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Caregivers' contributions to heart failure self-care: An updated systematic review

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Introduction

In 2011 a team of Canadian and U.S. nurse scientists met to address the existing need to measure the contributions of informal, unpaid caregivers (family and friends) to patient's heart failure (HF) self-care. ¹ As part of that initiative, a systematic review of the literature was conducted to establish the state of the science and identify items for the instrument, The Caregiver Contribution to Heart Failure Self-care (CACHS). ^{1,2} A systematic review paper, titled *Caregivers' contributions to heart failure self-care: A systematic review* was published in 2015. ²

At the time of the search and selection process for the systematic review (2012), the HF self-care caregiving literature was in its infancy with only 40 papers which directly measured caregivers contributions in quantitative studies or interviewed them in qualitative studies. ² The 2015 review identified 22 unique activities which were then linked to the three domains of the middle-range Theory of Self-care of Chronic Illness: self-care maintenance, monitoring, and management. Activities were synthesized into two broad caregiving categories, direct activities which were caregiving "hands on" activities such as blood pressure monitoring or weighing the patient or indirect activities which were caregiving "hands off" activities such as system navigation or interpersonal skills. ²

However, the search upon which the paper was based was conducted in September of 2012. There has been a significant body of work on HF caregiving since that time and recent guidelines support use of mechanical circulatory support, telehealth, and informal caregivers^{3,4} all suggesting a need to update the original paper. The purpose of this current paper is to update the 2015 systematic review of the empiric literature on informal, unpaid caregivers' contributions to HF patients' self-care. We address three research questions in this updated review:

1. What specific activities do informal caregivers of adults with HF take part in related to HF self-care?
2. Have the activities (or their measurement) that informal caregivers of adults with HF take part in related to HF self-care changed over time since the 2015?
3. What are the gaps in the science?

Methods

In keeping with the purpose, as far as possible, we followed the methodology of the 2015 paper. This included using Preferred Reporting Items for Systematic Reviews and

Meta-Analyses (PRISMA) checklist and flow diagram,^{5,6} using similar databases (albeit updated) and search terms, benchmarking activities using the middle-range Theory of Self-care in Chronic Illness,^{7,8} and evaluating quality using the Critical Appraisal Skills Program (CASP) checklists appropriate to the particular method of the paper.⁹ The current protocol was registered with PROSPERO (CRD42023400689) on 2/28/23.

Eligibility criteria

Studies were included in this review if they involved an informal, unpaid caregiver of an adult with HF (≥ 18 years of age) either as the outcome variable or as a measured unit in a quantitative study (IV or DV) or as a participant in a qualitative study. Only human studies, in peer reviewed, English-language journals, published in 2012 or later were included. All papers published in 2012 were examined separately and any papers already included in the 2015 paper (n=4) were excluded from this paper. Studies were also excluded if they included paid caregivers, mechanical circulatory support devices (as these create unique caregiving experiences), mixed diagnoses where it was difficult to determine HF-specific results (i.e., multimorbidity without specifying HF activities), meta-analyses, systematic reviews, case reports, protocols, psychometric papers, opinion pieces, and editorials or letters to the editors. A subsequent judgement was made by the team to exclude papers that used caregiving scales exclusively as these papers provided summative domain scores rather than data on specific activities thus precluding answering our research questions.

Information sources

Search strategies were developed with the assistance of a health sciences librarian with review expertise using a systematic process of identifying and testing terms. Comprehensive strategies, including both index and keyword methods, were devised and run in PubMed, CINAHL, Embase, and Cochrane CENTRAL. To minimize the risk of missing important records, only necessary filters were used (English language, publication date). Because the volume of literature has expanded substantially since the initial review was published, it was necessary to modify the previous search strategy to exclude results using specific subject terms and keywords. These terms were carefully evaluated to ensure that search strategy sensitivity was not compromised. Search strategies were finalized in January 2023.

Search strategy

The full PubMed strategy is provided as an example (see Box 1); all database search strategies are available in Supplemental Materials A.

