The Research Progress on Caregiver Burden in Elderly Patients with Chronic Heart Failure

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Abstract: With the acceleration of population aging in China, the number of elderly patients with chronic heart failure (CHF) has been increasing year by year. Chronic heart failure is one of the leading causes of death among the elderly. Family caregivers are the main force currently responsible for caring for heart failure patients, bearing multiple responsibilities such as daily care, health management, and emotional support. Facing long-term, high-intensity caregiving, caregivers endure significant physical and emotional burdens. This paper aims to review the concept, influencing factors, and interventions for the burden on caregivers of elderly patients with heart failure, in order to provide clinical guidance for alleviating caregivers' burden.

Keywords: Elderly; Chronic heart failure; Caregiver burden; Research progress

1. Introduction

Heart failure (HF) is a clinical syndrome caused by abnormal cardiac structure or function, resulting in impaired ventricular filling or ejection function^[1]. It is characterized by high mortality, poor prognosis, and a heavy disease burden ^[2-4]. With the aging population in China, the number of elderly patients with chronic heart failure has been increasing year by year, making it one of the leading causes of death among the elderly ^[5]. During the treatment and rehabilitation of patients, caregivers experience a series of stress responses. Long-term caregiving significantly increases the physical and emotional burden on caregivers ^[6], leading to a substantial decline in their quality of life. Caregivers have a 63% higher risk of death compared to those without caregiving responsibilities ^[7]. Scholars have pointed out that the overall burden on family caregivers in China is at a medium-to-high level, negatively affecting the caregivers' physical and mental health, which ultimately influences the quality of care and their own quality of life ^[8]. Therefore, this paper provides a review of the influencing factors and intervention strategies for the burden on caregivers of elderly patients with heart failure, aiming to offer guidance for clinical interventions to reduce caregivers' burden.

2. The Concept of Caregiver Burden

The concept of caregiver burden was first introduced by Grad and Sainsbury in 1966^[9], aiming to describe the multiple negative impacts experienced by family members while caring for a sick relative. Initially, the concept focused on the negative effects of caregiving on an individual's social, occupational, and personal roles. Grad^[9] defined it as any negative consumption experienced by family members during caregiving, including economic, time, and psychological costs. Subsequently, Hoenig^[10] proposed that caregiver burden should be divided into subjective and objective burdens to better understand this phenomenon. Subjective burden refers to the emotional and psychological responses experienced by caregivers while performing caregiving tasks, such as stress, anxiety, loneliness, and other negative emotions. Objective burden, on the other hand, involves actual events and activities, such as deteriorating financial conditions, limited personal time, and strained family relationships. Zarit^[11] further expanded on this concept, pointing out that caregiver burden not only includes negative physiological and psychological impacts but also encompasses economic and social aspects. Additionally, an increasing number of studies indicate that caregiver burden is a multidimensional concept, involving time-related burden, developmental limitations, physical burden, emotional burden, and social burden.

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3. Factors Influencing Caregiver Burden

3.1 Caregiver's Own Factors

3.1.1 Age

As the caregiver's age increases, the level of burden often becomes more severe. Research shows that age is positively correlated with caregiver burden (r=0.257, P=0.007)^[12]. Compared to younger caregivers, elderly caregivers often lack sufficient physical strength and stamina, making it difficult to complete physically demanding caregiving tasks, which significantly increases the burden. At the same time, elderly caregivers may also face their own health issues^[13].

3.1.2 Gender

Studies indicate that female caregivers generally experience a greater burden than male caregivers, primarily because they invest more time and energy in daily caregiving tasks, while male caregivers are more likely to provide economic support^[8]. Gender differences are one of the key factors influencing the caregiving experience^[14]. Female caregivers are more likely to experience negative emotions such as burden, stress, anxiety, and fatigue, and are also more susceptible to declines in self-esteem and feelings of pessimism. Female caregivers often neglect their own health needs, and due to their multiple roles, the physical and emotional stress is exacerbated. Additionally, traditional beliefs commonly view caregiving as a responsibility that women should bear, which may increase the burden on women. Moreover, because women generally have lower emotional regulation skills, their coping strategies may not be as effective^[14]. Therefore, although women invest more in caregiving, their mental and physical health are more likely to be impacted. Further research, based on large-scale, multi-center studies, is needed to explore the profound impact of gender on caregiver burden, in order to provide evidence for developing more effective support measures to help female caregivers reduce their burden and improve care quality.

