

Review

# Beyond the Heart: Psychological Distress and Caregiver Burden in Heart Failure

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### Background

Heart failure (HF) is a life-limiting syndrome with high morbidity. Although biomedical care has advanced, psychological distress in patients and burden among informal caregivers remain underassessed and undertreated.

### Objective

This review synthesizes evidence on: (i) prevalence, predictors, and trajectories of psychological distress in HF; (ii) the scope and determinants of caregiver burden; (iii) adaptive and maladaptive coping strategies; and (iv) implications for integrated clinical care and policy.

### Methods

A systematic search of PubMed, Scopus, PsycINFO, and Web of Science was conducted using combined terms for HF, psychological distress, caregiver burden, coping, and quality of life. Data extraction and thematic synthesis aligned with review objectives.

### Results

Psychological distress is common in HF. Pooled depression estimates typically range from 20% to 42%, and pooled estimates of anxiety from 15% to 30%, with several reviews reporting wider ranges depending on measurement and setting. Distress is consistently associated with advanced disease severity (New York Heart Association Class III–IV), high symptom burden, and social isolation. Informal caregivers experience significant emotional, physical, social, and financial strain. Higher burden is associated with greater patient severity/depression, caregiver female sex and spousal status, and limited support. Adaptive coping (problem-solving, social support) links to better outcomes; maladaptive strategies (avoidance, rumination) correlate with greater distress and burnout.

### Conclusion

Heart failure care should integrate routine psychosocial assessment, dyadic interventions, and caregiver support. Implementing structured mental health screening, collaborative care models, and respite and navigation services can improve outcomes, enhance quality of life, and sustain caregiving capacity.

## 1. INTRODUCTION

Heart failure (HF) is a global health crisis affecting over 64 million people worldwide, imposing significant clinical, economic, and psychosocial burdens that extend far beyond

cardiac physiology.<sup>1–3</sup> This global health challenge is defined by the heart's inability to maintain adequate circulation, leading to a progressive trajectory marked by high symptom burden, functional decline, and recurrent, often debilitating, hospitalizations, which disrupt patients' lives and

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strain healthcare systems.<sup>4</sup> While monumental strides have been made in pharmacologic and device-based therapies, significantly improving survival rates and slowing disease progression, the psychosocial dimensions of HF experience remain inadequately addressed within standard clinical pathways and routine care models.<sup>5-7</sup> This represents a critical gap in holistic patient management.

Psychological distress, manifesting as symptoms of depression, anxiety, and post-traumatic stress, is not merely an incidental comorbidity but a core component of the HF illness experience.<sup>8-13</sup> This distress is robustly associated with a cascade of adverse outcomes, including poorer adherence to complex medical regimens, decreased engagement in self-care behaviors, increased rates of hospital readmission, elevated healthcare utilization costs, and a higher risk of mortality. Parallel to the patient's struggle is the often-invisible burden shouldered by informal caregivers—typically family members or close friends—who provide essential, unpaid day-to-day support. These caregivers experience high rates of emotional strain, chronic physical exhaustion, profound social restriction, and substantial financial challenges, all of which compromise their own health and well-being.<sup>14-17</sup>

Critically, patient and caregiver well-being are not independent; they are tightly interdependent within a dyadic system.<sup>18,19</sup> The psychological state of one directly influences the health behaviors and outcomes of the other. For instance, a patient's depression can lead to poor self-care, triggering a clinical decompensation that exponentially increases caregiver stress. Conversely, a burned-out caregiver may provide suboptimal support, exacerbating the patient's anxiety and worsening disease management. Despite this intricate interdependence, most contemporary HF care models remain siloed, focusing predominantly on the individual patient's biomedical parameters and failing to systematically assess, acknowledge, or treat this dyadic burden.

Therefore, this review deliberately adopts an integrated biopsychosocial perspective. It moves beyond viewing psychological distress and caregiver burden as isolated individual responses to a chronic medical condition. Instead, it conceptualizes them as interconnected outcomes that are dynamically shaped by a complex interplay of factors: the underlying biological severity and trajectory of the heart disease itself; the individual psychological makeup and coping resources of both patient and caregiver; the interpersonal dynamics, communication patterns, and quality of the relationship within the dyad; the structure, accessibility, and responsiveness of formal healthcare and support systems; and the broader socioeconomic context, including financial resources, social capital, and cultural norms surrounding illness and caregiving. This systemic lens is essential for developing effective, person- and family-centered interventions.