Selection process

Prior to selecting studies, the PI conducted extensive training for the team (total 6 hours) on both title and abstract screening and full text screening. Training preparation included developing screening spreadsheets and a priori decision rules.

Studies yielded by the search were exported from EndNote to Excel and the inclusion and exclusion criteria added to the screening spreadsheet with an example. During subsequent training, 5–7 studies were screened together until all team members showed evidence of consistent screening techniques. Screening was a two-step process. In step 1, the yield from

the final search (after duplicates were removed) underwent title and abstract screen by four team members using the inclusion and exclusion criteria. In a confirmatory step each study was then screened by a different team member. Any discrepancies were discussed by four adjudicators. If consensus was not reached or if an abstract was not provided, the study advanced to full text screening. In step 2, the full text of each paper screened during step 1 was then reviewed by a different team member from the full team. A final review was then conducted during the data extraction so that each study was reviewed for inclusion or exclusion by at least four different team members working independently. No automation tools were used.

Data collection process

Data were collected from the individual studies using the study-specific spreadsheet developed for the 2015 analysis. After training, team members worked independently to extract information from ten studies each. As a quality check, one team member was held out from the data extraction step to review and adjudicate a 10% overlap of the studies. The information was then confirmed by at least one other team member during the synthesis phase. Once again, no automation tools were used.

Data items

Data items extracted were derived from the study questions and included domains related to the study itself (i.e., year published and where it was conducted, study design, setting, purpose, main outcome, etc.), and caregiver specific information (i.e., sample composition, relationship to care recipient, living arrangement, actual activity, etc.). Quality evaluation used the same method, the CASP checklists, as the 2015 paper. CASP provided standardized and valid criteria for multiple study designs which allowed for comparison across different types of studies.⁹ CASP is recommended for use in assessing for bias in qualitative studies¹⁰ (the preponderance of the studies in this review) with lower scores indicating greater risk for bias.⁹ Papers were evaluated using CASP criteria during data extraction and then ranked as low, moderate, or high quality and risk of bias by two unique team members who examined the categorization in a confirmatory step. Of 64 papers, 4 (6%) scored in the low quality and 7 (11%) scored in the moderate quality rank (Table 1). No studies were excluded based on CASP ranking.

Synthesis methods

The full team self-selected into three working groups (self-care maintenance, monitoring, and management). An ontology and series of decision rules (see Supplemental Materials B) were developed to standardize adjudication of activities across groups according to the Theory of Self-care of Chronic Illness.^{7,11} Following the 2015 paper, meta-synthesis techniques¹² using critical realist approaches¹³ were used to interpret the activities, then analyze the nature and relationships between activities and theory, and finally draw conclusions. In keeping with meta-synthesis techniques, the actual terms used in the individual studies are retained to accurately report the findings. This also allowed us to highlight the amount of ambiguity and redundancy in terminology. To answer our first research question (RQ #1), activities were first identified and individually categorized using the theory, then checked for alignment with the 2015 synthesis to assess for any

emerging domains. To answer RQ #2, a year-by-year analysis of activities was conducted looking for any patterns across time since the 2015 review. To answer RQ #3, working groups conducted a concurrent examination of undescribed or unmeasured activities that appear in the interprofessional caregiving literature. The team included gerontological experts (clinicians and academics) familiar with psychology, sociology, and multi-morbidity caregiving literature which allowed them to assess missingness in the HF caregiving literature. All final conclusions of the working groups across the three research questions were brought back to the full team for discussion and consensus before advancing to inclusion in this paper.

Results

Study Characteristics

2154 research reports were identified, of which 64 met criteria (Figure 1; Table 2). Included papers (qualitative n=50; quantitative n=7; mixed methods n=7) were published between 2013 and 2022 (all 2012 papers were either screened out or included in the 2015 paper), representing 2136 caregivers and 828 patients with HF (Table 3). In all included studies, the samples were comprised of female caregivers, ranging from 25% to 100% of the reported sample, with caregiver ages ranging from 18 to 92 years. Fifteen countries were represented (Table 3). The relationship of caregivers to patients included spouses and partners, parents, siblings, children, daughters-and-sons-in-law, grandchildren, friends, and other family members.

