significant room for improvement in regard to reducing the use of hospital services and preventing the deterioration of HRQoL. Some options include interventions in the community or during transitional care, such as case management, or detecting high-risk caregiver-patient dyads.

Limitations and Recommendations

Our study has some limitations. First, patients at risk of imminent death or with language or cognitive difficulties were excluded and as such, these results cannot be extrapolated to this population. Second, caregivers with cognitive difficulties were also excluded. Third, the quality of the dyadic relation was not evaluated, which could be a limitation due to the potential influence of the quality of the relationship on outcomes such as mortality, health status, distress, and caregiver burden (Hooker et al., 2015). Future studies should include patients with cognitive impairment, since this factor determines the dyadic relation among patients and caregivers (Bidwell et al., 2015), and it may indicate greater risk of readmission for people with heart failure (Agarwal, Kazim, Xu, Borson, & Taffet, 2016). Moreover, more research is necessary to obtain reliable methods to assess the quality of the dyadic relationship. Eventually, experimental studies are needed to explore tailored interventions according to different profiles of caregivers and patients' quality of life.

Conclusions

Increased use of hospital services is an independent predictor of the deterioration of the family caregivers' HRQoL. Both the physical and mental components of patients' and family caregivers' HRQoL interact and influence the other. Additional factors, such as the nature and intensity of the care provided, also affect the worsening of a family caregiver's HRQoL. Our study provides additional confirmation of some associations previously reported in the literature, although it overcomes some of the previous studies' shortcomings, such as cross-sectional designs and limited sample size.

Acknowledgement

This research project received a grant from the Andalusian Ministry of Health: PI-0521-2013.

Clinical Resources

- American Association of Heart Failure Nurses: <https://www.aahfn.org/default.aspx>
- HELP for heart failure caregivers: https://www.heart.org/HEARTORG/Conditions/HeartFailure/PreventionTreatmentofHeartFailure/For-Heart-Failure-Caregivers_UCM_306366_Article.jsp
- Heart Failure Association of the European Society of Cardiology. Resources for professional education: [https://www.escardio.org/Sub-specialty-communities/Heart-Failure-Association-of-the-ESC-\(HFA\)/Education](https://www.escardio.org/Sub-specialty-communities/Heart-Failure-Association-of-the-ESC-(HFA)/Education)
- Heart Failure Guidelines Toolkit: <https://www.heart.org/en/health-topics/heart-failure/heart-failure-tools-resources/heart-failure-guidelines-toolkit>

References

- Agarwal, K. S., Kazim, R., Xu, J., Borson, S., & Taffet, G. E. (2016). Unrecognized Cognitive Impairment and Its Effect on Heart Failure Readmissions of Elderly Adults. *Journal of the American Geriatrics Society*, *64*(11), 2296–2301. <https://doi.org/10.1111/jgs.14471>
