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INTEGRATIVE REVIEW ARTICLE

QUALITY OF LIFE OF CAREGIVERS TO PATIENTS WITH HEART FAILURE: INTEGRATIVE REVIEW

QUALIDADE DE VIDA DOS CUIDADORES DE PACIENTES COM INSUFICIÊNCIA CARDÍACA: REVISÃO INTEGRATIVA

CALIDAD DE VIDA DE LOS CUIDADORES DE PACIENTES CON INSUFICIENCIA CARDIACA: REVISIÓN INTEGRADORA

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ABSTRACT

Objective: to analyze the scientific production on quality of life of caregivers to patients with heart failure. **Methodology:** an integrative review, with a time frame of 5 years (2009-2013) and research in the Medline database. 17 articles were selected, analyzed and presented in two categories: The HF patient's caregiver as the focus of the article and the HF patient's caregiver as a facilitator of treatment. **Results:** Among the 17 articles analyzed, 58.8% were conducted in the United States, 11.7% in the UK, 11.7% in the Netherlands and 17.6% in Sweden. Of these, 82% had a quantitative approach; in general, women play the role of the caregiver, as well as men are the most prevalent among patients with heart failure. **Conclusion:** there is no effective treatment if the caregiver is forgotten, because independent of the study focus, the main objective of the research is for an optimization of treatment and reduction of signs and symptoms to occur. **Descriptors:** Heart Failure; Caregivers; Quality of Life.

RESUMO

Objetivo: analisar as produções científicas sobre qualidade de vida do cuidador de paciente com insuficiência cardíaca. **Metodologia:** revisão integrativa, com recorte temporal de 5 anos (2009-2013) e busca na base de dados Medline. Foram selecionados 17 artigos, analisado e apresentados em duas categorias: O cuidador do paciente com IC como foco do artigo e O cuidador do paciente com IC como facilitador do tratamento. **Resultados:** dentre os 17 artigos analisados, 58,8% foram conduzidos nos Estados Unidos, 11,7% no Reino Unido, 11,7% na Holanda e 17,6% na Suécia. Destes, 82% apresentaram abordagem quantitativa; de forma geral, as mulheres desempenham o papel de cuidador, assim como os homens são os mais prevalentes entre os pacientes com insuficiência cardíaca. **Conclusão:** não existe um tratamento efetivo se o cuidador for esquecido, pois independente do foco do estudo, o grande objetivo das pesquisas é que ocorra uma otimização do tratamento e diminuição dos sinais e sintomas. **Descritores:** Insuficiência Cardíaca; Cuidadores; Qualidade de Vida.

RESUMEN

Objetivo: analizar la producción científica sobre la calidad de vida del cuidador de los pacientes con insuficiencia cardíaca. **Metodología:** revisión integradora, con el marco de tiempo de 5 años (2009-2013) y la búsqueda en la base de datos Medline. Un total de 17 artículos, analizados y presentados en dos categorías: enfoque el cuidador del paciente con IC del artículo y el cuidador del paciente con IC como facilitador del tratamiento. **Resultados:** de los 17 artículos analizados, el 58,8% se realizaron en los Estados Unidos, el 11,7% en el Reino Unido, el 11,7% en los Países Bajos y el 17,6% en Suecia. De éstos, el 82% tenían un enfoque cuantitativo; en general, las mujeres desempeñan el papel de cuidador, así como los hombres son los más prevalentes entre los pacientes con insuficiencia cardíaca. **Conclusión:** no existe un tratamiento eficaz si el cuidador se olvida, porque independiente del enfoque de estudio, el objetivo principal de la investigación es que se produzca una optimización del tratamiento y la reducción de los signos y síntomas. **Descriptores:** Insuficiencia Cardíaca; Los cuidadores; Calidad de Vida.

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INTRODUCTION

With the advancement in technology and the development of new treatments, the life expectancy of the population has increased, as well as the incidence of heart failure (HF), which mostly affects older individuals.^{1,2}

HF is a complex clinical syndrome affecting much of the world population. It is estimated that worldwide 23 million people are affected by this disease.¹ This is commonly associated with other chronic comorbidities, which determines its unpredictability and frequent and prolonged hospitalizations.³ For affecting mainly elderly individuals who have other chronic diseases and limitations arising from its signs and symptoms, people with HF usually need a caregiver to assist in daily activities and management of the disease.

