Depressive symptoms in the family caregivers of patients with heart failure: an integrative review

Sintomas depressivos em cuidadores familiares de pacientes com insuficiência cardíaca: revisão integrativa
Síntomas depresivos en cuidadores familiares de pacientes con insuficiencia cardíaca: una revisión integradora

Marianna Sobral Lacerda
Patrícia Rezende do Prado
Alba Lúcia Bottura Leite de Barros
Juliana de Lima Lopes

ABSTRACT

Objectives: Identify the occurrence of depressive symptoms in family caregivers of patients with heart failure and the correlation of other variables with depressive symptoms.

Design/Method: The literature review was conducted in the Web of Science, Medline, LILACS and PubMed databases in March 2017. Papers published between 2004 and 2016, written in English, Spanish or Portuguese were included. The descriptors used were health, heart failure, depression, caregivers, and family.

Results: 26 papers were selected. 6% to 64% reported depressive symptoms. Depressive symptoms were associated with patients’ and caregivers’ characteristics. In most cases, depressive symptoms were greater among family caregivers than in the general population and were mainly associated with care burden and quality of life.

Conclusions: The studies report depressive symptoms in caregivers of patients with heart failure.

Keywords: Heart failure. Depression. Family. Caregivers.

RESUMO

Objetivos: Identificar a ocorrência de depressão em cuidadores familiares de pacientes com insuficiência cardíaca e a correlação de outras variáveis com a depressão.


Resultados: Foram selecionados 26 trabalhos. 6% a 64% reportaram sintomas depressivos. Os sintomas depressivos foram associados com as características dos pacientes e cuidadores. Em sua maioria, os sintomas depressivos foram maiores entre os cuidadores familiares que a população em geral e se relacionou principalmente com a sobrecarga do cuidado e a qualidade de vida.

Conclusão: Os estudos identificaram sintomas depressivos nos cuidadores de pacientes com insuficiência cardíaca.


RESUMEN

Objetivos: Identificar la ocurrencia de síntomas depresivos en los cuidadores familiares de pacientes con insuficiencia cardiaca y la correlación de otras variables con los síntomas depresivos.


Resultados: Se seleccionaron 26 trabajos. De 6% a 64% reportaron síntomas depresivos. Los síntomas depresivos se asociaron a características de pacientes y cuidadores. En la mayoría de los casos, los síntomas depresivos fueron mayores entre los cuidadores familiares que en la población general y se relacionaron principalmente con la carga asistencial y la calidad de vida.

Conclusiones: Los estudios identificaron síntomas depresivos en los cuidadores de pacientes con insuficiencia cardiaca.

INTRODUCTION

Cardiovascular diseases are the main cause of death in the world and accounted for approximately 17.7 million deaths in 2015, which corresponds to 31% of all deaths\(^{(1)}\). Cardiovascular diseases include heart failure (HF), the final route of most heart diseases. HF is a public health problem and mainly affects the elderly. More than 650,000 HF new cases are diagnosed every year in the United States alone\(^{(2)}\).

A patient with a chronic disease experiences many changes in daily routine that stem from the pathology itself. These changes differently impact the lives of family caregivers\(^{(3,4)}\) who, in many cases, provide social support to patients helping them overcoming, monitoring and managing the disease, and maintaining self-care\(^{(5,6)}\). It is known that social support is one of the factors associated with the quality of life of patients, while the quality of the relationship established between patient and caregiver directly affects caregivers\(^{(7,8)}\). An analysis of the relationship between care delivery and mortality revealed that caregivers supporting partners who reported stress presented an approximately 63% greater risk of dying in four years, when compared with individuals who were not caregivers\(^{(9)}\).

Due to the importance of the family/patient relationship, various studies have been conducted in the field of cardiology, especially addressing HF. Depression has been assessed in family caregivers of patients with HF and sometimes an analysis of quality of life, caregiver burden, anxiety and/or perceived control is also included. It is known that depression is a common disorder and is frequently associated with functional impairment and compromised physical health, and also accounts for a large number for re-hospitalizations among these patients\(^{(10–11)}\).