RQ #1: Specific activities in which informal caregivers take part

Self-care maintenance.—Defined as a set of behaviors to maintain health and prevent symptom exacerbations; of the included papers, 91% (n=58/64) identified caregivers' activities in this domain. Table 4 shows the specific self-care maintenance activities that informal caregivers perform including support for medication (n=42/58, 72%), diet and fluid maintenance (n=29/58, 50%), and medical appointments (n=19/58, 33%). While many reported caregiver activities followed evidence-based self-care recommendations (e.g., reducing salt, encouraging physical activity, and medication adherence), “nagging” activities were also reported.^{14–16} Caregivers reported that patient perceptions of encouragement as nagging had a negative impact, suggesting that caregivers need additional skill training on how to motivate their care partners and support in carrying this out (e.g. autonomy supportive communication).¹⁷ Caregivers also reported providing health maintenance behaviors (e.g. ADLs) which do not appear in the middle range theory⁷ such as “providing personal care such as toileting, dressing, bathing” and “basic self-care activities”^{18–21}

In keeping with the 2015 synthesis, caregivers' activities continued to fall into the two categories of “hands on” and “hands off” activities. Although few papers reported “hands on” self-care maintenance activities, such as caregivers directly administering medications (n=5/58; 9%); all papers reported “hands off” maintenance activities, e.g. managing routine medications. “Hands off” activities comprised the majority of caregivers' contributions (n=42/58, 72%).

Self-care monitoring.—Defined as “a process of routine, vigilant body monitoring, surveillance, or ‘body listening’” (p 196)⁷ self-care monitoring activities appeared in over half the papers (n=35/64, 55%; Table 4). The theory’s self-care monitoring categories include tracking, awareness, interpretation, and recognition/attribution. Our initial attempts to benchmark caregiver activities against these categories were unsuccessful primarily due to limited specificity in the papers about caregivers’ involvement in the processes of interpretation or recognition. Instead, three major categories of caregiver monitoring activities emerged from the data across studies: 1) collecting or tracking clinical data such as using/managing technology or systems that collected or tracked clinical data;^{18,22–32} 2) monitoring for signs/symptoms of HF such as physical assessments (e.g., listening to the patient’s heart) or routine observations for signs/symptoms; and 3) communication with providers (either active or passive) to facilitate ongoing clinician awareness of the patient’s condition (e.g., sharing tracked information during appointments and using portals or telemonitoring systems/apps to send monitored information to providers). Importantly, communication activities in the latter category were distinct from symptom management-related communication in that they were part of regular monitoring activities that occurred independent of changes in the patient’s condition.

As in the 2015 synthesis, monitoring activities could be categorized as direct or indirect with 46% (n=16/35) reporting “hands on” activities and 77% (n=27/35) describing “hands off” activities. Monitoring heart failure symptoms either directly on, toward, or in conjunction with the patient was the most reported caregiver “hands on” activity (n = 10/35, 47%). However, more “hands off” versus “hands on” activities were reported across studies. The most common “hands off” caregiving activity was general patient monitoring (i.e., did not include monitoring symptoms; n = 10/35, 47%), that involved monitoring comorbidities, safety issues, and medication side effects, plus maintaining awareness, and watching over the patient. Monitoring HF symptoms for the patient (n = 8/35; 23%) was also frequently reported and included maintaining vigilance and observing for symptom changes, as well as symptom recognition. Nonetheless, determining whether symptom monitoring was “hands on” or “hands off” was challenging in some cases, as adequate specificity to make a determination was sometimes missing. Additionally, increased use of technology during the COVID-19 pandemic, when virtual calls (e.g., Facetime, Zoom, etc.), telehealth, and telemonitoring were normalized, suggests the emergence of a new “hybrid” category in which technology was applied to the patient’s body as a “hands on” activity but was also used by caregivers to monitor patient symptoms “hands off”.