Caregivers are family members or close friends, unpaid, providing assistance to a patient with a chronic disease. Unlike other chronic diseases, the patient caregivers with HF suffer a great physical, psychological and financial overload by the oscillations of the disease and prolonged timeframe.⁴ Some positive points are mentioned in this care process, however the burden to the caregiver is clear, as to that some forget to take care of their own health, affecting their quality of life.

The family support promotes self care by patients and some studies have shown how important it is to have the focus on this part of the population, because it can directly influence the course of treatment.^{2,4,5} By having great influence on treatment and being relevant to professionals in the general health it is important for nurses to know what points need to be addressed in the future to implement interventions aimed at the welfare of the patient and the caregiver.¹

OBJECTIVE

- To analyze the scientific production on quality of life of caregivers to patients with heart failure.

METHOD

This article is drawn from the dissertation << Cross-cultural adaptation and validation of the Family Caregiver Quality of life scale (FAMQOL) for use in Brazil >> submitted to the Graduate Program in Cardiovascular Sciences, Universidade Federal Fluminense / UFF in 2013.

Descriptive study of integrative review type, which includes analysis of research / publications to time delimitation 2009-2013. The data collection period was from August to September 2013. The research question was << *What is being researched on the quality of life of caregivers to patients with HF in the last 5 years?* >>

Inclusion criteria were: original articles, dissertations and theses in English, Portuguese and Spanish. Articles that did not answer the study questions were excluded.

The Medline database was consulted via Pubmed and the search strategy was the PICO. Figure 1 is described structured approach of the PICO used for formulation of the MESH descriptors and terms in Medline. Controlled descriptors according to each segment of the PICO strategy carried out the search using as Boolean AND and OR operators were selected. The search strategy followed the following structure: P (Mesh: Heart failure caregiver or caregivers or family caregiver or family caregivers) and I (not applicable) and C (not applicable) and O (Mesh: Quality of Life).

Strategy	MESH Terms
P	Heart failure or caregiver
And	caregivers or family caregiver or family caregivers
I	
And	-----
C	
And	-----
O	Quality of life
And	

Figure 1. Description of the search strategy

We found 96 items with Mesh terms: heart failure and caregiver or caregivers or family caregiver or family caregivers and quality of life. 44 articles were excluded after applying temporal boundaries and two by the required languages, leaving 50 articles for analysis.

These 50 articles were referred to two researchers for an independent evaluation. At the end were selected by both the consistent

items with the subject of study and final analysis, only the matching articles were selected

Among the 50 articles, the first researcher selected 30 and the second researcher selected 25, and of these, 16 were chosen for both. Since there was divergence in the choice of articles, a meeting was needed with the two researchers to obtain a consensus. It

is emphasized that for this the full reading of the selected articles by a single researcher was necessary. After the meeting the researchers agreed on the selection of 17

articles to answer the question of the study. The organization chart of the steps in this process was as follows.

