

*Review article*

## Care Needs of Patients with Heart Failure: A Systematic Review

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### SUMMARY

**Background/Aim.** Heart failure is the leading public health concern as its prevalence increases and the cost of care increases dramatically due to poor prognosis. Ineffective disease management can increase morbidity and lead to repeated hospitalizations. The aim of this systematic review was to determine the care needs of patients treated for heart failure.

**Methods.** The databases of PubMed, Medline, Scopus, Cochrane, Google Scholar, and Persian databases including SID, Iran Medex, and Magiran were searched until January 2022 to identify relevant articles. The included studies were descriptive, analytical, cross-sectional and qualitative studies, which were conducted on care needs and heart failure disease. Out of 1,199 relevant published studies, a total of 16 studies were finally systematically reviewed. The quality of the articles was assessed by three researchers using the Mixed Methods Appraisal Tool (MMAT). The data were analyzed qualitatively.

**Results.** Sixteen studies involving 53,299 heart failure patients were included in the study. The findings from researches indicated a moderate to high level of unmet needs in the area of care which consists of health care needs, educational and learning needs, emotional, social and psychological needs and support, counselling and home care services and some special needs for women.

**Conclusion.** This study highlights the need for provision of care in several areas and these require need assessment, management, decision-making, and care planning. Importantly, the provision of a support system to help patients cope during illness and bereavement is necessary.

**Keywords:** care needs, heart failure, patient's needs, heart failure disease, systematic review

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## INTRODUCTION

Globally, non-communicable diseases (NCDs) account for two out of every three deaths and more than 36 million deaths annually (1). Nearly 80% of NCD deaths occur in low- and middle-income countries (2). Cardiovascular disease (CVD) is responsible for one in three deaths worldwide, with 80% of deaths occurring in developing countries (3). Unlike most CVDs (4 - 7), heart failure is a major public health problem because of its increasing prevalence. The prevalence rate of heart failure is approximately 2% - 3%, 10% after the age of 70 years, and 15% - 20% after the age of 80 years (8). Not only is heart failure a common, chronic and progressive disease but the poor prognosis can dramatically increase the cost of treatment. Today, appropriate treatment strategies include lifestyle changes (salt restriction, exercise, alcohol withdrawal, etc.) and medications to treat heart failure. The American Heart Association has identified heart failure as one of the most expensive diseases, costing more than \$31 billion annually. This is a heavy burden on national economies due to repeated hospitalizations and loss of work capacity (9 - 12).

Heart failure is a chronic syndrome in which the heart is unable to pump enough blood to meet the body's metabolic needs due to impaired cardiac function and increased neurohormonal activity (13). Because the disease requires long-term care after diagnosis, it affects patients and their families physically, psychologically, and socially and creates an economic burden for patients and their families. Patients often require assistance with activities of daily living, such as shopping, cleaning, showering, and dressing (14). Ineffective disease management by patients and their families is the main factor that increases morbidity and recurrent hospitalizations. Patients and their families need specific knowledge and skills to manage heart failure, therefore, need assessment is essential to address and coordinate this challenge. Healthcare professionals also play an important role in the interdisciplinary team (cardiologist, nurse, midwife, dietician, social worker, gerontologist, psychologist, etc.). They counsel patients and their families, ensure medical compliance, and coordinate patient education and care (4, 10). In this context, the present systematic review was conducted to identify the care needs of patients treated for heart failure.