Self-care management.—Defined as activities that caregivers do or recommend in response to the signs and symptoms of a heart failure exacerbation, a little under half the papers (n=30/64, 47%) included such activities (Table 4) with communication with the healthcare team (n=11/30, 37%) the most frequent activity.

In keeping with the 2015 synthesis, self-care management activities easily classified into “hands on” and “hands off” with some papers reporting both types of activities. According to this classification 10% (n=3/30; Table 4) of the papers were exclusively describing “hands on” activities such as administering a medication in response to a symptom, and in half of the papers (n=15/30, 50%) authors exclusively described

“hands off” activities such as communication with health care providers. One-third of the papers (n=10/30, 33%) addressed both types of activities or used terms that did not allow for a proper differentiation, e.g. “symptom and medication management” or “manage HF and other comorbidities.” Although synthesizing activities in this review resulted in support for the earlier conceptualization of caregiver activities, we found that the identified caregiving self-management activities could also be divided into two different categories: 1) established symptom response and 2) complex or emergent care. Established symptom response activities were actions that caregivers did or recommended in response to symptom perception, such as medication management in response to symptoms, treatment implementation, communication with healthcare providers, and management of comorbidities. Complex or emergent care activities included actions that were time sensitive and completed in response to life-threatening signs and symptoms that were suggestive of an acute heart failure exacerbation, such as calling an ambulance or managing critical situations.

RQ #2: Change in activities over time since the 2015 review

Self-care maintenance.—Reporting the number of papers published each year provides insights into emerging research trends and growing attention to the topic over time. Papers reporting activities in this domain were published in each year of the review period with the most papers published in 2022 (n=10) and 2016 (n=9), Table 2. Included were medication-related maintenance activities with the greatest number of papers published in 2019 (n=7) and 2022 (n=8). Diet and fluid maintenance activities were the second-most frequently reported activities with no noticeable changes in publication frequency between 2013 and 2022. Additionally, the 2015 review included four studies in the general category ‘Arranging resources,’ whereas this update showed a significant uptick in studies describing this type of activity. Overall, in more recent reports compared to the 2015 paper, authors studied a broader range of caregiver activities and behaviors per study, as well as across the entire period of this updated review (Table 4).

Self-care monitoring.—Change over time was greatest in this domain as the theory itself evolved to include symptoms¹¹ and monitoring technology and digital healthcare advanced^{33,34} and research followed suit. Papers reporting activities in this domain were published at a rate of 2–8 papers per year (Table 2). The concept of vigilance in monitoring emerged between 2013 – 2016, with an emphasis on constant symptom monitoring or “watching over” the patient.^{16,35,36} Following 2016, vigilance remained, but tracking and monitoring emerged as a more prevalently described activity from 2017 – 2019, with key features including symptom monitoring strategies and education support.^{15,23,37} From 2020 onwards, a clear trend emerged toward greater publication of papers that reported data on caregiver-provider communication strategies. Involvement of caregivers in existing patient-facing symptom monitoring and tracking strategies were introduced (i.e., in-home monitoring) and when combined with telehealth, an emphasize on communication trended upward.^{22,24}

Self-care management.—The number of studies describing caregiver self-care management activities remained steady across the time period (2013–2022). There were no patterns or trends observed in self-care management topics or activities over time.

In summary, in answer to RQ#2, measurement of activities such as use of telehealth equipment changed over the period covered by this review (2013–2022). Change over time in self-care maintenance was in quantity rather than new activities. Change over time in self-care monitoring was the greatest of the three domains, likely stemming from changes in theory and technology. Finally, there was no change over time in publication of self-care management activities.