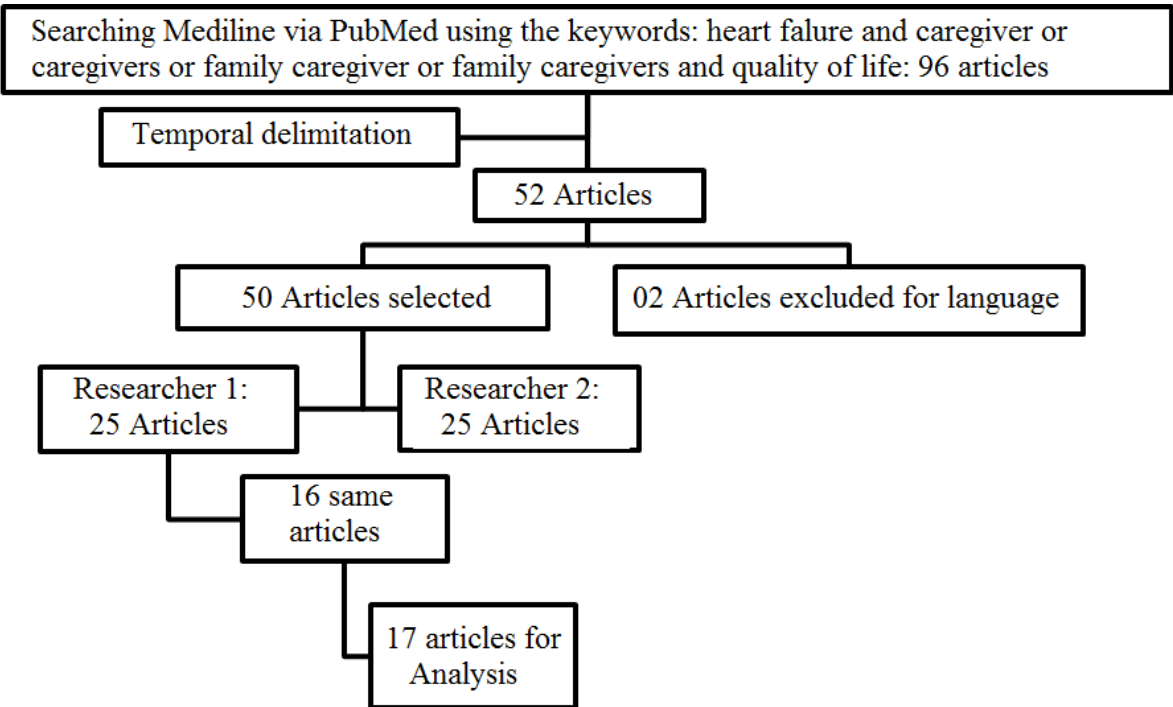


Figure 2. Steps of the integrative review

RESULTS

The 17 articles selected for analysis are arranged on the following two figures:

Title	Author	Magazine	Year and Type	Country
Caring for a spouse with end-stage heart failure through implantation of a ventricular assist device left the destination therapy.	Kitko LA, Hupcey JE, JH Gilchrist, Boehmer JP.	Heart Lung. 2013 Mar 13.	2012 - IQ	USA
Family Caregivers of Patients With Heart Failure: A Longitudinal Study.	Pressler SJ, Smith G, et al.	J Cardiovasc Nurs. 2012 Jun 29.	2012 - L and P	USA
Patient and caregiver congruence: The Importance of dyads in heart failure care.	Retrum JH , Nowels CT , Bekelman DB .	J Cardiovasc Nurs. 2013 Mar-Apr; 28 (2): 129-36.	2013 - IQ	USA
Caregiver care.	LG Collins, K. Swartz	Am FamPhysician. 1; 83 (11): 1309-17.2011	2011 - Rv	USA
A New Instrument to Measure Quality of Life of Heart Failure Family Caregivers.	NAUser JA, Bakas T, Welch JL.	J Cardiovasc Nurs. 2010 Dec 1.	2010 - EV	USA
Caregiving for Patients Requiring left ventricular assistance device support.	Baker K, M Flattery, J Salyer, KH Haugh, M. Maltby	Heart Lung. 2010 May-Jun; 39 (3): 196-200. Epub 2009 Oct 1.	2009 - Qt	USA
Working and caregiving: a comparison of employed and unemployed caregivers of older heart failure Patients.	Saunders MM.	Nurs Pract Holist. 2010 Jan-Feb; 24 (1): 16-22.	2010 - T	USA
Indicators of health-related quality of life in heart failure family caregivers.	Saunders MM.	J Community Health Nurs. 2009 Oct; 26 (4): 173-82.	2009 - T	USA
The effects of depressive and anxiety Symptoms on quality of life in Patients with heart failure and Their spouses: testing dyadic dynamics using Actor-Partner Interdependence Model.	Chung ML, Moser DK, Lennie TA, Rayens MK.	J Psychosom Res 2009 Jul; 67 (1):. 29-35. Epub 2009 Mar 5.	2009 - T	USA
Family caregiver outcomes in heart failure.	Pressler SJ, et al.	Am J Crit Care. Mar; 18 (2): 149-59. 2009	2009 - L and P	USA

Figure 3. Selection of articles published in the US. Longitudinal: L; Prospective: P; Randomized Clinical Trial: ECR; Transversal: T; Qualitative: Qt; Validation study: EV; Review: RV; Qualitative: IQ