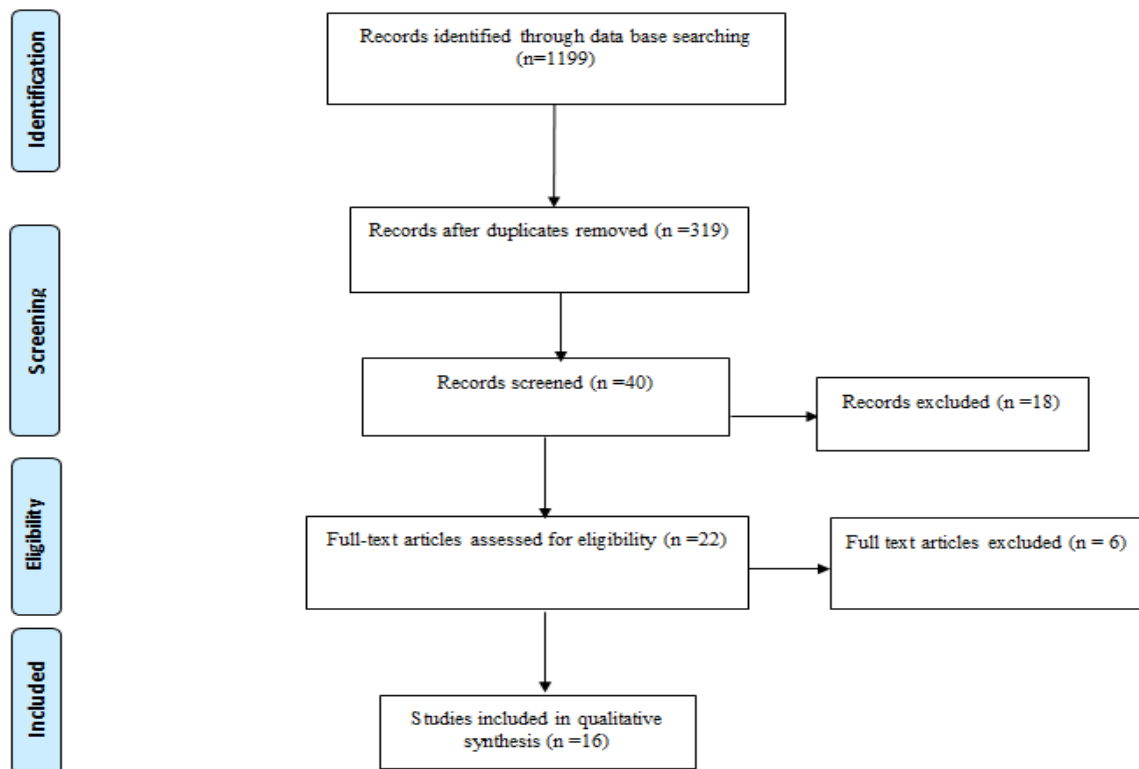
## METHODS

The present study is a systematic review structured according to the PRISMA (Preferred Reporting Items for Systematic Review and Meta-analysis) protocol, aimed at identifying the care needs of patients with heart failure. EMBASE, Science Direct, PubMed /MEDLINE, Scopus and Cochrane as well as SID, Iran Medex, Magiran, Irandoc and Google Scholar were searched until January 2022. Searches were conducted using Persian and equivalent English keywords such as: care needs, health needs, heart failure, heart disease and home care without time and language restrictions. The reference section of all articles was evaluated to find other possible sources. First, all articles related to long-term care needs and heart failure were collected, and then all articles that mentioned keywords in their titles or abstracts were included in the initial list. Inclusion criteria were: descriptive, analytical, cross-sectional, and qualitative studies on care needs and heart failure. Exclusion criteria were: unpublished articles, duplicate citations, other chronic diseases, lack of access to full-text articles, and *in vitro* studies. At this stage, 303 articles that did not meet the requirements were removed from the study.

The titles and abstracts of the articles were assessed by two independent investigators and a third investigator to resolve any disagreements. To increase the validity and reliability of the study, three investigators separately assessed the quality of the articles using MMAT (15). The content of the articles was carefully and repeatedly reviewed and analyzed. The MMAT scores the articles based on the type of study and has two basic questions for primary assessment and also five questions for each of the articles (16). Each question received a score, with the lowest score for each type of study being zero and the maximum score being seven. Articles with a score greater than four were included in the study. A data extraction form was used to extract the information required for the systematic review.

## RESULTS

A total of 16 studies were included, involving seven cross-sectional studies, two descriptive studies, five qualitative studies, one survey and one review. The selection process of the included studies is described in Figure 1.



**Figure 1.** PRISMA flow diagram of study selection progress

Among them, five papers were related to Iranian authors and eleven papers were published by researchers from other countries. The flow chart of the study selection process is shown in Figure 1. The details of the form included author's name, year of study, study location, study design, participants, sample size, instrument, and outcome (Table 1).

Table 2 shows the evaluation of article quality using MMAT.