In this context, the following research questions emerged: Do the family caregivers of HF patients present depressive symptoms? What are the factors that influence the emergence of depressive symptoms among family caregivers? It is believed that the answers to these questions can support interventions focused on the health and wellbeing of family caregivers, and their involvement in care plans devised by a multi-professional team. Based on these questions, this study’s objective was to identify in the literature the occurrence of depressive symptoms in family caregivers of patients with heart failure and the correlation of other variables with these symptoms.

METHOD

This integrative literature review was conducted according to the following stages\(^{(12–13)}\): identification of the theme and establishment of research questions based on the PECO strategy\(^{(13)}\) (P, target population = family caregivers of patients with HF; E, exposure = factors related to depressive symptoms in family caregivers of patients with HF; C, comparison = does not apply; and O, outcomes = depressive symptoms in family caregivers of patients with HF); establishment of inclusion and exclusion criteria; establishment of information to be extracted from papers; assessment of papers selected; interpretation and presentation of the synthesis of results. The research question was: Do the family caregivers of patients with heart failure present depressive symptoms? What are the factors related to depressive symptom among these family caregivers?

The literature search was conducted in 2016 in the Web of Science, Medline, LILACS and PubMed databases, using the following health science descriptors: Heart Failure, Depression, Family, and Caregivers. Inclusion criteria were papers published between 2004 and 2016, written in English, Spanish or Portuguese, assessing depressive symptoms, the research subjects of which were family caregivers of patients with HF. Exclusion criteria were papers assesseing depressive symptoms in caregivers of children with HF, literature reviews, meta-analyses, and methodological studies. Two reviewers independently read the titles and abstracts and then compared results to establish which full texts would be read. These two evaluators read the papers selected and those that met the inclusion criteria were included in the review.

The papers were read to determine what information should be extracted from papers. A spreadsheet was developed to store data concerning the studies’ methodological and thematic aspects, including the following information: title, year of publication, names of authors, information concerning the patients with heart failure (age, race, gender, education and marital status), information concerning the family caregivers (age, race, gender, marital status, and kinship), questionnaire used to assess depressive symptoms, depressive symptoms score, and results.

Level of evidence was assessed according to the classification provided by the Oxford Centre for Evidence-Based Medicine (CBME)\(^{(15–16)}\), which is based on the study design. According to this criterion, evidence is classified as 1a (systematic review of randomized controlled trials), 1b (individual randomized controlled trial with narrow confidence interval), 1c (all died before and some survived after the beginning of the treatment but none died during the treatment), 2a (systematic review of cohort studies), 2b (individual cohort study, including low-quality randomized controlled trials), 2c (outcome research and ecological studies),
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3a (systematic review of case-control studies), 3b (individual case-control studies), 4 (case-series or poor quality cohort and case-control studies), and 5 (expert opinion). Studies were hierarchically organized and ordered according to evidence.

The checklist by Downs and Black (15) was used to measure the quality of studies. This tool includes clinical trials and observational studies and presents 27 items with five sub-items: 1) reporting (which assesses whether the information provided in the paper is sufficient to allow readers make an unbiased assessment of the study’s findings); 2) external validity (which addresses the extent to which the study’s findings can be generalized to the population from which the study subjects were derived); 3) bias (which addresses biases in the measurement of the intervention and the outcome); 4) confounding (which addresses bias in the selection of study subjects); and 5) power (which assesses whether the negative findings from a study can be due to chance). The score for clinical trials range from 0 to 32. Seventeen items were assessed for the observational methods, items 4, 8, 12 to 15, 19, 23, 24 and 27 were excluded because they correspond to experimental studies. Hence, the score for this type of study ranges from 0 to 18 points. Observational studies (cross-sectional, cohort and case-control) with a minimum score of 12 and clinical trials scoring above 19 were considered good quality studies (16).

The interpretation and presentation of a synthesis of the results were based on the critical assessment of authors and the presence or absence of depressive symptoms in the family caregivers of patients with HF.