### 1.1. OBJECTIVES

Despite a growing body of literature and increased clinical recognition of psychosocial contributors to HF outcomes, a comprehensive synthesis of the interplay between patient psychological distress and caregiver burden remains relatively limited. This review aims to bridge this gap by providing a holistic synthesis. Its specific objectives are to: (i) synthesize the current evidence on the epidemiology, key predictors, and clinical correlates of psychological distress in adults with HF; (ii) characterize the multifaceted nature,

measurable magnitude, and primary domains (emotional, physical, social, financial) of burden experienced by their informal caregivers; (iii) examine the spectrum of coping mechanisms—both adaptive and maladaptive—employed by patients and caregivers, and evaluate how these strategies mitigate or exacerbate distress within the dyad; and (iv) translate these findings into a set of clear, actionable, and evidence-informed recommendations aimed at clinicians, healthcare systems, and policymakers to foster the integration of comprehensive psychosocial care into standard HF management.

### 1.2. SIGNIFICANCE OF THE RESEARCH

Heart failure management stands at a pivotal crossroads. Holistic, effective, and sustainable care necessitates a fundamental paradigm shift from an exclusively organ-centric, biomedical model to a comprehensive biopsychosocial model that explicitly acknowledges and addresses the psychological and social dimensions of illness.<sup>20-23</sup> The persistent failure to integrate this perspective into routine care has tangible, negative consequences: it compromises patient clinical outcomes and quality of life, jeopardizes the physical and mental health (termed as specific, measurable manifestations of distress) of the essential informal caregiver workforce, and ultimately threatens the economic and practical sustainability of home-based care, which is the cornerstone of HF management.<sup>24-26</sup> This review plays a crucial role by integrating, critiquing, and synthesizing existing evidence on patient suffering, caregiver burden, and their mediating coping processes. It aims to inform and educate clinicians—including cardiologists, primary care physicians, nurses, and mental health professionals—about the critical psychosocial facets of HF. It seeks to guide researchers by identifying persistent gaps in the literature and proposing prioritized directions for future inquiry. Furthermore, it intends to provide policymakers and healthcare administrators with a consolidated evidence base to advocate for and design system-level changes, such as revised payment models and integrated care pathways. Ultimately, the goal is to accelerate the implementation of truly person- and family-centered interventions that can improve outcomes, enhance quality of life for both patients and caregivers, and build more resilient care dyads and families facing the challenges of HF.

## 2. METHODS

This review employed a narrative review methodology to synthesize current evidence on psychological distress and caregiver burden in HF. This methodological approach was selected as the most appropriate for the review's aims. It combines the rigor and reproducibility of a systematic literature search strategy with the flexible, integrative thematic synthesis characteristic of narrative reviews. This is particularly suitable for examining a complex, multidisciplinary field like psychosocial oncology, where evidence originates from heterogeneous study designs (e.g., randomized trials, longitudinal cohorts, cross-sectional surveys, qualitative studies), utilizes a wide array of measurement tools, and involves diverse patient populations and healthcare contexts. A formal meta-analysis, while valuable for generating precise pooled statistical estimates, was deliberately not conducted. This decision was based on the anticipated and observed high degree of methodological heterogeneity

across studies—particularly in the instruments used to measure psychological constructs (e.g., different depression scales with varying cut-offs), the characteristics of sampled populations (varying in age, HF etiology, comorbidity, and cultural background), and the settings of care (primary, secondary, tertiary; different countries and health systems). Such heterogeneity would significantly limit the clinical interpretability and validity of any single pooled estimate, making a narrative synthesis a more robust and insightful approach for this comprehensive overview.

A systematic literature search was conducted in the following electronic databases: PubMed, Scopus, PsycINFO, and Web of Science. The search strategy utilized the keywords: “heart failure,” “cardiac failure,” “psychological distress,” “depression,” “anxiety,” “caregiver burden,” “family caregiver,” “informal care,” “coping,” “resilience,” and “quality of life.” The search was restricted to studies on human adults and published in English. For the purposes of this review, conceptual clarity is paramount. Therefore, “psychological distress” is operationally defined and used as an umbrella term encompassing the commonly co-occurring symptoms of depression (e.g., low mood, anhedonia), anxiety (e.g., excessive worry, nervousness), and post-traumatic stress (e.g., hyperarousal, intrusion related to cardiac events). “Caregiver burden” is defined as the multidimensional strain—encompassing emotional (e.g., stress, depression), physical (e.g., fatigue, health decline), social (e.g., role strain, isolation), and financial (e.g., out-of-pocket costs, lost income) domains—experienced by an informal caregiver as a direct result of their caregiving responsibilities. Inclusion criteria were: (i) focus on adult populations ( $\geq 18$  years) related to HF (patients/caregivers); (ii) inclusion of patient and/or caregiver psychosocial outcomes; (iii) original research articles, systematic reviews, or meta-analyses published in peer-reviewed academic journals. Exclusion criteria included: (i) studies focusing exclusively on acute HF without a chronic HF context; (ii) studies involving pediatric populations ( $<18$  years); (iii) editorials and conference abstracts (due to lack of peer-reviewed detail); and (iv) studies not published in English. Titles and abstracts were screened for relevance by the primary author, followed by a full-text review of potentially eligible articles against the inclusion/exclusion criteria. Data extraction focused on the study design, sample characteristics, key findings on distress/burden prevalence, predictors, coping strategies, and intervention outcomes. The synthesis was not a simple aggregation of findings but was structured thematically to align with the study objectives, enabling the integration of evidence across study types to build a coherent narrative.