3.1.3 Caregiving Duration

Surveys show that caregivers spend at least 16.2 hours per week on caregiving, with daily caregiving time for heart failure patients ranging from 5 to 8 hours^[15-17]. This long-term caregiving leads to significant psychological stress and emotional burden for caregivers. Furthermore, as caregiving time increases, the risks faced by caregivers also rise, leading to decreased caregiving quality and declining health, which further exacerbates caregiver burden^[18]. Especially in the case of long-term caregiving for heart failure patients, some caregivers may not be psychologically prepared, making them more likely to experience emotional fatigue and psychological distress ^[19].

3.1.4 Coping Strategies

The burden experienced by caregivers is closely related to their coping strategies. Positive coping strategies can alleviate the caregiver's burden, while negative coping mechanisms may exacerbate it. Farajzadeh^[20] pointed out that caregivers often lack sufficient preparation before transitioning to their new role. Positive interventions for caregivers can effectively help reduce their caregiving burden, improve caregiving quality, and enhance their health.

3.1.5 Psychological State

Psychological burden is considered one of the major issues for caregivers. More than half (57%) of caregivers report that stress, anxiety, sleep issues, and depression have negatively affected their health^[21]. A cross-sectional study by Tang^[22] revealed that 62.35% of caregivers might show symptoms of anxiety, and 38.83% might be depressed, with anxiety and depression symptoms positively correlated with caregiver burden. Additionally, research shows that caregivers with better psychological health have a lower risk of clinical events (95% CI 0.20-0.84, P = 0.01)^[23]. Therefore, regularly assessing caregivers' psychological state and providing proactive psychological interventions for both patients and caregivers are important for reducing caregiver burden and improving their psychological health.

3.2 Patient's Own Factors

3.2.1 Age, Cardiac Function, and Self-management Level

Research by Wang Zhen^[13] shows that the older the patient and the higher the heart function grade, the greater the caregiver's burden. In contrast, the higher the patient's self-management level, the lighter

the caregiver's burden. This suggests that improving the patient's self-management skills, thereby enabling them to perform more daily self-care tasks, can reduce the caregiver's workload and lower the caregiver's burden, especially when the patient's cardiac function improves.

3.2.2 Depression

Compared to caregivers of non-depressed patients, caregivers of depressed patients experience a higher level of burden. Depression in heart failure patients affects their self-care abilities, and due to cognitive control issues and difficulty in decision-making, they become more dependent on caregivers, thereby increasing the caregiver's burden^[24]. Healthcare professionals should focus on the patient's mental health, alleviate their anxiety, provide more professional psychological support, and enhance the patient's self-care abilities.

3.2.3 Comorbidities

When patients have multiple comorbidities in addition to heart failure, the situation becomes more complex, and caregivers need to deal with more difficult and intricate issues. Especially when caregiving requirements for different diseases conflict, and caregivers lack the relevant knowledge and skills to manage these issues, they feel overwhelmed [13]. Research by Halm et al. [25] also showed that the poorer the patient's health status, the more severe the caregiver's depressive symptoms.

3.2.4 Social Support

Studies show that social support is negatively correlated with caregiver burden, and caregivers who receive more support from family members and professional institutions tend to have more time or energy to care for themselves and the patient, as well as to handle family and social activities. This helps to minimize the caregiver's burden^[26-27]. Currently, due to insufficient medical resources in China, caregiver support mainly comes from family members, specifically in the form of emotional support. Therefore, healthcare professionals should provide more social support to caregivers to alleviate their burden. This can include offering professional information and support to family caregivers in the community, strengthening home-based elderly care services, and providing caregiver support groups^[28].

4. Intervention Strategies

4.1 Timely Intervention Model

Timely intervention, also known as the timing theory^[29], divides the patient care process into five stages: diagnosis, stabilization, preparation, implementation, and adaptation. At each stage, appropriate interventions are provided according to the patient's and caregiver's different needs, to meet the caregiver's demands and alleviate the caregiving burden. Wang Chunxia^[30] developed a demand-oriented intervention program based on timing theory, which effectively improved caregivers' caregiving abilities and reduced their caregiving burden. Tan Yanqing[31] applied family caregiving based on timing theory and successfully improved the psychological state of both patients and caregivers, alleviating caregiving burden. Therefore, intervention strategies based on timing theory are crucial for alleviating caregivers' burdens.