RQ #3: Gaps in the science

Significant gaps persist across domains. Our understanding of self-care maintenance activities is limited due to lack of specificity in behavior and activity descriptions, difficulty in quantifying time/effort spent on caregiving, absence of sleep and stress management activities, and underrepresentation of motivational and emotional support behaviors. Many descriptions of how caregivers contributed to self-care maintenance were general (i.e., basic care management,³⁸ quality of life,^{38,39} being a “resource person for illness”³⁵ and “gathering information”²⁸). There was a lack of quantification of time spent caregiving and the levels of difficulty of specific caregiving activities. Similarly, notable gaps exist across self-care monitoring studies related to communication with providers, ambiguity of what is meant by “symptom monitoring,” and the emerging area of in-home technology use. Finally, given technological advancements, we expected more studies to focus on the use of technology to support caregivers’ self-care management, e.g. caregiver portals to facilitate communication with healthcare providers, electronic decision support tools for self-care management, etc. Crossover between monitoring and management behaviors using technology may contribute to these seeming gaps.

Discussion

The purpose of this paper was to update a 2015 systematic review.² Using findings from both the 2015 and current paper allows examination of HF caregiver activities across 28 years, from inception of the science (1994) to 2022. In the following section we discuss specific activities and gaps in the science in-depth.

Our analysis uncovered activities previously unreported as caregivers’ contributions to patient HF self-care, suggesting that the theory itself bears re-evaluation. Compared to the 2015 review, five new categories of potential maintenance activities (medical appointments, transportation, health-related communication, and supporting activities of daily living [ADLs], and instrumental ADLs [IADLs]) were reported by caregivers, none of which were currently explicit in the Theory of Self-care of Chronic Illness. For example, the latter two activities (ADLs, IADLs) were excluded from the 2015 dataset based on the decision to benchmark activities against the theory. Given that caregivers continued to report contributing to ADLs and IADLs in 17 HF caregiving studies published since 2013, this caregiving activity should be considered as part of future theoretical updates. With advances in evidence-based HF care, patients may live with frailty, cognitive decline, multi-morbidity

and other health issues after diagnosis and caregivers may contribute more time and effort in ADLs and IADLs. Adding “scaffolding type activities” such as ADLs and IADLs to the middle range theory will allow capturing activities occurring concurrently with specific chronic illness’ self-care activities which may otherwise act as an impediment to adequate disease specific self-care.

We’ve highlighted significant gaps in the HF caregiving science which should serve as guidance for future research. Gaps in the science across all three domains (maintenance, monitoring, and management) were identified. Gaps were identified when poorly defined terms and phrases made it difficult to discern how activities related to the three self-care domains, as limited definitions and descriptions obscured the complexity of caregiving. Greater descriptive precision would be useful for understanding the nature of caregiver contributions. For example, although several reported caregiver activities like providing transportation (a scaffolding activity)^{40–42} appear mundane, transportation and attending medical appointments may require working caregivers to take time off, potentially impacting future employment and earnings. Gaining a more detailed and comprehensive understanding of even mundane activities will help support caregivers’ needs. Another gap is the absence of sleep promotion and stress management activities such as Tai-Chi, yoga, meditation.^{43,44} This gap is particularly surprising given the crucial role of sleep in the overall well-being of patients and their caregivers.⁴⁵ A gap identified in the self-care maintenance results is the underrepresentation of motivational behaviors, which are likely embedded in activities such as physical activity, diet, and medications. Motivation is positively associated with self-care.⁴⁶ A recent systematic review of nine randomized control trials reported motivational interviewing (MI) interventions have been successful at improving self-care in patients.⁴⁷ The MOTIVATE-HF trial provided evidence that including caregivers with patients in MI interventions may increase effect sizes.⁴⁸ All this suggests that further examination of motivation and MI in caregivers is warranted.

Within the self-care monitoring domain, a major gap was the ambiguity of the term “symptom monitoring” without explicating the specific symptom(s) being monitored, or how the caregiver is specifically involved in the monitoring process. Umbrella terms such as “symptom monitoring”⁴⁹ or a variant thereof (e.g., symptom recognition²³, observing for signs/symptoms^{19,50}) are used when describing caregiving activities obscuring our understanding of the process or gestalt of monitoring activities provided by caregivers. Agreement and use of specific definitions and measurement for symptom monitoring is suggested. Additionally, it was not always clear how monitoring activities were completed in terms of technology use. Use of technology such as telemonitoring²² and patient portals⁴⁹ adds another layer of complexity to caregiving activities, so ascertaining specifically how and how often it is used is important in determining the extent of caregiving activities in self-care monitoring and how caregivers should be included in designing/testing digital health interventions for HF.