Cal and Altay (2017) evaluated the quality of life and home care needs of patients treated for heart failure and found that patients needed caregivers at home, and the level of home care needs was significantly correlated with the number of children, educational status, and living in a village (10). Coletta Simko et al. evaluated the educational needs of adults with congenital heart disease using paired t-tests, McNamara Chi-squared tests, and logistic regression models. They identified several areas of educational need. Adult education concerns include: birth control, pregnancy, and genetic counseling

(17). The Task Force recommends that all patients need to be well informed about the risks of pregnancy associated with their condition and the contraceptive options available to avoid pregnancy if desired. Finally, genetic counseling regarding inheritance, etiology, recurrence risk, and prenatal diagnostic options should be available to all patients with congenital heart disease (18). Farr et al. found that patients had "some" difficulty in four of five functional areas, including: communication, self-care, fine motor skills, and gross motor skills, and that the level of difficulty in these five functional areas was associated with receipt of special education services (19).

The study by Harrison, et al. showed that patients were concerned about health and psychological issues. Patients were most concerned about medical issues, including: heart rhythm problems, treatment options, infections, diagnoses, surgeries, and medications. In addition, more than 70% of pa-

**Table 1:** Basic characteristics of the included studies

| No. | Author; Year; Location                  | Design                            | Participants                                                     | Sample size | Instrument                                                                                                                                                                 | Outcome                                                                                                                                                                                                                                                  |
|-----|-----------------------------------------|-----------------------------------|------------------------------------------------------------------|-------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 1.  | Riley et al.; 2011; United Kingdom (20) | Cross-sectional                   | Adults with congenital heart disease                             | N = 99      | Health-related quality of life short-form (SF-36v2); Illness Perception Questionnaire (IPQ-R); Hospital Anxiety and Depression Scale (HAD)                                 | Poorer quality of life is linked to higher levels of anxiety and depression among an elderly population of patients with congenital heart disease.                                                                                                       |
| 2.  | Harrison et al.; 2011; Canada (21)      | Cross-sectional                   | Adults with congenital heart disease (ACHD) patients             | N=123       | Researcher-made questionnaire                                                                                                                                              | In addition to financial and transportation challenges, there are other potential barriers to care. Many patients require education on when to seek urgent medical attention. The concerns of this patient population extend beyond medical information. |
| 3.  | Gholami et al.; 2014; Iran (22)         | Qualitative approach              | Cardiovascular patients; family caregivers; healthcare providers | N=31        | Semi-structured interviews list                                                                                                                                            | Content analysis revealed four main themes: disease-related information needs, healthcare-related information needs, health system-related information needs, and life-related information needs.                                                        |
| 4.  | Pryor et al.; 2013; Australia (23)      | Qualitative, descriptive          | Individuals who have experienced a cardiac event                 | N=9         | Semi-structured interviews                                                                                                                                                 | To facilitate recovery from a serious cardiac event, informational, psychological, and social support are crucial.                                                                                                                                       |
| 5.  | Svavarsdóttir et al.; 2016; Norway (24) | Qualitative study                 | Health professionals                                             | N= 19       | Individual interviews                                                                                                                                                      | Individualized patient-centered education and lifestyle counseling should be provided.                                                                                                                                                                   |
| 6.  | Hays et al.; 2020; United States (25)   | Descriptive mixed-methods study   | Adults with congenital heart disease (CHD)                       | N= 22       | ACHD Self-management Experience Questionnaire; Adult CHD Adaptive Behavior Assessment; Stanford Quality of Life Questionnaire                                              | Four prominent themes emerged regarding self-management: psychological support, health education, coping skills for mental stress, and navigating healthcare systems.                                                                                    |
| 7.  | Murray et al.; 2000; Iran (26)          | Qualitative research              | Women with coronary artery disease                               | N=17        | In-depth interviews                                                                                                                                                        | Women needs: support programs, family support (or education) programs, homecare programs, more public information                                                                                                                                        |
| 8.  | Asadi-Lari et al.; 2003; UK (27)        | Descriptive cross-sectional study | Cardiac patients                                                 | N=242       | Nottingham Health Needs Assessment (NHNA) questionnaire; Semi-structured interview; Seattle Angina Questionnaire (SAQ); Short Form 12 (SF-12); EuroQol-5 dimension (EQ-5D) | Patients expressed a desire for more social support, including suitable accommodation, companionship, and social visits, as well as physical support, such as assistance with healthcare access, household chores, and mobility aids.                    |
| 9.  | Davidson et al.; 2008; Australia (28)   | Cross-sectional study             | Patients with heart failure (25)                                 | N=540       | Heart Failure Needs Assessment Questionnaire (HFNAQ)                                                                                                                       | Psychological and social concerns were found to be more prevalent than physical needs.                                                                                                                                                                   |
| 10  | Rafii et al.; 2009; Iran (29)           | Descriptive-comparative study     | Heart failure Patients                                           | N=250       | Congestive Heart Failure Patient Learning Needs Inventory (CHFPLNI)                                                                                                        | The patients identified the 'Medication' subscale as most important to learn, while nurses emphasized the significance of the 'Risk factors' subscale. Both groups recognized the importance of 'Diet Information'.                                      |
| 11  | Imani A, Imani E. 2011; Iran (30)       | Cross-sectional study             | Patients with coronary artery disease                            | N=200       | Educational needs assessment items                                                                                                                                         | Most patients had moderate to high educational needs regarding cardiac diseases and their                                                                                                                                                                |