RESULTS

A total of 581 papers were identified: 26 in Medline, 59 in LILACS, 274 in PubMed, and 222 in the Web of Science. After reading the abstracts and excluding those that did not meet the inclusion criteria and/or those that appeared more than once, the full texts of 297 papers were selected; all of these were written in English (Figure 1). Most studies were published in North America: 14 in the United States (54.0%) and two in Canada (7.7%), while 10 (38.3%) were published in Europe (five in Sweden, three in the United Kingdom, one in the Netherlands, and one in Turkey). No studies were found in Brazil addressing depressive symptoms in this population.

Number of papers identified with descriptors: 581
Papers excluded after reading the title and those that appeared more than once: 276 + 8 = 284
Titles and abstracts that were read: 297
271 papers excluded after analysis because did not meet the inclusion criteria
26 papers were included in the study

Figure 1 - General description of the integrative review process

No papers were published in 2004, 2007 or 2016, while the largest number of papers was published in 2013 (n=5), followed by 2009 and 2015 (n=4 each), 2005, 2006, 2008, 2010, 2012 and 2014 (n= 2 each) and 2011 (n=1). Note that 50% of the papers were published in journals from the nursing field. Study designs included cross-sectional (n=17), cohort (n=2), and randomized clinical trials (n=7). The interventions of randomized studies were directed to family caregivers, patients or both. The studies’ level of evidence was 1B, 2B and 2C, confirming appropriate design. In regard to the quality of studies, the randomized studies scored between 19 and 21, cohort studies between 14 and 17, and cross-sectional studies scored between 9 and 14. Most studies (65.38%) presented good methodological quality (table 1).
Characteristics of family caregivers

The studies’ sample sizes ranged from 19 to 393 family caregivers, aged between 37.1 and 75 years old, most were Caucasian (66% to 93.6%), and female (62% to 100%). From 29.3% to 100.0% of the caregivers were either married to the patient or were in a stable relationship and lived in the same home. Living in the same home was one of the inclusion criteria established by some studies. Among the studies assessing the use of medication by caregivers, 7% to 10% of the caregivers were taking antidepressants at the time of assessment. In regard to the presence of comorbidities, two studies included caregivers with depressive symptoms, who represented 4% and 5% of the population under study, though the use of antidepressants were not reported.

The studies differed in regard to how data were presented: when data were presented in terms of years of schooling, the means ranged from 12.9 to 13.5 years; when in terms of level of education, from 9.6% to 79% studied beyond high school, while from 20% to 85.9% studied up to high school. In regard to occupation, the economically active population ranged from 12.5% to 68%. Physical exercise and smoking were assessed by two studies only, while only one study assessed alcohol consumption.

Table 1 - Type of study, level of evidence, and quality of studies. 2004-2016

<table>
<thead>
<tr>
<th>Author/Year</th>
<th>Type of Study/ Level of Evidence</th>
<th>Quality of Study</th>
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<tbody>
<tr>
<td>Pihl et al. (2005)</td>
<td>Cross-sectional study / 2C</td>
<td>10</td>
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<tr>
<td>Hooley et al. (2005)</td>
<td>Cohort study / 2B</td>
<td>14</td>
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<tr>
<td>Barnes et al. (2006)</td>
<td>Cross-sectional study / 2C</td>
<td>10</td>
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<tr>
<td>Molloy et al. (2006)</td>
<td>Randomized study / 1B</td>
<td>21</td>
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<tr>
<td>Saunders (2008)</td>
<td>Cross-sectional study / 2C</td>
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<td>Saunders (2008)</td>
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<td>Saunders (2009)</td>
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<td>Luttik et al. (2009)</td>
<td>Cross-sectional study / 2C</td>
<td>11</td>
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<td>Pressler et al. (2009)</td>
<td>Cohort study / 2B</td>
<td>17</td>
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<td>Chung et al. (2009)</td>
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<td>Agren et al. (2011)</td>
<td>Cross-sectional study / 2C</td>
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<td>Trivedi et al. (2012)</td>
<td>Cross-sectional study / 2C</td>
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<td>Agren et al. (2012)</td>
<td>Randomized study / 1B</td>
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<td>Pressler et al. (2013)</td>
<td>Cohort study / 2B</td>
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<td>McMillan et al. (2013)</td>
<td>Randomized study / 1B</td>
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<td>Löfvenmark et al. (2013)</td>
<td>Randomized study / 1B</td>
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<tr>
<td>Malik et al. (2013)</td>
<td>Cross-sectional study / 2C</td>
<td>12</td>
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<tr>
<td>Harkness et al. (2013)</td>
<td>Cross-sectional study / 2C</td>
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<td>Lum et al. (2014)</td>
<td>Cross-sectional study / 2C</td>
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<td>Zincir et al. (2014)</td>
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<td>Piette et al. (2015)</td>
<td>Randomized study / 1B</td>
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<tr>
<td>Buck et al. (2015)</td>
<td>Cross-sectional study / 2C</td>
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Source: Research data, 2017
Instrument used to assess depressive symptoms