4.2 Dual Disease Management Model

The dual disease management model emphasizes that both the patient and informal caregiver share the responsibility in disease management. It suggests that disease assessment, management behaviors, and psychological health should be addressed on a dual level, not just at an individual level^[32]. Research shows that active dual-response interventions can not only effectively reduce the psychological distress patients experience due to their illness but also alleviate the caregiving burden, particularly the caregiving stress perceived by spouses, thus improving their caregiving abilities^[32]. Yang W^[33] and others implemented a dual disease management intervention for heart failure patients and their caregivers, which included five modules: (1) family involvement, (2) open communication, (3) coping effectiveness, (4) reducing uncertainty, and (5) sharing dual life stories. Measurements of dual coping, bodily perceptions, self-care, and anxiety and depression scales were conducted after 4, 12, and 24 weeks, revealing that dual-care interventions improved the behaviors and health of heart failure patients, reduced caregivers' burdens, and increased perceived social support. A study by G^[34] of 2,122 caregivers found that dual-care interventions benefited caregivers in terms of depression, anxiety,

loneliness, and health-related quality of life. Additionally, research indicates that promoting and maintaining positive social relationships in the caregiver-patient dyad is a promising approach to interventions aimed at reducing the burden on heart failure caregivers^[35]. Vellone^[36] also found that when the relationship between the patient and caregiver is of good quality, caregivers' confidence and participation in self-care improve. Furthermore, when both parties receive appreciation, assistance, confidence, comfort, and emotional support during disease management, the caregiver's burden is effectively alleviated.

4.3 Transition Care Intervention Model

The transition care intervention model refers to a series of nursing interventions designed to maintain the continuity and coordination of care during disease treatment and rehabilitation. This model can effectively improve caregivers' social support and caregiving skills, thereby alleviating their caregiving burden. Zhang Xi [37] implemented transition care interventions for the family caregivers of 240 chronic heart failure (CHF) patients. The intervention included health lectures, video learning, and situational simulations. The results showed that after 5 weeks of intervention, caregivers' burden was significantly reduced, and their social support and caregiving satisfaction levels were increased. Additionally, Liu Linsheng [38] provided comprehensive intervention during the disease transition phase for patients, covering disease knowledge, caregiving skills, psychological counseling, interpersonal relationships, and resource utilization. After the intervention, the caregivers of chronic heart failure patients experienced significant reductions in caregiving burden and increased social support. However, to more comprehensively evaluate the long-term effects of this model, future long-term follow-up studies are needed to verify its impact on caregivers of CHF patients.

4.4 Palliative Care

The palliative care model has played a positive role in alleviating caregivers' psychological burdens and improving patients' quality of life. Studies have shown that implementing palliative care interventions for caregivers of patients with severe heart failure (CHF) can effectively reduce the burden on caregivers and improve the patient's quality of life^[39]. Ng^[40] applied palliative care interventions to heart failure caregivers, focusing on the assessment and management of physical and psychological symptoms, social support, timely management of psychological and survival issues, setting care goals, and discussing treatment preferences and end-of-life issues based on patients' and families' beliefs and values. The intervention was conducted through phone calls and home visits. After two months of intervention, physical, psychological, social, and survival aspects of life quality were significantly improved, and caregivers' burdens during the transition from hospital to home were alleviated. These results suggest that incorporating palliative care concepts not only benefits the patient's physical health but also effectively reduces the caregiver's burden, making it a viable strategy worth promoting.

5. Conclusion and Outlook

Caregivers of elderly heart failure patients often face significant burdens, which not only have long-term negative impacts on their physical and mental health but may also affect the patient's rehabilitation and quality of life. Therefore, reducing caregiver burden is of great importance for improving the patient's quality of life. Caregiver burden often manifests as physical, psychological, and economic stress, especially during hospitalization of CHF patients, where caregivers' needs should be addressed. Healthcare professionals can strengthen psychological assessment and counseling for caregivers, innovate nursing interventions, and establish diverse support systems. Additionally, it is recommended to provide caregivers with continuity of care services between the hospital and home, ensuring that caregivers receive timely assistance as the patient's condition changes. By integrating smart healthcare technologies, providing caregivers with health education on disease knowledge, caregiving skills, and symptom management via online platforms, caregivers' caregiving abilities can be improved, thereby reducing their caregiving burden.

References

[1] Writing Committee Members, ACC/AHA Joint Committee Members. 2022 AHA/ACC/HFSA Guideline for the Management of Heart Failure[J]. J Card Fail, 2022, 28(5): e1-e167.