|    |                                        |                                                         |                                             |          |                                                                                                         | conditions.                                                                                                                                                                    |
|----|----------------------------------------|---------------------------------------------------------|---------------------------------------------|----------|---------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 12 | Rostami et al.; 2011; Iran (31)        | Descriptive-study                                       | Patients with myocardium infarction         | N=27     | Learning needs of cardiac patients questionnaire                                                        | Most of the patients had strenuous need to self-care education after MI                                                                                                        |
| 13 | Cal, Altay 2017; Turkey (10)           | Cross-sectional study                                   | Patients treated for heart failure          | N=180    | Katz Daily Living Activities Scale<br>MacNew Heart Disease Health-related Quality of Life Questionnaire | The most common home care assistance needed included cleaning, cooking, eating, bathing, and toileting.                                                                        |
| 14 | Simko et al.; 2006; United States (17) | Prospective, cross-sectional, case-control study design | Adults with congenital heart disease        | N=124    | The New York Heart Association (NYHA) Functional Classification                                         | Various educational needs, including birth control, pregnancy, and genetic counseling, were identified for adults with congenital heart disease.                               |
| 15 | Farr et al.; 2018; United States (19)  | Population-based survey                                 | Children and adolescents with heart disease | N=51,416 | Self-reported data from National Survey of Children with Special Health Care Needs (NS-CSHCN) Survey    | Participants reported 'a lot' of difficulty in five functional areas: learning/concentration, communication, self-care, gross motor skills, and fine motor skills.             |
| 16 | Foster et al.; 2001; (32)              | Narrative review                                        | -                                           | -        | -                                                                                                       | The healthcare needs of adults with congenital heart disease were classified into three categories: reproductive issues, exercise and rehabilitation, and psychosocial issues. |

<sup>1</sup>Health-related quality of life short-form<sup>2</sup>IPQ-R<sup>3</sup>HAD<sup>4</sup>Adults with congenital heart disease<sup>5</sup>Nottingham Health Needs Assessment<sup>6</sup>Heart Failure Needs Assessment Questionnaire<sup>7</sup>Chfplni**Table 2.** Evaluation of articles quality using MMAT

| Number | Author-year                       | Type of study                           | Score  | Article quality |
|--------|-----------------------------------|-----------------------------------------|--------|-----------------|
| 1      | Hays et al., 2020; (25)           | Descriptive mixed-methods online survey | 6 of 7 | Good            |
| 2      | Farr et al., 2018; (19)           | Survey                                  | 5 of 7 | Moderate        |
| 3      | Cal, Altay, 2017; (10)            | Cross-sectional                         | 6 of 7 | Good            |
| 4      | Svavarsdóttir et al.; 2016 (24)   | Qualitative study                       | 6 of 7 | Good            |
| 5      | Gholami et al.; 2014; (22)        | Qualitative research                    | 6 of 7 | Good            |
| 6      | Pryor et al.; 2013; (23)          | Qualitative, descriptive                | 6 of 7 | Good            |
| 7      | Riley et al.; 2011; (20)          | Cross-sectional                         | 6 of 7 | Good            |
| 8      | Harrison et al.; 2011; (21)       | Cross-sectional                         | 5 of 7 | Moderate        |
| 9      | Imani A, Imani E. 2011; Iran (30) | Cross-sectional                         | 5 of 7 | Moderate        |
| 10     | Rostami et al.; 2011; Iran (31)   | Descriptive                             | 5 of 7 | Moderate        |
| 11     | Rafii et al., 2009; (29)          | Descriptive-comparative                 | 5 of 7 | Moderate        |
| 12     | Davidson et al.; 2008; (28)       | Cross-sectional                         | 5 of 7 | Moderate        |
| 13     | Coletta Simko et al.; 2006; (17)  | Cross-sectional,                        | 5 of 7 | Moderate        |
| 14     | Asadi-Lari 2003; (27)             | Descriptive cross-sectional             | 6 of 7 | Good            |
| 15     | Murray et al.; 2000; Iran (26)    | Qualitative research                    | 5 of 7 | Moderate        |
| 16     | Foster et al.; 2001; (32)         | Narrative review                        | -      | -               |

tients reported concerns about the following life-style issues: exercise, obtaining insurance, and healthy eating. In the psychosocial domain, more than 50% reported concerns about personal responsibility for health, mental health, death and dying, documenting important patient information and health care needs (21).