The instruments used to assess depressive symptoms among family caregivers differed in terms of the questionnaires used, time, place, and how assessments were applied. The instrument most frequently used was the Beck Depression Inventory – II (BDI-II) (4,18,27,30,36-37), followed by the Hospital Anxiety and Depression Scale (HADS) (20,33-35), the Center for Epidemiological Studies Short Depression Scale (CES-D 10) (21-23,26,38-39), the Center for Epidemiological Studies Depression Scale (CES-D) (24,29), the Patient Health Questionnaire-8 (PHQ-8) (25,31), the Patient Health Questionnaire-9 (PHQ-9) (8,40), the Brief Symptom Inventory (BSI) (26), the Profile of Mood States (POMS) (32), Zung Self-Rating Depression Scale (SDS) (17), and the Geriatric Depression Scale (GDS) (19). Seventeen out of the 26 studies performed a single assessment of depressive symptoms, one study implemented two assessments (baseline and at 6 months), and eight studies implemented three assessments, from baseline up to 16 months. In terms of how the assessments were implemented, 14 studies used self-administered questionnaires, while nine studies used interviews, two employed both self-administered instruments and interviews, and one study did not report how assessments were implemented.

Occurrence of depressive symptoms and interventions proposed

From 6% to 64% of the caregivers assessed in all the studies presented depressive symptoms. Scores ranged from 5.4 to 12.2, on average, when depressive symptoms were assessed by the BDI-II; from 3.4 to 4.8, when assessed by the PHQ-8; from 0.92 to 11.2, when using the CES-D 10; from 2.8 to 4.6, when the HADS was used; 8.0 to 9.9, when using the POMS; and from 4.13 to 4.47, when the PHQ-9 was used. The other questionnaires assessing depressive symptoms were used only once or presented the mean score only once: the score obtained when BSI was used was 0.77 (26); 0.50, when using the SDS (17); and 13.9, when the CES-D was used (29). The other studies did not report scores in their results.

In regard to randomized clinical trials, interventions involved educational programs (33,38) and the COPE method (32) (creativity, optimism, planning, and expert information), which were directed to family caregivers, physical exercise programs directed to patients (29), and psychosocial and/or educational programs directed to both patients and caregivers (30,37,39).

The interventions directed to patients and family caregivers involved strategies focused on recognizing and modifying factors that contributed to emotional and physical problems and in the implementation of self-care strategies (50) a psychoeducational program that involved the interdisciplinary team that helped in the processing of patients’ and spouses’ experiences (57) and guidance focused on positive communication, HF-related health, self-care and the participation of caregivers in disease management (59). The programs involved education through computer programs, learning material, and counseling with nurses (56), dialogue between participants and professionals (57); and contact through e-mail and telephone (59). Over time, depressive symptoms ranged between 0 and 19% of the control group and from 8% to 20% of the caregivers in the intervention group.

Factors related to depressive symptoms

The factors related to depressive symptoms were: functional status, perceived control, quality and/or satisfaction with the relationship established between patient and caregiver, caregiver burden, greater number of caregiver comorbidities, larger number of medications for the patient, caregiver and patient quality of life, social support/lack of family support, perception of care, time spent in care activities, difficult in providing care, caregiver and patient mental health, sleep quality, severity of patient disease, patient hospitalization and death, patient age, patient depressive symptoms, uncertainty in regard to the disease, caregiver stress, worse maintenance of patient self-care, and caregiver experiences.