### 3. RESULTS

#### 3.1. PREVALENCE OF PSYCHOLOGICAL DISTRESS IN PATIENTS WITH HEART FAILURE

Patients with HF consistently exhibit markedly elevated rates of depression and anxiety when compared to age-matched populations.<sup>27–30</sup> The sheer prevalence of these conditions underscores their significance. Pooled estimates suggest that clinically significant depressive symptoms affect approximately 20% to 42% of HF patients, while anxiety symptoms are prevalent in about 15% to 30% of this population.<sup>31–37</sup> It is crucial to note, however, that these are typical ranges; some meta-analyses report even wider variations, a discrepancy primarily attributable to

methodological heterogeneity. This heterogeneity includes the use of different screening and diagnostic instruments, varying severity thresholds for defining a “case,” differences in sample characteristics, and cultural factors influencing the reporting of psychological symptoms. Post-traumatic stress symptoms, often related to traumatic experiences, such as sudden cardiac arrest, implantable cardioverter-defibrillator (ICD) shocks, or intensive care unit admissions, are reported in roughly 10% of patients and have been associated with increased HF hospitalizations.<sup>38</sup> Beyond these core disorders, sleep disorders (including insomnia and sleep-disordered breathing) and severely impaired health-related quality of life are nearly ubiquitous and show strong, bidirectional correlations with psychological distress. It is therefore imperative to interpret any single prevalence figure with caution, recognizing that the true burden is influenced by a complex interplay among disease factors, measurement approaches, and clinical and cultural settings.

The development and persistence of psychological distress in HF are not random but are linked to a constellation of identifiable factors, which can be broadly categorized:

- Disease-related factors: Higher New York Heart Association (NYHA) class (III–IV), frequent hospitalizations ( $\geq 2$ /year), reduced functional capacity, ICD shocks, and multimorbidity (e.g., chronic obstructive pulmonary disease, renal disease).<sup>39–48</sup>
- Psychosocial factors: Social isolation, low perceived social support, socioeconomic disadvantage, and a history of mental health disorders.<sup>49–53</sup>
- Symptom burden: Dyspnea, fatigue, pain, and sleep disturbances show strong, dose–response associations with depressive and anxious symptoms.<sup>54–57</sup>

Figure 1 illustrates the prevalence of key psychological symptoms among HF patients, synthesized from recent analyses.<sup>1,9,31,58–62</sup> In summary, psychological distress is a prevalent comorbidity in HF, closely tied to both biomedical disease markers and psychosocial vulnerability factors. Addressing distress in HF patients requires a comprehensive approach that targets not only the underlying cardiac disease but also the psychological, social, and behavioral factors that contribute to emotional suffering.

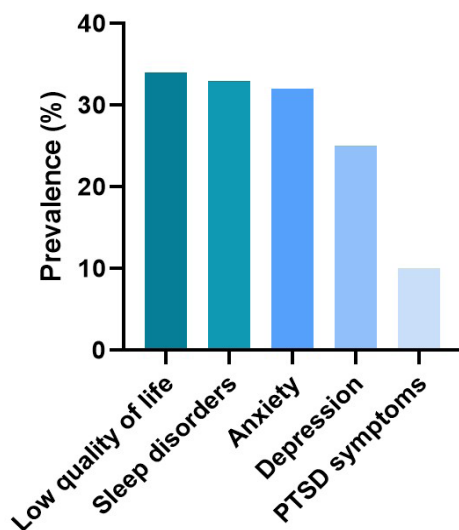
#### 3.2. CAREGIVER BURDEN AMONG CAREGIVERS OF PATIENTS WITH HEART FAILURE

The role of the informal caregiver is universally acknowledged as pivotal to the successful management of HF at home, yet this essential role is associated with a significant and multifaceted burden.<sup>63–66</sup> Caregivers, who are usually spouses or adult children with a mean age often over 60 years, report high levels of strain across several distinct but interrelated domains:

- Emotional burden (defined as caregivers’ subjective distress from caregiving tasks): Feelings of stress, helplessness, constant worry about the patient’s condition, anxiety, and clinically significant depression are common.<sup>67,68</sup> Quantitatively, studies indicate that up to 78% of HF caregivers report experiencing notable stress, and approximately 40% exhibit symptoms meeting thresholds for depression—a rate comparable to, or sometimes even higher than, that observed in the patients themselves.<sup>69,70</sup>
- Physical burden: Chronic sleep deprivation due to

caregiving duties (e.g., nighttime symptom monitoring), persistent fatigue that impairs their own daily functioning, body aches, and general deterioration of personal health are frequently reported.<sup>71,72</sup>

- **Social burden:** Caregiving responsibilities consume time and energy, often leading to strained relationships with the patient (e.g., conflict over illness management), reduced contact with friends, and withdrawal from social and recreational activities, affecting over 50% of caregivers and fostering profound isolation.<sup>73</sup>
- **Financial burden:** Costs related to care, including travel, medications, and specialized dietary needs, as well as lost income from reduced work hours, create significant financial strain.<sup>74-76</sup> Financial burden is particularly acute for low-income caregivers and those without health insurance, who may struggle to afford essential care supplies or forego their own medical care to prioritize the patient.