Title	Author	Magazine	Year	Country
Living with breathlessness: The survey of caregivers of breathless Patients with lung cancer or heart failure.	FA Malik , Gysels M , Higginson IJ .	Palliat Med. 2013 Jul; 27 (7): 647-56.	2013 T	United Kingdom
Tools to measure quality of life and carer burden in informal carers of heart failure Patients: A narrative review.	Whittingham K Barnes S, Gardiner C.	Palliat Med. 2013 Feb 26.	2013 Rv	United Kingdom
Dyads Affected by chronic heart failure: a randomized study Evaluating effects of education and psychosocial support to Patients with heart failure and Their partners.	Ågren S, LS Evangelista, Hjelm C, A. Strömberg	J Card Fail.2012 May; 18 (5): 359-66.	2012 ECR	Sweden
Family caregiving in chronic organ failure advanced.	DJ Janssen, MA Spruit, Wouters EF, Schols JM.	J Am Med Dir Assoc. 2012 May; 13 (4): 394-9.	2012 T	Netherlands
Quality of life and Symptoms of depression in advanced heart failure Patients and Their partners.	Jaarsma T, Johansson P, S Agren, A. Strömberg	Curr Opin Support Palliat Care. 2010 Dec; 4 (4): 233-7.	2010 Rv	Sweden
The partners of Patients with chronic heart failure experience caregiver burden?	Agren S, L Evangelista, A. Strömberg	Eur J Cardiovasc Nurs.2010 Dec; 9 (4): 254-62.	2010 T	Sweden
Quality of life in partners of people with congestive heart failure: gender and Involvement in care.	Luttik ML, Jaarsma T, Lesman I, Sanderman R, M. Hagedoorn	J Adv Nurs. 2009 Jul; 65 (7): 1442-51.	2009 T	Netherlands

Figure 4. Selection of articles published in other countries.
Clinical Trial: EC; Transversal: T; Review: RV

From the analysis of the data of figures one and two, it's found that of the 17 articles analyzed, 10 of them (58.8%) were performed in the United States, two (11.7%) in the UK, two (11.7 %) in the Netherlands and three (17.6%) in Sweden. Of these, 14 showed a quantitative approach, and 07 with a transversal methodology.

In characterizing the caregivers and patients from identified articles, it can be said in general that it is women who play this role of caregiver, as well as that men are the most prevalent among patients with HF.

The characterization in terms of age, sex and the person who has the caregiver role is in Figure 5:

Author / Year	Patient		Caregiver		Caregiver
	Average Age ± SD	Sex	Average Age ± SD	Gender (%)	
Malik, 2013 ⁶	72.3 ± 9.6	Male 75%	65.8 ± 12.7	Female 82%	Spouse 70%
Kitko, 2013 ⁷	67	Male 80%	62	Female 80%	Spouse 100%
Whittingham, 2013 ³	Not verified	Not verified	Not verified	Not verified	Not verified
Pressler, 2013 ⁸	69 ± 12.6	Male 54%	59.7 ± 15	Female 76%	Spouse 68%
Agren, 2012 ⁹	71 ± 11.5	Male 75%	68.5 ± 11	Female 75%	Spouse 100%
Retrum, 2013 ¹⁰	71	Male 64%	60	Female 94%	Spouse 58%
Collins, 2011 ⁴	69	Female	49	Female	Daughter / spouse
Janssen, 2012 ¹¹	74.8 ± 8.1	Male 75.6%	67.3 ± 11.5	Female 80%	Spouse 77.8%
NAUser 2011 ¹²	72.5 ± 13.3	Male 68%	62.3 ± 13.3	Female 89%	Spouse 62%
Jaarsma, 2010 ¹³	Not verified	Not verified	Not verified	Not verified	Not verified
Agren, 2010 ¹⁴	71 ± 12	Male 75%	69 ± 12	Female 75%	Spouse 100%
Baker, 2010 ¹⁵	Not verified	Not verified	51	Female 83%	Spouse 50%
Saunders, 2010 ¹	77.5 ± 10	Not verified	Not verified	Female 90%	Spouse 68%
Saunders, 2009 ¹⁶	77.6 ± 9.8	Female 51%	58.1 ± 14.6	Female 84%	Son 50%
Chung, 2009 ¹⁷	61.7 ± 12.5	Male 74%	57.5 ± 11.9	Female 74%	Spouse 100%
Luttik, 2009 ¹⁸	Not informed	Not informed	67 ± 12	Female	Spouse 100%
Pressler, 2009 ¹⁹	69 ± 12.6	Male 54%	59.7 ± 15.0	Female 76%	Spouse 68%

Figure 5. Characterization of caregivers and patients regarding gender, age and relationship.