- Baumstarck, K., Alessandrini, M., Hamidou, Z., Auquier, P., Leroy, T., & Boyer, L. (2017). Assessment of coping: A new French four-factor structure of the brief COPE inventory. *Health and Quality of Life Outcomes*, *15*(1), 8. <https://doi.org/10.1186/s12955-016-0581-9>
- Bidwell, J. T., Lyons, K. S., & Lee, C. S. (2017). Caregiver well-being and patient outcomes in heart failure: A meta-analysis. *The Journal of Cardiovascular Nursing*, *32*(4), 372–382. <https://doi.org/10.1097/JCN.0000000000000350>
- Bidwell, J. T., Vellone, E., Lyons, K. S., D'Agostino, E., Riegel, B., Juárez-Vela, R., ... Lee, C. S. (2015). Determinants of heart failure self-care maintenance and management in patients and caregivers: A dyadic analysis. *Research in Nursing & Health*, *38*(5), 392–402. <https://doi.org/10.1002/nur.21675>
- Blair, J. E. A., Huffman, M., & Shah, S. J. (2013). Heart failure in North America. *Current Cardiology Reviews*, *9*(2), 128–146.
- Brown, S. L., Smith, D. M., Schulz, R., Kabeto, M. U., Ubel, P. A., Poulin, M., & Langa, K. M. (2009). Caregiving behavior is associated with decreased mortality risk. *Psychological Science*, *20*(4), 488–494. <https://doi.org/10.1111/j.1467-9280.2009.02323.x>
- Cagle, J. G., Bunting, M., Kelemen, A., Lee, J., Terry, D., & Harris, R. (2017). Psychosocial needs and interventions for heart failure patients and families receiving palliative care support: A systematic review. *Heart Failure Reviews*, *22*(5), 565–580. <https://doi.org/10.1007/s10741-017-9596-5>
- Chang, S., Zhang, Y., Jeyagurunathan, A., Lau, Y. W., Sagayadevan, V., Chong, S. A., & Subramaniam, M. (2016). Providing care to relatives with mental illness: Reactions and distress among primary informal caregivers. *BMC Psychiatry*, *16*, 80. <https://doi.org/10.1186/s12888-016-0786-9>
- Ciapponi, A., Alcaraz, A., Calderón, M., Matta, M. G., Chaparro, M., Soto, N., & Bardach, A. (2016). Burden of heart failure in Latin America: A systematic review and meta-analysis. *Revista Espanola De Cardiologia (English Ed.)*, *69*(11), 1051–1060. <https://doi.org/10.1016/j.rec.2016.04.054>
- Conrad, N., Judge, A., Tran, J., Mohseni, H., Hedgcock, D., Crespillo, A. P., & Rahimi, K. (2018). Temporal trends and patterns in heart failure incidence: A population-based study of 4 million individuals. *The Lancet*, *391*(10120), 572–580. [https://doi.org/10.1016/S0140-6736\(17\)32520-5](https://doi.org/10.1016/S0140-6736(17)32520-5)
- Deek, H., Chang, S., Newton, P. J., Noureddine, S., Inglis, S. C., Arab, G. A., & Davidson, P. M. (2017). An evaluation of involving family caregivers in the self-care of heart failure patients on hospital readmission: Randomised controlled trial (the FAMILY study). *International Journal of Nursing Studies*, *75*, 101–111. <https://doi.org/10.1016/j.ijnurstu.2017.07.015>
- Diez-Quevedo, C., Rangil, T., Sanchez-Planell, L., Kroenke, K., & Spitzer, R. L. (2001). Validation