**Figure 1. Prevalence of psychological symptoms in patients with heart failure (HF) (%).** This figure synthesizes pooled prevalence rates of common psychological symptoms reported in the HF literature, highlighting that impaired health-related quality of life and sleep disturbances are the most prevalent, followed by clinically significant anxiety and depression. These data underscore the high psychosocial burden in HF, which often coexists with physical symptoms and warrants integrated assessment in clinical practice. Abbreviation: PTSD: Post-traumatic stress disorder.

Caregiver burden is not static; it dynamically intensifies in tandem with increased patient illness severity, functional decline, and the frequency of health crises.<sup>77</sup> Its impact, however, is moderated by several key factors. Caregivers who are female, in a spousal relationship with the patient, caring for patients with advanced disease or cognitive impairment, and those who report low levels of perceived support—whether from other family members, friends, or the formal healthcare systems—consistently report higher levels of burden and worse mental health outcomes.<sup>78-81</sup> The determinants of caregiver depressive symptoms themselves are multifactorial and complex. One illustrative study found that 54% of the variance in these symptoms could be explained by a combination of factors: the method of

payment for the patient's treatment, recent patient hospital readmissions ( $\leq 3$  months), caregiving duration, overall burden levels, and the use of both adaptive and maladaptive coping strategies.<sup>82</sup> This underscores that burden is not a simple function of patient health but is filtered through the caregiver's resources and responses. Furthermore, a worsening patient's NYHA functional class is directly associated with measurable increases in caregiver burden across all domains—physical, emotional, and social.<sup>83</sup> Caregivers identified through screening as “high-risk”—often based on low social support, high initial burden, or poor coping skills—report greater subsequent levels of burden and depression, highlighting a subgroup in urgent need of targeted intervention.<sup>84,85</sup>

Crucially, caregiver mental health is not an isolated outcome; it is a strong predictor of patient outcomes. Studies demonstrate that caregiver depression and burden are associated with worse patient medication adherence, poorer diet compliance, and higher rates of emergency department visits and unplanned hospitalizations.<sup>86-88</sup> This dyadic linkage is quantified in previous studies. For example, one study reported that elevated caregiver burden correlates with significantly worse patient physical health outcomes (64.5% vs. 35.5%).<sup>89</sup> Figure 2 outlines the primary domains and reported prevalence of burden among HF caregivers as synthesized from the associated analyses.<sup>69,74,89</sup> Taken together, caregiver burden in HF is a multidimensional construct that escalates predictably with patient disease progression. It is deeply intertwined with, and can be exacerbated or buffered by, the caregiver's own psychosocial resources, coping capacities, and the support systems (or lack thereof) surrounding them. This establishes the care dyad, not the individual patient, as a critical unit for clinical assessment and intervention.

### 3.3. COPING STRATEGIES OF PATIENTS AND CAREGIVERS

Coping processes—the cognitive and behavioral efforts used to manage external and internal demands appraised as taxing or exceeding one's resources—substantially modulate the impact of HF-related stress for both patients and informal caregivers.<sup>90-92</sup> Consistent with the influential transactional model of stress and coping, coping strategies are commonly grouped into problem-focused strategies (aimed at managing or altering the stressor itself), emotion-focused strategies (aimed at regulating the emotional response to the stressor), and avoidance-focused strategies (aimed at evading the stressor or its associated feelings).<sup>93,94</sup> Importantly, coping in the context of a chronic illness like HF is dynamic, context-dependent, and dyadic-oriented. The strategies employed by one member of the dyad (e.g., a patient denying symptoms) can directly influence the stress appraisal, coping choices, and well-being of the other (e.g., increasing caregiver frustration and anxiety), creating a reciprocal feedback loop within the care partnership.

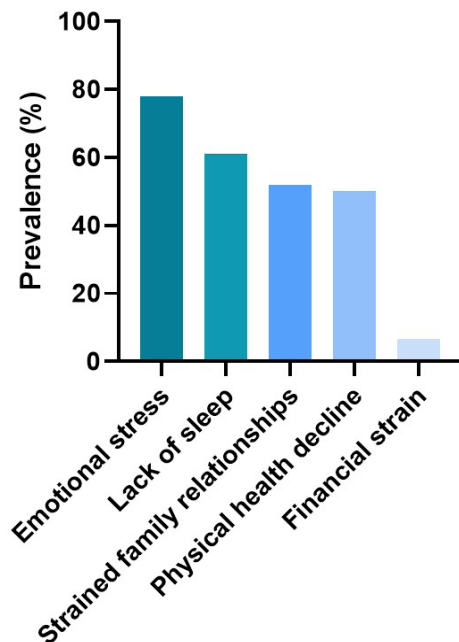
#### 3.3.1. ADAPTIVE COPING STRATEGIES

Adaptive coping strategies support effective illness management and emotional regulation, reducing the negative impact of heart failure on both patients and caregivers.