- [2] Groenewegen A, Rutten FH, Mosterd A, et al. Epidemiology of heart failure[J]. Eur J Heart Fail, 2020, 22(8): 1342-1356.
- [3] CASSIDYL, HILLL, FITZSIMONSD, et al. The impact of psychoeducational interventions on the outcomes of caregivers of patients with heart failure: a systematic review and meta-analysis[J]. International Journal of Nursing Studies, 2021, 114:103806.
- [4] Riegel B. Dickson VV, Lee CS, et al. A mixed methods study of symptom perception in patients with chronic heart failure[J]. Heart Lung, 2018, 47(2):107-14.
- [5] Hanon O, Belmin J, Benetos A, et al. Consensus of experts from the French Society of Geriatrics and Gerontology on the management of heart failure in very old subjects [J]. Archives of cardiovascular diseases, 2021, 114(3): 246-259.
- [6] Yin Rongping, Gu Rong, Hu Anni, et al. Influence of filial piety values on care-giving burden among caregivers of patients with chronic heart failure[J]. Chinese Journal of Modern Nursing, 2019,25(22):2847-2850.
- [7] Toth P P, Gauthier D. Heart failure with preserved ejection fraction: disease burden for patients, caregivers, and the health-care system [J]. Postgraduate Medicine, 2021, 133(2): 140-145.
- [8] Zhu Meihua, Sun Lichun. Influencing factors of psychological detachment and its correlation with caregiver burden in caregivers of cancer patients[J]. Chinese Journal of Modern Nursing, 2018,24(18):2132-2135.
- [9] GRAD J,SAINSBURY P.Problems of caring for the mentally ill at home[J]. Proceedings of the Royal Society of Medicine, 1966, 59(1): 20-23.
- [10] HOENIG J,HAMILTON M W.The schizophrenic patient in the community and his effect on the household[J].Int J Soc Psychiatry, 1966,12(3):165-176.
- [11] Zarit SH, Todd PA, Zarit JM. Subjective burden of husbands and wives as caregivers: a longitudinal study[J]. Gerontologist, 1986, 26(3): 260-266.
- [12] Ghasemi M, Arab M, Mangolian Shahrbabaki P. Relationship between caregiver burden and family functioning in family caregivers of older adults with heart failure [J]. Gerontol Nurs. 2020;46(6):25-33.
- [13] Wang Zhen, Chen Guanran, Dong Yanli. Analysis of burden of family caregivers and its influencing factors in elderly patients with chronic heart failure [J]. Chinese Journal of Modern Nursing, 2019, 25(4): 501-504.
- [14] Wei S, Miranda JJ, Mamas MA, et al. Sex differences in the etiology and burden of heart failure across country income level: analysis of 204 countries and territories 1990-2019[J]. Eur Heart J Qual Care Clin Outcomes. 2023 Nov 2;9(7):662-672.
- [15] ROSENDE-ROCA M, CANABATE P, MORENO M, et al. Sex, Neuropsychiatric Profiles, and Caregiver Burden in Alzheimer's Disease Dementia: A Latent Class Analysis[J]. J Alzheimers Dis, 2022,89(3):993-1002.
- [16] Hu X, Hu X, Su Y, et al. Quality of life among primary family caregivers of patients with heart failure in Southwest China[J]. Rehabil Nurs. 2018;43(1):26-34.
- [17] Hu X, Huang W, Su Y, et al Depressive symptoms in Chinese family caregivers of patients with heart failure: a cross-sectional study [J]. Medicine. 2017;96(13):e6480.
- [18] Nicholas Dionne-Odom J, Hooker SA, Bekelman D, et al. Family caregiving for persons with heart failure at the intersection of heart failure and palliative care: a state-of-the-science review[J]. Heart Fail Rev. 2017;22(5):543-557.
- [19] Metin ZG, Helvacı A. The correlation between quality of life, depression, anxiety, stress, and spiritual well-being in patients with heart failure and family caregivers[J]. Turk J Cardiovasc Nurs. 2020;11(25):60-70.
- [20] Farajzadeh A, Akbarfahimi M, Maroufizadeh S, Et al. Factors associated with quality of life among caregivers of people with spinal cord injury[J]. Occupational Therapy International, 2021,2021:9921710.
- [21] Hayashi E, Mitani H, Murayama H, et al. Characterizing the role of, and physical and emotional burden on caregivers of patients with heart failure: Results from a cross-sectional survey in Japan [J]. Geriatric nursing, 2021, 42(2): 379-385.
- [22] TANG Y, HUA Y, HUANG X, et al. Psychological burden of patients with head and neck cancer undergoing radiotherapy and their family caregivers: a cross-sectional survey[J]. J Multidiscip Healthc, 2023, 16:927-935.
- [23] Bidwell JT, Vellone E, Lyons KS, et al. Caregiver determinants of patient clinical event risk in heart failure[J]. Eur J Cardiovasc Nurs. 2017;16(8):707-714.
- [24] BURTON A M,SAUTTER J M,TULSKY J A, et al. Burden and well-being among a diverse sample of cancer, congestive heart failure, and chronic obstructive pulmonary disease caregivers[J]. J Pain Symptom Manage,2012,44(3):410-420.