DISCUSSION

After reading the selected 17 articles, these were categorized into two themes: The caregiver as focus of the article and the caregiver as a facilitator of treatment.

♦ The patient's caregiver HF as focus of the article

Twelve articles in this review had the caregiver as a focus of the work. In general, the goal was to characterize caregivers of patients with chronic diseases, identify the positive and negative aspects of the care process and report this experience.

The caregiver can be defined as a family member or friend who offers care without financial benefits and has grown exponentially due to the chronic nature of some diseases and the aging of the population, making it increasingly necessary to develop tools to assess this population.^{1, 12} In most cases they forget to take care of their own health and undergo a physical, considerable psychological and financial overload, with its representation mainly in women, as wives or daughters.¹

There are also several positive and negative factors as to take care of a loved one, but the burden was identified as the most common to the caregiver. The positives are minimal, however, the well-being and satisfaction are important points which sometimes stand out about the negative aspects and show that the positive aspects exist and can not be disregarded, as they are also important reflections this care process.¹¹

On the negative side, especially caregivers of patients with HF, for some features of the disease, suffer major impacts and overload on their physical, mental, financial well-being that influences their quality of life.¹⁶ However, there are features that become more vulnerable to this impact, such as being young, female and existing prior physical and emotional problems. In addition, external factors can increase this burden, as the severity of the patient's disease, recent hospitalization in emergency and low social support around.^{3,16} Unlike expected, the patient's age, severity of dyspnea, gender and smoking does not influence this burden according to some authors.¹¹ As to the age of the caregiver, years of care and hours of care per day, these do not influence according to others.¹⁶

To illustrate that caregivers of patients with HF suffer major impacts, in one study, it was shown that both caregivers of patients with HF and caregivers of patients with lung cancer have similar needs and challenges, however caregivers of patients with HF feel more alone in the care process and suffer when the disease is of long duration and oscillation in the signs and symptoms.⁶

In another study, which compared partners of healthy people to partner with HF, it became clear that the latter had a worse perception of general health.¹⁸ In assessing caregivers patients with severe and mild symptoms, both with HF, the 1st demonstrated spend more time in the tasks, and most arduous consider them and suffer the greatest impact on quality of life and anxiety.⁸

Changes in the caregiver's lives are inevitable and are more complex to deal with behavioral problems of the patient and to have to live with one's friend in favor of this new function.¹⁹ To learn how the life of the caregiver is modified, researchers sought to evaluate the changes in performance of daily tasks, in self-control, on depressive symptoms, anxiety, and quality of life over time. Self control of the caregiver, as well as their quality of life and their anxiety level remain unchanged throughout the time of the care, unlike the depressive symptoms and the time taken to carry out activities that were unexpectedly reduced over the months.⁸

Taking the professional life of the caregiver into account, about being employed or not, we evaluated the depression and the welfare of those in a single moment and it was concluded that depression is not influenced by the fact that he is unemployed unlike wellbeing, which was noticeably better in employed caregivers.¹ This fact probably shows the possibility that the work provides the caregiver a way not to experience full-time modifications imposed by the disease.

In another study, the analysis was made from more specific groups, ie in caregivers of patients with advanced-stage heart failure patients with a device called "*left ventricular assist device*" (LVAD). This is a type of circulatory support device which is implanted to improve the left ventricular function.⁷

Caregivers reported the importance of adaptation in their lives to the care, however it became clear that the pre-implantation phase, the physical limitations of the patient and the oscillations were many, requiring much physical effort from caregivers.⁷

After implantation, caregivers created new routines of life mainly because they were lay on the subject and present a fear in connection to a device failure. In general, the uncertainty for the future prevailed after device placement.⁷ Corroborating this finding, caregivers of patients with LVAD when asked about the relationship with the patient reported suffering from the changes imposed by the treatment. The financial burden, the demand of time and the social impact are part of everyday life for caregivers of chronically ill patients, however, the help and support from the health team must exist and is seen as a protective factor.¹⁵

♦ The patient's caregiver with HF as a facilitator of treatment

Some studies have been conducted in view of the caregiver, but with the focus mainly on

patients, and caregivers being considered a "facilitator" of treatment.