- **Problem-focused coping:** Includes active, instrumental engagement with the illness. For patients, this includes

vigilant symptom monitoring and management, strict adherence to medications and diet, timely medical care-seeking during exacerbations, proactive information-seeking about HF, engaging in advance care planning, and establishing structured self-care routines.<sup>95-100</sup> For caregivers, it involves learning caregiving skills, efficiently managing appointments and medications, and problem-solving daily challenges. Across numerous studies, greater use of problem-focused coping is consistently associated with lower levels of depressive symptoms, improved health-related quality of life, enhanced self-care confidence and maintenance, and fewer HF-related hospitalizations for patients.<sup>101-103</sup>

- **Emotion-focused coping:** Includes efforts to manage the emotional distress caused by HF. This includes practices like mindfulness meditation and acceptance-based therapies, relaxation training (e.g., deep breathing), positive reappraisal (finding meaning or silver linings), spiritual or religious engagement, and actively seeking emotional support from family, peers, or clinicians.<sup>49,104-106</sup> These strategies are generally linked to reduced anxiety and depressive symptoms, better dyadic adjustment (improved relationship quality and teamwork), and significantly improved caregiver well-being and sense of competence.<sup>107-109</sup> A key dyadic insight is that adaptive coping in one member can benefit both; for example, a caregiver's use of mindfulness may reduce their own reactivity, allowing them to provide calmer, more effective support, which in turn lowers the patient's distress.



**Figure 2. Domains and relative prevalence of burden among informal caregivers of heart failure (HF) patients.** This bar chart illustrates both the multidimensional nature and the relative frequency of burden experienced by HF caregivers. Emotional exhaustion emerges as the most widespread domain, reflecting the chronic emotional toll of caregiving. These findings emphasize that caregiver burden is not only common but also multifaceted, necessitating support strategies that address emotional, physical, social, and financial strains.

### 3.3.2. MALADAPTIVE COPING STRATEGIES

In contrast, maladaptive coping strategies exacerbate stress and are associated with worse psychological health and disease outcomes.

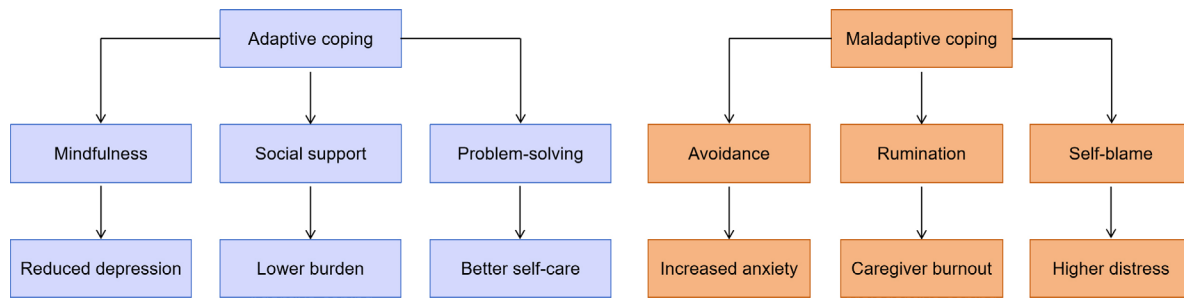
- **Avoidance and behavioral disengagement:** Examples include patients delaying or avoiding necessary medical appointments, skipping medications, or psychologically denying the severity of their illness. Caregivers may avoid discussing prognosis or future care needs. These strategies are strongly associated with poorer overall disease management, more frequent clinical exacerbations, and higher levels of psychological distress.<sup>110-113</sup>
- **Rumination:** Repetitive negative thinking about symptoms, disease prognosis, or caregiving challenges is another maladaptive pattern. It strongly correlates with elevated anxiety and depression and is a known precursor to caregiver burnout, a state of emotional, physical, and mental exhaustion.<sup>114-116</sup>
- **Self-blame and substance use:** Patients or caregivers engaging in self-reproach for the illness or reliance on alcohol/sedatives to manage distress experience worse mood symptoms, poorer quality of life, and reduced treatment adherence.<sup>117-119</sup>

### 3.3.3. MODERATORS AND CONTEXTUAL CONSIDERATIONS

The use and effectiveness of coping strategies are shaped by multiple demographic, relational, and contextual factors.