- [25] Halm MA, Bakas T. Factors associated with caregiver depressive symptoms, outcomes, and perceived physical health after coronary artery bypass surgery[J]. J Cardiovasc Nurs. 2007 Nov-Dec; 22(6):508-15.
- [26] NEMCIKOVA M,KATRENIAKOVA Z,NAGYOVA I.Social support,positive caregiving experie-nce, and caregiver burden in informal caregivers of older adults with dementia [J]. Front Public Health, 2023, 11:1104250.
- [27] SHOKRGOZAR S,ROUZBEHAN V,ZARE R, et al. Evaluation of patient social support, caregiver burden, and their relationship with the course of the disease in patients with bipolar disorder[J]. Int J Soc Psychiatry, 2022, 68(8): 1815-1823.
- [28] Hu X, Dolansky MA, Hu X, et al. Factors associated with the caregiver burden among family caregivers of patients with heart failure in southwest China[J]. Nurs Health Sci. 2016 Mar;18(1):105-12.
- [29] Cameron Jill I, Gignac Monique A M. "Timing It Right": a conceptual framework for addressing the support needs of family caregivers to stroke survivors from the hospital to the home[J]. Patient Edu Couns, 2008, 70(3):305-314.
- [30] Wang Chunxia, Qian Qian. Effects of family-centered care on negative emotion and quality of life in patients with acute coronary syndrome based on "Timing It Right"[J]. Chinese Journal of Modern Nursing, 2018, 24(25): 3034-3039.
- [31] Tan Yanqing, Liu Xiulan. Observation on the application of family nursing model based on the timing theory in acute myocardial infarction[J]. Chinese Journal of Practical Nursing, 2017, 33 (36): 2814-2818.
- [32] Yu DS, Qiu C, Li PWC, et al. Effects of dyadic care interventions for heart failure on patients' and caregivers' outcomes: A systematic review, meta-analysis and meta-regression[J]. Int J Nurs Stud. 2024 Sep;157:104829.
- [33] Yang W, Cao Y, Li Y, et al. Effectiveness of a family customised online FOCUS programme aimed on building resiliency in dyad relationship to support dyadic illness management in persons with heart failure and their informal caregiver: a randomised clinical trial protocol[J]. BMJ Open. 2022 Jul 27;12(7):e061405.
- [34] G S, Tan WA, Lee ARYB, et al. Behavioral Interventions for the Patient-Caregiver Unit in Patients with Chronic Heart Failure: A Systematic Review of Caregiver Outcomes[J]. J Multidiscip Healthc. 2022 Apr 29;15:921-939.
- [35] Cooney TM, Proulx CM, Bekelman DB. Changes in Social Support and Relational Mutuality as Moderators in the Association Between Heart Failure Patient Functioning and Caregiver Burden[J]. J Cardiovasc Nurs. 2021 May-Jun 01;36(3):212-220.
- [36] VELLONE E,CHUNG M L,ALVARO R,et al.the influence of mutuality on self- care in heart failure patients and caregivers: a dyadic analysis [J].J Fam Nurs,2018,24(4):563-584.
- [37] Zhang X, Sun M, Hu Y, et al. A study on the effect of transitional care intervention in family caregivers of patients with chronic heart failure[J]. Journal of Nursing Administration. 2023, 23(08):608-612.
- [38] Liu, LS, Song D, Fan J. The application effect of the transitional care model in family caregivers of patients with chronic heart failure[J]. World Latest Medicine Information Abstracts. 2019 19(96), 298-300
- [39] Stene GB, Hauken MA, Ahmedzai HH, et al. Integration of palliative rehabilitation in cancer care: a multinational mixed method study[J]. BMC Palliat Care. 2024 Nov 18;23(1):267.
- [40] Ng AYM, Wong FKY. Effects of a Home-Based Palliative Heart Failure Program on Quality of Life, Symptom Burden, Satisfaction and Caregiver Burden: A Randomized Controlled Trial[J]. J Pain Symptom Manage. 2018 Jan;55(1):1-11.