- and utility of the patient health questionnaire in diagnosing mental disorders in 1003 general hospital Spanish inpatients. *Psychosomatic Medicine*, 63(4), 679–686.
- Dolgin, M., & New York Heart Association (Eds.). (1994). *Nomenclature and criteria for diagnosis of diseases of the heart and great vessels* (9th ed., 3rd print). Boston, MA: Little, Brown.
- Duggleby, W., Williams, A., Ghosh, S., Moquin, H., Ploeg, J., Markle-Reid, M., & Peacock, S. (2016). Factors influencing changes in health related quality of life of caregivers of persons with multiple chronic conditions. *Health and Quality of Life Outcomes*, 14, 81. <https://doi.org/10.1186/s12955-016-0486-7>
- Dunbar, S. B., Clark, P. C., Reilly, C. M., Gary, R. A., Smith, A., McCarty, F., & Ryan, R. (2013). A trial of family partnership and education interventions in heart failure. *Journal of Cardiac Failure*, 19(12), 829–841. <https://doi.org/10.1016/j.cardfail.2013.10.007>
- Gómez-Martínez, L., Orozco-Beltrán, D., Quesada, J. A., Bertomeu-González, V., Gil-Guillén, V. F., López-Pineda, A., & Carratalá-Munuera, C. (2018). Trends in premature mortality due to heart failure by autonomous community in Spain: 1999 to 2013. *Revista Española de Cardiología (English Edition)*, 71(7), 531–537. <https://doi.org/10.1016/j.rec.2017.09.026>
- Graven, L. J., & Grant, J. S. (2014). Social support and self-care behaviors in individuals with heart failure: An integrative review. *International Journal of Nursing Studies*, 51(2), 320–333. <https://doi.org/10.1016/j.ijnurstu.2013.06.013>
- Guha, K., & McDonagh, T. (2013). Heart failure epidemiology: European perspective. *Current Cardiology Reviews*, 9(2), 123–127.
- Heo, S., Lennie, T. A., Moser, D. K., & Kennedy, R. L. (2014). Types of social support and their relationships to physical and depressive symptoms and health-related quality of life in patients with heart failure. *Heart & Lung: The Journal of Critical Care*, 43(4), 299–305. <https://doi.org/10.1016/j.hrtlng.2014.04.015>
- Hooker, S. A., Grigsby, M. E., Riegel, B., & Bekelman, D. B. (2015). The impact of relationship quality on health-related outcomes in heart failure patients and informal family caregivers: An integrative review. *The Journal of Cardiovascular Nursing*, 30, S52–S63. <https://doi.org/10.1097/JCN.0000000000000270>
- Jaarsma, T., Riegel, B., & Strömberg, A. (2017). Reporting on self-care in research studies: Guidance to improve knowledge building. *The Journal of Cardiovascular Nursing*. <https://doi.org/10.1097/JCN.0000000000000405>
- Jaarsma, T., Strömberg, A., Ben Gal, T., Cameron, J., Driscoll, A., Duengen, H.-D., & Riegel, B. (2013). Comparison of self-care behaviors of heart failure patients in 15 countries worldwide. *Patient Education and Counseling*, 92(1), 114–120. <https://doi.org/10.1016/j.pec.2013.02.017>
- Jowsey, T., McRae, I., Gillespie, J., Banfield, M., & Yen, L. (2013). Time to care? Health of informal older carers and time spent on health related activities: An Australian survey. *BMC Public Health*, 13, 374. <https://doi.org/10.1186/1471-2458-13-374>
- King, A. J. L., Johnson, R., Cramer, H., Purdy, S., & Huntley, A. L. (2018). Community case management and unplanned hospital admissions in patients with heart failure: A systematic review and qualitative evidence synthesis. *Journal of Advanced Nursing*, 74(7), 1463–1473. <https://doi.org/10.1111/jan.13559>
- Liljeroos, M., Ågren, S., Jaarsma, T., Årestedt, K., & Strömberg, A. (2017). Long-term effects of a dyadic psycho-educational intervention on caregiver burden and morbidity in partners of patients with heart failure: A randomized controlled trial. *Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care and Rehabilitation*, 26(2), 367–379. <https://doi.org/10.1007/s11136-016-1400-9>
- Luttik, M. L., Jaarsma, T., Lesman, I., Sanderman, R., & Hagedoorn, M. (2009). Quality of life in partners of people with congestive heart failure: Gender and involvement in care. *Journal of Advanced Nursing*, 65(7), 1442–1451. <https://doi.org/10.1111/j.1365-2648.2009.05004.x>
- Mahoney, F. I., & Barthel, D. W. (1965). Functional evaluation: The Barthel Index. *Maryland State Medical Journal*, 14, 61–65.
- Maunder, R. G., Nolan, R. P., Park, J. S., James, R., & Newton, G. (2015). Social support and the consequences of heart failure compared with other cardiac diseases: The contribution of support received within an attachment relationship. *Archives of Cardiovascular Diseases*, 108(8–9), 437–445. <https://doi.org/10.1016/j.acvd.2015.03.005>
- Montes-Santiago, J., Arévalo Lorigo, J. C., & Cerqueiro González, J. M. (2014). [Epidemiology of acute heart failure]. *Medicina Clínica*, 142(Suppl. 1), 3–8. [https://doi.org/10.1016/S0025-7753\(14\)70075-2](https://doi.org/10.1016/S0025-7753(14)70075-2)
- Mroz, E. L., Poulin, M. J., Grant, P. C., Depner, R. M., Breier, J., Byrwa, D. J., & Wright, S. T. (2018). Caregiver self-esteem as a predictor of