- **Gender differences:** Several studies suggest women (both as patients and caregivers) may report more rumination and emotion-focused strategies like seeking support, while men may show greater behavioral disengagement. These patterns are likely influenced by deeply ingrained societal role expectations and the specific context of the caregiving relationship.<sup>120-122</sup>
- **Caregiver risk profiles:** High-risk caregivers report lower social support, weaker problem-solving skills and family functioning, and greater burden.<sup>84</sup> Caring specifically for patients with advanced HF symptoms is independently associated with increased caregiver strain and poorer physical health, underscoring the need for stage-specific, targeted support interventions.<sup>123</sup>
- **Coping style correlates:** An anxious preoccupation coping style, characterized by hypervigilance and catastrophic thinking, is linked to poorer psychosocial and spiritual outcomes for the caregiver.<sup>124</sup>
- **Rurality:** Geographic isolation and limited access to specialized medical services, support groups, and respite care in rural areas significantly worsen caregiver outcomes. Here, technology-mediated solutions, such as telehealth consultation networks, digital peer support, and mobile health applications, show promise in mitigating these geographic and access barriers.<sup>125</sup>

**Figure 3** summarizes the common adaptive and maladaptive coping strategies and their general associations with outcomes for HF patients and caregivers. Overall, coping is a critical mediator and potentially modifiable target in the HF stress process. Adaptive strategies serve as vital protective factors, fostering resilience and better dyadic management, while maladaptive strategies act as potent exacerbating



**Figure 3. Adaptive and maladaptive coping strategies in heart failure dyads and their associated outcomes. This comparative table summarizes how different coping approaches are generally associated with psychosocial and health outcomes in patients and caregivers. Adaptive strategies (e.g., problem-solving, mindfulness) are associated with better emotional regulation and self-care, whereas maladaptive strategies (e.g., avoidance, rumination) correlate with heightened distress and poorer illness management. The contrast reinforces the importance of promoting adaptive coping within dyadic interventions.**

factors, deepening distress and dysfunction for both members of the care partnership. This underscores the importance of interventions that build coping skills.

### 3.4. THE ROLE OF ORGANIZATIONAL AND SOCIAL SUPPORT

Beyond individual and dyadic coping, the perception and reality of support from external systems play a decisive role in buffering psychological distress for patients and alleviating caregiver burden.<sup>126-128</sup> Perceived support from empathetic, communicative healthcare providers and a well-coordinated health system can itself be therapeutic. Evidence-informed organizational supports that have demonstrated benefit include:

- Structured caregiver education and skills training programs, which systematically teach disease management, symptom recognition, and care techniques, leading to increased caregiver self-efficacy, competence, and reduced subjective burden.<sup>129,130</sup>
- Access to respite care services, which provide planned, temporary relief from caregiving duties, is crucial for preventing burnout, allowing caregivers to attend to their own health, and helping to sustain long-term caregiving capacity.<sup>131-133</sup>
- Integrated care models that embed mental health professionals (e.g., psychologists, social workers) directly within cardiology or HF management teams are highly effective. These models facilitate the co-management of psychosocial and cardiac needs through regular team communication, shared care plans, and warm handoffs, breaking down the traditional mind-body care divide.<sup>134-136</sup>
- Telehealth and digital interventions—such as remote patient monitoring systems with integrated psychosocial check-ins, supportive mobile applications for symptom tracking and education, and virtual peer support groups—are expanding access to support. They are particularly valuable for reaching populations in rural or underserved settings where in-person services are scarce.<sup>137-139</sup> For example, a telehealth early palliative care intervention for family caregivers of patients with advanced HF has been shown to significantly improve caregiver quality of life and mood.

Conversely, systemic barriers actively contribute to distress and burden. Fragmented care, poor communication, and lack of care coordination among different healthcare providers and teams, and the systemic failure to recognize, document, or valorize the essential contributions of informal caregivers are all associated with higher levels of frustration, anxiety, and strain for the dyad.<sup>140,141</sup> At the more intimate interpersonal level, perceived social support from family and friends, while generally reported as high, tends to be lower among specific vulnerable subgroups: male caregivers, individuals living alone with limited natural networks, those under significant financial strain, and those caring for patients with more severe heart disease, who may also withdraw socially.<sup>142,143</sup> This highlights that both formal system design and informal social network strength are critical, modifiable determinants of the dyad's psychosocial well-being.

## 4. DISCUSSION

This study indicates that psychological distress in patients and the multidimensional burden on their informal caregivers are not peripheral or secondary concerns in HF; they are core, defining features of the illness experience for millions of families worldwide.<sup>144</sup> Both phenomena are consistently associated with a triad of negative consequences: problems with adherence to life-sustaining treatments, increased utilization of high-cost healthcare services (especially hospitalizations), and worse long-term clinical outcomes, including higher mortality. The relationship is fundamentally bidirectional and dyadic. It is important to frame this cautiously: while the evidence for association is strong, the predominance of cross-sectional data in the literature limits definitive causal conclusions. Nevertheless, the logical and observed pathways are clear. Patient depression and anxiety can directly undermine the motivation, energy, and cognitive clarity needed for effective self-care (e.g., fluid restriction, daily weighing), precipitating avoidable clinical deterioration and hospitalizations, which in turn dramatically heightens caregiver strain and worry. In a reciprocal cycle, a caregiver who is emotionally exhausted, depressed, or overwhelmed may become less patient, less attentive, or less effective in providing the practical and emotional

support the patient needs, inadvertently further compromising patient outcomes. This vicious cycle underscores the clinical and ethical imperative for care models that move beyond the individual patient to incorporate routine dyadic assessment and family-centered care.