The quality of the relationship established between patient and caregiver was negatively associated with depressive symptoms, as well as satisfaction or perception of patients in regard to the relationship, quality of life of both caregivers and patients, maintenance of patient self-care, functional status, perceived control, positive care experience, social support, and perception of patients regarding social support (8,17-19,23,26,34,40).

A positive association with depressive symptoms was found when family caregivers reported greater difficulty in providing care, more time spent with care activities, caregiver burden, greater number of caregiver comorbidities, greater number of patient medications, worse outcome for patients at 6 months (more likely to die or be hospitalized), patient age, uncertainty regarding the disease, patient depressive symptoms, lack of family support, or caregiver stress (17-18,22,27,29,34-36).
DISCUSSION

This study’s results enabled identifying the occurrence of depressive symptoms among family caregivers of patients with heart failure. Even though the incidence of depressive symptoms among caregivers was lower than among patients, it shows the impact of the disease in the lives of family caregivers. Such impact appears in changes caregivers experience in their daily lives, quality of life, psychological factors, such as increased levels of anxiety and depressive symptoms, in addition to burden that stems from the work of providing care. The negative impact caregivers experience also directly impacts the patient affected by the disease(40), as both become patients and require social and medical support, as well as family support.

Note that family members often assume the role of caregiver even when they have some physical comorbidity, experience emotional distress or burden, and often neglect their own health in favor of providing care to the patient(41). As a result, they experience overload and become vulnerable to the various ways care delivery may have a negative impact on their health and wellbeing. In this context of disease within the family, the caregiver needs to adapt to his/her new role, reorganizing life to be able to accompany the patient’s new routine. Given the need to adapt, caregivers may develop depressive symptoms, insomnia (due to the need to be in a continuous state of alertness), stress (due to daily activities, and the patient’s health condition and severity of the disease), discouragement (due to fatigue, depressive symptoms, and severe patient condition), and psychosomatic illnesses (headache and gastritis)(41). Therefore, various studies indicate that the primary family caregiver requires special care, since his/her physical and emotional health directly influences the wellbeing of patients and the care provided, as well as the quality of life of both patient and caregiver(41).

The presence of depressive symptoms among family caregivers of patients with HF was assessed in the studies included in this review and in previous studies, in which 21%(40), 23% (44) and 45% (45) of caregivers presented these symptoms, corroborating the results found. Even with the high prevalence of depressive symptoms among caregivers, only two studies reported medication treatment(17,23). In the first study, 46.8% of the caregivers presented depressive symptoms and only 10.0% used medication(17) while in the second study, 64.0% of the caregivers presented depressive symptoms but only 7.0% took antidepressants(22). Overload and depressive symptoms are factors that affect the health and quality of life of caregivers. Hence, greater attention is required by caregivers with depressive symptoms on the part of the healthcare staff, as well as social support to improve their quality of life, which in turn influences the quality of care provided to patients(40).

Depressive symptoms are correlated with various factors: functional status, perceived control, quality and/or satisfaction with the relationship established between patient and caregiver, caregiver burden, number of caregiver comorbidities, greater number of patient medications, quality of life of both caregiver and patient, social support/lack of family support, perception of care delivery, time spent with care activities, difficulty in providing care, mental health of both caregiver and patient, quality of sleep, severity of patient disease, patient hospitalization and death, patient age, patient depressive symptoms, uncertainty about the disease, caregiver stress, worse maintenance of patient self-care, and caregiver experiences. A good relationship may benefit caregivers or even decrease burden, while a poor relationship does not benefit caregivers or may even leave caregivers more susceptible to overload(40). Providing care to a patient with heart failure includes various activities, such as helping the patient to maintain self-care activities, monitoring and managing the disease, in addition to activities stemming from decompensated heart failure and re-hospitalizations. All these activities overload caregivers, who give up their social and professional lives in favor of caring for the patient. Social isolation, lack of socialization with other people, and lack of activities not linked to care delivery all favor the emergence of depressive symptoms among caregivers.

Caregivers assume an immense responsibility in the management of patients’ health, including activities such as monitoring symptoms, providing emotional support, administering medication, food and exercises, tasks that may trigger a perception they are experiencing greater stress when providing care, worse perceived control, in addition to a worse functional condition and a greater amount of time spent with care activities(27), which also favor the emergence of depressive symptoms.