Riley et al. reported high levels of anxiety and depression in an elderly population of patients with congenital heart disease. This issue highlights the need to routinely assess anxiety and depression in this patient population and to provide appropriate psychological support (20). A qualitative study by Gholami et al. examined the information needs of patients with cardiovascular disease and reported four central themes, including disease-related, health care-related, health system-related, and life-related information needs. Some of these information needs are related to prognosis, role playing, mental and sexual health, health system performance, modern medicine, and Islamic and traditional medicine (22).

In another qualitative study by Pryor et al., participants clearly articulated that informational, psychological, and social support are essential to enable recovery from a major cardiac event. In this context, peer support services were introduced as a means of social support (23). In a qualitative study by Svavarsdóttir et al., updated theoretical and clinical knowledge and advanced communication skills were considered essential for patient education. These include the ability to build interpersonal relationships with patients, identify their learning needs, facilitate effective dialogue, and provide individualized patient-centered education and lifestyle counseling (24).

In another study by Hays et al., four major themes emerged, including a plan for the future (education about health and life expectations), coping needs (skills for managing psychological distress), access to care (navigating health care systems), and desire for connection (psychological support) (25). In a grounded theory study conducted by Murray et al., for women over 60, maintaining functional capacity, memory problems, and a focus on resilience were the main issues. For women under 60, emotional concerns predominated. Both groups had to deal with overprotective family members. These findings may contribute to the development of more effective public education campaigns (26). The study and findings of Asadi-Lari et al. showed that patients wanted more social (appropriate housing,

companionship, social visits) and physical (assistive devices, access to health services, housework) support (27).

Davidson et al. assessed the prevalence of needs in patients with heart failure and found a high prevalence of needs in the social and psychological domains. The most commonly reported needs were related to difficulty being motivated to do activities and go out, feeling anxious and short of breath, and feeling in control of life. Participants also described high levels of unmet needs related to anger, frustration, control, and fear of having a heart attack or stroke (30). A descriptive-comparative study by Rafii et al. identified the learning needs of patients with heart failure. "Medication" and "risk factors" were perceived as the most important titles to learn, and the importance of "dietary information", "activity", "anatomy and physiology", and "psychological factors" was agreed upon (31).

Imani et al. assessed the educational needs for self-care training among patients with coronary artery disease. According to the results, patients had moderate to high educational needs about the cardiac diseases and its conditions including: activity and rest, exercise program, cardiovascular drugs, medications, the symptoms of cardiac disease, and limitation of food supply (26). In a descriptive study done by Rostami et al, most of the patients had a strong need for self-care education after MI. The most important educational needs topics were: medication information, lifestyle factors, anatomy, physiology, and physical activity (27).

## DISCUSSION

According to the results of this study, there is a high prevalence and poor prognosis of heart failure disease, but surprisingly, the literature on the care needs of these patients is relatively sparse. Patients with heart failure disease have moderate to high levels of unmet care needs consisting of: health care needs, education and learning needs, emotional, social and psychological needs and support, counseling and home care services, and some specific needs for women. Patients expressed the need to learn to navigate a new way of life and emphasized that support from family, friends and healthcare professionals (social support) was important for this adjustment and overall well-being. They also expressed the need for the ongoing support and the need to reinforce some information at different stages of

their disease and its conditions, including: cardiovascular drugs, medications, risk factors, anatomy and physiology of heart failure disease, obtaining insurance, the symptoms of heart disease. This finding is consistent with a previous one which found that the information needs of patients with heart disease are often unmet and they often require high levels of input from health services but receive little (33).