From the articles allocated in this category, a large part works with the patient's partners, ie person living and dealing with the difficulties of everyday life. The support and attention from caregivers are important tools to achieve the patient's well-being and to slow down the progression of the disease.¹⁴

When evaluating a sample of caregivers through a cross-sectional study, it became clear through questionnaires that the higher the caregivers' burden is, the worse physical function of the patient is.¹⁴ In addition to this, in order to identify the relationship of depressive symptoms and anxiety in the patient's quality of life with HF and caregiver spouse, it became clear that the higher depressive symptoms and anxiety of the caregiver are, the greater the negative impact on the quality of life of the patient is.¹⁷

These findings bring us evidence of how important it is that the caregiver is healthy for the patient's treatment to be effective. Thinking from the perspective of interventions, they should be directed to both the patient and the caregiver, as one directly influences the quality of life of the other.

A clinical trial, randomized and controlled in order to assess which aspects of life of a partner-patient binomium are modified as a result of participation in a shared care program that combines cognitive, psychosocial and behavioral therapy was performed.⁹

This integrated care program helped caregivers to modify factors that contributed to the emotional worsening, and provide a moment of dialogue and resolution of problems and questions. The important finding of this study was that the self-control by the patient improved significantly after three months of intervention.⁹

To assess the relation caregiver / patient as a binomial a qualitative study was conducted to analyze the congruences and inconsistencies in the statements of both. The study focused on changes in quotes of life in the future and how to deal with the disease.^{10, 20}

Congruence and incongruence in the speeches of the members was easily identifiable in areas such as the management of diseases and perspectives on the future and in addition to this it was evident the influence of the caregiver in the patient's emotional and vice versa. Relations between older people were shown to have a greater

level of communication and the lack of communication was related to a higher level of stress.¹⁰ This finding confirms the importance of the link and dialogue so that the patient has a better quality of life related to emotional aspects.

In order to identify the factors that are related to quality of life and depressive symptoms of patients and caregivers of patients with HF we reviewed also identified key interventions that should be implemented to improve the quality of life and decrease symptoms Both depressants.¹³

Regarding factors associated with a worse quality of life for both the patient and the caregiver, are sex and age, for the younger patients having a poorer quality of life, as well as women. For depression, it is related to younger patients, the fact that they lived alone, difficulty of sleeping and disease severity.¹³

As proposed interventions to improve quality of life and decrease depressive symptoms are, education about self care and the practice of physical exercise. These are considered indispensable elements in programs for patients with HF, as well as the multidisciplinary team, with a focus both the patient and the caregiver so that the goals are all met.¹³

CONCLUSION

This review addressed several points related to the care process, due to the chronic nature of a disease. After analyzing the articles and characterization of the caregivers was shown that this role is mainly from the female person, and their representation as spouses, as to the daughters.

With the proven influence of the caregiver on quality of life of the patient, the focus of treatment should be reviewed as to obtain satisfactory results in the treatment of the patient, the same can not be seen from a unique and isolated point of view, since people who deal daily with the changes imposed by the disease also suffer and should be prepared for it.

For these caregivers to be prepared, interventions should be proposed by health teams, seeking the incorporation and participation of the same. It is important that both the patient and the caregiver know that there will be significant changes in the life of each one, but above all they know how to understand them and face them in the best possible way.

With the separation of the approaches in two different threads, it is observed that there is no effective treatment if the caregiver is forgotten, because independent of the study focus, the main objective of the research is for to occur an optimization of treatment and reduction of signs and symptoms.

The review made the importance of focusing on patient-caregiver relationship clear, and emphasized that both should be worked out in a single, integrated way. It is suggested that further studies are to be conducted to further examine the proposed interventions and the analysis of their effectiveness.

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