The number of medications used by patients, combined with a greater number of comorbidities presented by patients and caregivers, and a lack of support on the part of other family members, are factors that lead to increased caregiver burden and make caregivers more vulnerable to depressive symptoms(40,18,21,28).

Patients with some degree of decompensated heart failure (functional class III and IV), may become even more dependent, which worsens their own quality of life(26) and...
that of their caregivers, potentially leading to more frequent or intense depressive symptoms\(^{(17)}\). Degree of dependence may also be related to patient age, which may increase depressive symptoms in caregivers and patients\(^{(17)}\).

Most participants were family caregivers (spouses and children) living with the patient, which may increase responsibility and concerns due to affective ties. Such zeal may increase caregiver stress, with a consequent increase in depressive symptoms\(^{(19)}\).

Patients whose caregivers reported greater burden and more depressive symptoms were more likely to die or become hospitalized in the following 6 months, showing there is a close relationship between patients and caregivers\(^{(18)}\). The relationship between caregiver burden and caregiver depressive symptoms remains unclear; that is, whether a depressed caregiver feels more burdened or feels they are burdened leads the caregiver to feel more depressed, is unknown\(^{(18)}\).

Caregivers with more depressive symptoms tend to experience worse quality of life\(^{(20)}\) than individuals who do not present such symptoms, as depressive symptoms directly interfere in the physical and emotional aspects of one’s life, which in turn are directly influenced by the care activities required by patients. Patients with poor social support are more likely to depend on their families, increasing burden and decreasing the wellbeing of caregivers\(^{(29)}\).

Therefore, nurses should identify the factors that impact the depressive symptoms of family caregivers of patients with HF, in order to improve the quality of life of this population and patients. One interventional study that included greater attention to the needs of caregivers of patients with HF reports a significant decrease in the number of re-hospitalizations, length of hospitalization, and patient mortality\(^{(47)}\).

Caregivers of patients with HF report greater overload, depressive symptoms, and perception of stress, as well as worsened quality of life\(^{(44-46)}\). Similar results were found in this study, while patients who presented high levels of support on the part of partners reported greater self-care than patients with poor to moderate social support\(^{(50)}\).

Recognizing depressive symptoms in caregivers is extremely important to preventing the potential negative effects of caregivers and patients. The support that health workers provide may lead to less drastic changes that accrue from the patients’ disease and take place in the lives of caregivers. Interventions directed to family caregivers aiming to minimize the impact of depressive symptoms, or even to improve symptoms, are necessary to achieving optimal results in the treatment of patients and preventing family caregivers from becoming ill.

The literature presents much information related to complications accruing from depressive symptoms. Based on such knowledge, its early diagnosis and treatment are essential, especially when associated with other comorbidities.

This study allowed the identification of the prevalence and related factors that contribute to the presence of depressive symptoms in the family caregivers of patients with heart failure and supported the dissertation “Anxiety, stress and depression of relatives of patients with heart failure under outpatient treatment”\(^{(51)}\).

**CONCLUSION**

The studies assessed here identified depressive symptoms in caregivers of patients with heart failure. In most of the studies, such prevalence was greater than in the healthy population, showing the impact of the disease on the lives of caregivers. Depressive symptoms were associated with different variables and most studies identified a negative relationship with quality of life and positive relationships with caregiver burden, which influenced the quality of the care provided.

The assessment of family caregivers, which was the focus of the studies, is of great relevance because the changes that take place in the lives of patients directly affect the habits and routines of family caregivers, forcing them to adapt to life considering the needs of patients. The impact of the disease on family life included, in addition to depressive symptoms, aspects such as social factors, quality of life and anxiety.

The changes family caregivers experience directly affect patients and may represent a negative impact, such as an increased number of hospitalizations. Despite the changes imposed on the lives of patients, they found in family caregivers the support necessary to maintain their treatment appropriately. Therefore, the physical and mental health of family caregivers is extremely important to improving the conditions of patients with HF and preventing potential complications to caregivers themselves.

A limitation identified in this study is related to the small number of papers found in the literature.

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