- patient relationship satisfaction: A longitudinal study. *Journal of Palliative Medicine*, 21(3), 376–379. <https://doi.org/10.1089/jpm.2017.0231>
- Navarro-Sandoval, C., Uriostegui-Espíritu, L. C., Delgado-Quiñones, E. G., & Sahagún-Cuevas, M. N. (2017). [Depression and burden on primary caregivers of elderly persons with physical dependence of the UMF 171]. *Revista Médica Del Instituto Mexicano Del Seguro Social*, 55(1), 25–31.
- Northwood, M., Ploeg, J., Markle-Reid, M., & Sherifali, D. (2018). Integrative review of the social determinants of health in older adults with multimorbidity. *Journal of Advanced Nursing*, 74(1), 45–60. <https://doi.org/10.1111/jan.13408>
- O'Connell, R. L., & Lim, L. L. (2000). Utility of the Charlson Comorbidity Index computed from routinely collected hospital discharge diagnosis codes. *Methods of Information in Medicine*, 39(1), 7–11.
- Pérez-Cruz, M., Muñoz-Martínez, M. Á., Parra-Anguita, L., & Del-Pino-Casado, R. (2017). [Coping and subjective burden in primary caregivers of dependent elderly relatives in Andalusia, Spain]. *Atencion Primaria*. <https://doi.org/10.1016/j.aprim.2016.09.012>
- Poulin, M. J., Brown, S. L., Ubel, P. A., Smith, D. M., Jankovic, A., & Langa, K. M. (2010). Does a helping hand mean a heavy heart? Helping behavior and well-being among spouse caregivers. *Psychology and Aging*, 25(1), 108–117. <https://doi.org/10.1037/a0018064>
- Prazeres, F., & Santiago, L. (2016). Relationship between health-related quality of life, perceived family support and unmet health needs in adult patients with multimorbidity attending primary care in Portugal: A multicentre cross-sectional study. *Health and Quality of Life Outcomes*, 14(1), 156. <https://doi.org/10.1186/s12955-016-0559-7>
- Salvador-Piedrafita, M., Malmusi, D., Mehdipanah, R., Rodríguez-Sanz, M., Espelt, A., Pérez, C., ... Borrell, C. (2017). Views on the effects of the Spanish Dependency Law on caregivers' quality of life using concept mapping. *International Journal of Health Services: Planning, Administration, Evaluation*, 47(2), 233–257. <https://doi.org/10.1177/0020731416685494>
- Saunders, M. M. (2008). Family caregiver support and hospitalizations of patients with heart failure. *Home Healthcare Nurse*, 26(10), 624–632. <https://doi.org/10.1097/01.NHH.0000341226.40640.ad>
- Sayago-Silva, I., García-López, F., & Segovia-Cubero, J. (2013). Epidemiology of heart failure in Spain over the last 20 years. *Revista Espanola De Cardiologia (English Ed.)*, 66(8), 649–656. <https://doi.org/10.1016/j.rec.2013.03.012>
- Schmidt, S., Vilagut, G., Garin, O., Cunillera, O., Tresserras, R., Brugulat, P., ... Alonso, J. (2012). [Reference guidelines for the 12-Item Short-Form Health Survey version 2 based on the Catalan general population]. *Medicina Clínica*, 139(14), 613–625. <https://doi.org/10.1016/j.medcli.2011.10.024>
- Stamp, K. D., Dunbar, S. B., Clark, P. C., Reilly, C. M., Gary, R. A., Higgins, M., & Ryan, R. M. (2016). Family partner intervention influences self-care confidence and treatment self-regulation in patients with heart failure. *European Journal of Cardiovascular Nursing: Journal of the Working Group on Cardiovascular Nursing of the European Society of Cardiology*, 15(5), 317–327. <https://doi.org/10.1177/1474515115572047>
- Sullivan, M. T. (2003). Caregiver Strain Index (CSI). *Home Healthcare Nurse*, 21(3), 197–198.
- Timonet Andreu, E., Morales Asencio, J. M., Canca Sanchez, J. C., Sepulveda Sanchez, J., Mesa Rico, R., & Rivas Ruiz, F. (2015). Effects and consequences of caring for persons with heart failure: (ECCUPENIC study) a nested case-control study. *Journal of Advanced Nursing*, 71(12), 2987–2997. <https://doi.org/10.1111/jan.12732>
- Timonet-Andreu, E., Canca-Sanchez, J. C., Sepulveda-Sanchez, J., Ortiz-Tomé, C., Rivas-Ruiz, F., Toribio-Toribio, J. C., & Morales-Asencio, J. M. (2018). Overestimation of hours dedicated to family caregiving of persons with heart failure. *Journal of Advanced Nursing*. <https://doi.org/10.1111/jan.13727>
- Van Spall, H. G. C., Rahman, T., Mytton, O., Ramasundarahettige, C., Ibrahim, Q., Kabali, C., ... Connolly, S. (2017). Comparative effectiveness of transitional care services in patients discharged from the hospital with heart failure: A systematic review and network meta-analysis: Comparative effectiveness of transitional care services in patients hospitalized with heart failure. *European Journal of Heart Failure*, 19(11), 1427–1443. <https://doi.org/10.1002/ejhf.765>
- Vara, M.-J. (2014). Long-term care for elder women in Spain: Advances and limitations. *Journal of Aging & Social Policy*, 26(4), 347–369. <https://doi.org/10.1080/08959420.2014.939894>
- Vilagut, G., Valderas, J. M., Ferrer, M., Garin, O., López-García, E., & Alonso, J. (2008). [Interpretation of SF-36 and SF-12 questionnaires in Spain: Physical and mental components]. *Medicina Clínica*, 130(19), 726–735.
- Xie, H., Cheng, C., Tao, Y., Zhang, J., Robert, D., Jia, J., & Su, Y. (2016). Quality of life in Chinese

family caregivers for elderly people with chronic diseases. *Health and Quality of Life Outcomes*, 14(1), 99. <https://doi.org/10.1186/s12955-016-0504-9>

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