#### 4.1. A DYADIC INTERACTION FRAMEWORK FOR HEART FAILURE PATIENTS AND CAREGIVERS

A deeper synthesis of the evidence reveals that patient and caregiver experiences are not merely parallel tracks running side-by-side; they are fundamentally interwoven within a single, dynamic dyadic system, best understood through a biopsychosocial systems lens. Beyond psychosocial processes, emerging multilevel models further conceptualize distress and burden as embedded within interacting neurobiological and physiological systems (e.g., stress-response axes, neural circuits of empathy and regulation), which reciprocally influence behavioral and health outcomes across the dyad. Patient factors (biological: NYHA class IV; psychological: anxiety) directly impact caregiver factors (emotional burden: worry; social role: constant vigilance), which in turn feed back to influence patient factors (biological: reduced adherence worsens cardiac function). For instance, a patient's use of avoidance coping (e.g., denying worsening edema) may lead to missed medications and delayed care-seeking, triggering a severe health crisis (acute pulmonary edema) that overwhelms the caregiver's capacity, inducing a crisis of confidence and burnout. Conversely, a caregiver experiencing burnout may emotionally withdraw or become irritable, reducing the quality of instrumental and emotional support, which exacerbates the patient's feelings of depression, loneliness, and helplessness, creating an environment hostile to effective self-management. This interdependency powerfully underscores the fundamental limitation of interventions that target only the patient or the caregiver in isolation. A systems perspective emphasizes that distress and burden are not simply individual deficits or weaknesses. They are context-dependent processes that emerge from and are sustained by multiple interconnected factors: the biological disease process, the psychological resources of two individuals, the dyadic relationship dynamics, the structure of the healthcare system they navigate, and the socioeconomic resources available to them. Future care models must therefore explicitly conceptualize the "HF dyad" as the essential unit of intervention. This requires assessing their shared stressors, improving their communication and collaborative problem-solving skills, and providing support that acknowledges their intertwined fates.

Translating this framework into practice is both feasible and strongly warranted. A foundational step is the integration of brief, validated psychosocial screening into every routine HF encounter—at diagnosis, during annual reviews, and especially after major clinical events like hospitalization or an ICD shock. Recommended tools include the Patient Health Questionnaire-9 (PHQ-9) and Generalized Anxiety Disorder-7 (GAD-7) (or Hospital Anxiety and Depression Scale [HADS]) for patients, and the Zarit Burden Interview or Caregiver Strain Index for caregivers, with stepped responses guided by symptom severity. Tailored interventions should follow screening: for patients, cognitive-behavioral therapy and mindfulness-based approaches show benefit; for caregivers, skills training, peer support, and respite services are key components.<sup>145-147</sup> Embedding

these elements within collaborative HF care pathways has demonstrated improved outcomes, enhanced quality of life, and a greater sustainability of the home-based caregiving arrangement.

#### 4.2. LIMITATIONS AND FUTURE RESEARCH DIRECTIONS

The current evidence base has notable limitations: numerous studies are cross-sectional, limiting causal inference; measurement tools and thresholds vary widely, complicating comparisons; and samples often underrepresent racially/ethnically diverse and socioeconomically disadvantaged populations. This lack of representativeness raises serious concerns about the equity, generalizability, and cultural relevance of current findings and the interventions developed from them. These populations often face compounded barriers to care and may experience unique psychosocial stressors, meaning their needs may be both greater and different. To address these gaps, future research should prioritize:

- Longitudinal, dyadic studies to track the same patient-caregiver pairs over months or years are urgently needed. Such studies can elucidate the co-evolution of patient distress and caregiver burden across the HF trajectory, identify critical transition points (e.g., after first hospitalization), and clarify temporal and causal precedence within the dyadic relationship.
- Randomized controlled trials evaluating integrated, dyadic psychosocial interventions that are pragmatically embedded within real-world HF service delivery. These trials should be powered to detect effects not only on patient clinical outcomes (e.g., hospitalizations, mortality) but equally on caregiver outcomes (burden, depression, quality of life) and should include rigorous cost-effectiveness analyses.
- Qualitative and mixed-methods research focused on capturing the lived experiences, values, and preferences of underserved and minority populations. This research is essential to inform the development of culturally tailored, acceptable, and effective interventions that address specific contextual barriers and strengths.
- Health services research that moves beyond efficacy to assess real-world strategies for scaling up successful psychosocial care models. This includes studying workflow training needs, workflow integration, sustainable financing mechanisms (e.g., through value-based payment), and the use of digital tools to increase reach and fidelity.