The findings of a study by Nivel et al. explain that providing information through various modes of communication is necessary to meet patients' needs, have their participation in decisions for treatment and optimal management of life (34). The present study addresses the obvious psychological and emotional needs of patients with heart failure. It has been shown that patients with heart disease often suffer from multiple symptoms, reduced physical functioning, psychological problems (such as anxiety, panic, and depression), and some restrictions in their lifestyle (reduced physical functioning and social isolation). As a result of these issues, they require intense emotional and psychological adjustment and also social support. The results of this study are consistent with current findings (35).

The results of this study suggest a significant need for social needs and support in patients with heart failure. In this regard, the results of another research showed that with increased community support, patients with heart disease and their families may cope better with the condition and the need for emergency hospital admissions may be reduced (36). Kwame et al. reported that through social support services (peer support), provision of social programs and supportive environment, participants can share experiences along with the provision of information and emotional support, promote a sense of belonging, reduce feelings of isolation and encourage healthy behaviors such as exercise, healthy eating and adherence to medication regimens (37). Selman et al. explained that social support provided by community health workers and social workers can also impact patient outcomes such as symptom burden and quality of life (38). The results of this study suggested a significant need for health care, counseling and home care services among patients with heart failure. A recent study of a cardiology department at a university hospital in Togo reported a lack of support and poor medical care, and it addressed the importance of focusing on

the needs and priorities of patients with heart failure by health systems (39).

This review highlights some special health care needs for women with heart failure disease, including: information about pregnancy risks associated with their condition, availability of contraceptive devices, genetic counseling, and prenatal diagnosis. It has been shown previously that contraception, preg-

nancy, and genetic counseling are of great concern to adults with heart disease and that counseling on these issues should be provided by the adolescent/adult's cardiologist (40).

## CONCLUSION

This study highlights a gap in the provision of care and ongoing support for people with heart failure. Participants identified a need for information from healthcare professionals, emotional and practical support from their family and friends, and the empathic support potentially provided by peer support programs (as social support). Information about pregnancy risks associated with their condition, of contraception, genetic counseling, and prenatal diagnosis during pregnancy are of great concern to women with heart disease. This review highlights that ongoing care and support have the potential to significantly improve the well-being of individuals, reduce the likelihood of a secondary event, and reduce the burden of disease.

## Conflict of interest

The authors report no conflicts of interest

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## Nega bolesnika sa srčanom insuficijencijom: sistematski pregled literature

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### SAŽETAK

**Uvod/Cilj.** Srčana insuficijencija predstavlja jedan od glavnih problema javnog zdravlja budući da se njena prevalencija povećava, a troškovi nege drastično uvećavaju zbog loših prognoza. Neefikasno lečenje bolesti može dovesti do povećanog morbiditeta i ponovljenih hospitalizacija. Ovaj sistematski pregled literature sproveden je sa ciljem da se utvrdi kakva je nega potrebna bolesnicima lečenim od srčane insuficijencije.

**Metode.** Baze podataka *PubMed*, *Medline*, *Scopus*, *Cochrane*, *Google Scholar*, kao i persijske baze podataka među kojima su *SID*, *Iran Medex* i *Magiran*, pretraživane su do januara 2022. godine. U obzir su uzete opisne studije, analitičke studije, studije preseka i kvalitativne studije koje su bile sprovedene sa ciljem ispitivanja nege i srčane insuficijencije. Od ukupno 1199 relevantnih objavljenih studija, sistematski je pregledano ukupno 16 studija. Kvalitet članaka procenila su tri istraživača koja su koristila MMAT (engl. *Mixed Methods Appraisal Tool* – MMAT). Podaci su analizirani kvalitativno.

**Rezultati.** Naša studija je obuhvatila 16 studija koje su uključile 53.299 bolesnika sa srčanom insuficijencijom. Nalazi istraživanja ukazali su na to da je nivo neispunjenih potreba u oblasti nege koja se sastoji od zdravstvenih potreba, obrazovnih potreba i potreba za učenjem, emocionalnih, socijalnih i psiholoških potreba i podrške, savetovanja i usluga kućne nege, kao i izvesnih posebnih potreba kod žena, bio u rasponu od umerenog do visokog.

**Zaključak.** U ovoj studiji je istaknuta potreba za pružanjem nege u nekoliko oblasti koje zahtevaju procenu potreba, upravljanje, donošenje odluka i planiranje nege. Neophodno je obezbediti sistem podrške kako bi se pomoglo bolesnicima da se izbore sa tokom bolesti.

**Ključne reči:** potrebe za negom, srčana insuficijencija, potrebe bolesnika, sistematski pregled