### 5. IMPLICATION AND FURTHER SUGGESTION

#### 5.1. FOR CLINICAL PRACTICE

The growing evidence linking psychological distress to adverse outcomes in heart failure necessitates its integration into routine clinical care. The following recommendations outline key strategies for identifying and addressing the psychosocial needs of both patients and their caregivers.

- Implement routine screening for psychological distress in all adults with HF at baseline, at least annually, and after major clinical events (e.g., hospitalization, ICD shocks) using validated tools (e.g., PHQ-9 or HADS for depression/anxiety; GAD-7 for anxiety; brief sleep

- screening). Use measurement-based care with clear referral and follow-up pathways (strong evidence).<sup>148</sup>
- (ii) Routinely assess caregiver burden and well-being during patient visits using brief, validated instruments (e.g., Zarit Burden Interview-Short Form, Caregiver Strain Index, PHQ-2/9, GAD-7). Document caregiver identity and needs in the electronic health record and provide targeted referrals (strong evidence).<sup>54</sup>
  - (iii) Integrate mental health professionals (e.g., psychologists, clinical social workers) into multidisciplinary HF teams to deliver collaborative, stepped care, including brief cognitive behavioral therapy (CBT)/problem-solving therapy, motivational interviewing, and sleep interventions, with in-person and telehealth options (moderate evidence).<sup>149</sup>
  - (iv) Develop and deliver structured caregiver education and support programs that include HF self-management, symptom monitoring, medication management, communication skills, stress-management techniques (e.g., CBT, mindfulness), crisis planning, and navigation to respite and community resources. Offer peer support and culturally/linguistically appropriate materials (moderate evidence).<sup>150</sup>

## 5.2. FOR HEALTH POLICY

Realizing comprehensive psychosocial support for heart failure dyads requires systemic changes that extend beyond individual clinical encounters. Policy-level interventions are essential to create an enabling environment that values, reimburses, and sustains caregiver-inclusive care models.

- (i) Align payment models to reimburse psychosocial assessment and interventions for patients and caregivers within HF care bundles and value-based contracts; enable billing for caregiver assessment and education; ensure telehealth parity for behavioral health services (emerging evidence/policy innovation).<sup>151</sup>
- (ii) Enact policies that recognize and support informal caregivers, including paid family leave, workplace flexibility, caregiver training benefits, and targeted tax credits or stipends; require caregiver identification and consent-to-contact in health records (policy imperative).<sup>152</sup>
- (iii) Fund the development, rigorous evaluation, and dissemination of evidence-based digital and hybrid psychosocial supports for HF dyads, with standards for accessibility, multilingual content, privacy, and interoperability with clinical systems (research and development priority).

## 5.3. FOR RESEARCH

Despite significant advances in understanding the psychosocial dimensions of heart failure, critical knowledge gaps remain. Future research must prioritize rigorous, dyadic-focused investigations to establish the efficacy, implementation strategies, and economic value of integrated psychosocial interventions.

1. Conduct large, multicenter randomized and pragmatic trials of dyadic interventions (e.g., collaborative care, CBT/problem-solving, mindfulness-based approaches, caregiver skills training), powered for patient outcomes (health-related quality of life, adherence, hospitalizations, mortality), caregiver outcomes (burden, mood,

quality of life), and cost-effectiveness (high priority).<sup>153</sup>

2. Investigate the long-term economic impact of integrating psychosocial care on utilization and costs (e.g., hospital readmissions, emergency visits), including budget impact and return-on-investment analyses across diverse care settings (high priority).<sup>154</sup>
3. Develop, validate, and implement brief dyadic assessment tools suitable for busy clinics and remote monitoring; establish psychometric properties, actionable cut-points, and minimal clinically important differences; integrate tools into electronic health records with decision support (methodological priority).<sup>155</sup>

## 6. CONCLUSION

In summary, HF care must adopt a biopsychosocial model that addresses both the “heart and mind.” Psychological distress and caregiver burden should be understood not as unfortunate add-ons but as system-level phenomena that emerge from dynamic, reciprocal interactions among biological disease processes, individual psychological and cognitive responses, dyadic interpersonal regulation and communication, and the broader societal and health-care support structures (or lack thereof) surrounding the patient-caregiver unit. Coordinated action by clinicians, health systems, and policymakers is essential. This action must focus on systematically recognizing, routinely assessing, and effectively treating psychological distress and caregiver burden as standard components of high-quality HF care. By doing so, we can meaningfully improve clinical and person-centered outcomes, enhance the quality of life, and safeguard the sustainability of informal care.

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## CONFLICT OF INTEREST

The authors declare no competing interests.

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## ETHICS APPROVAL AND CONSENT TO PARTICIPATE

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