The self-care management domain also included gaps in explicit descriptions of technology-based activities. For example, if caregivers were described as using technology to monitor symptoms, how this information was shared with clinicians was rarely described explicitly in the paper. This missing information creates a gap in knowledge related to

caregivers' technological competence. Another gap relates to the relational aspects of self-care management. Despite the recent increase in examination of dyadic heart failure management,⁵¹ there was limited information in these studies on the amount of caregiver involvement, whether the patient wanted the caregiver involved and how dyadic congruence influenced caregivers' contribution to self-care management. Additionally, there is limited research about how the quality of the relationship between persons with heart failure and their caregivers informs self-care management decisions for established symptom response or complex/emergent care situations.⁵² Further examination may uncover a significant mechanism for improving symptom management. Addressing these gaps has the potential to lead to better data for research, policy implications, and support for both heart failure patients and their caregivers in managing self-care.

Limitations

The limitations of this systematic review include the search terms used in the databases selected and the inclusion and exclusion criteria. Different terms used in other databases using different criteria may have resulted in other papers being identified. In addition, meta-synthesis involves qualitative techniques which may influence interpretations. Finally, because we did not conduct a meta-analysis and to be inclusive as possible, we retained studies (17%) which had some risk of bias. While acknowledging these limitations, the author(s) sought to thoughtfully mitigate them by using best practices such as pre-registration of the protocol in PROSPERO, strict application of PRISMA criteria, extensive training and providing to all readers the materials used in the data acquisition and analysis for the sake of replicability.

Implications for practice, research, and policy

This systematic review has clear implications for practice, research and policy. In terms of practice, caregivers are HF care co-providers with clinicians, and as such, should be consulted for information regarding on-going care and conferred with before instituting new recommendations. The caregiver may be best situated to determine whether the new activity is acceptable, feasible, and sustainable in the context of the patient (and caregiver's) life, abilities, and resources/supports. Research implications include the gaps noted earlier in the paper – studies are needed which include specificity in activity definitions, time on task, determining levels of difficulty for specific activities, caregiver sleep and stress management strategies, teaching caregivers motivational techniques, communication, and technology use. Practice and research implications result in the policy implications of this review. Lack of evidence related to caregiving and failure to recognize caregivers as co-providers of care results in poor policy and increasingly inadequate support for caregivers at a time when care is more and more focused on outpatient care and population health. Reimbursement for telehealth on the state level and technology infrastructure in rural areas are determined by the policies in place. Similarly, reimbursement for informal caregiving including the cost of education and/or skill building are impacted. Without changes in practice and generation of rigorous, actionable data, caregivers' contributions to HF self-care will remain "hidden work" and therefore undervalued, underfunded, and ultimately undone.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Data sharing:

Additional data and associated documentation will be made available to qualified researchers upon reasonable request. Requests should be made to the corresponding author. A methodologically sound proposal is required, and requestors will be asked to sign a data sharing agreement.

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Box 1.**PubMed 1/30/23****#1**

“Heart Failure”[Mesh] OR heart failure[Title/Abstract] OR CHF[Title/Abstract] OR cardiac failure[Title/Abstract] OR heart decompensation[Title/Abstract] OR myocardial failure[Title/Abstract]

#2

“Caregivers”[Mesh] OR “Caregiver Burden”[Mesh] OR caregiver[Title/Abstract] OR caregivers[Title/Abstract] OR carer[Title/Abstract] OR carers[Title/Abstract] OR caregiving[Title/Abstract] OR care giver[Title/Abstract] OR care givers[Title/Abstract]

#3

“Letter” [Publication Type] OR “Editorial” [Publication Type] OR “Comment” [Publication Type] OR “Review” [Publication Type] OR “Systematic Review” [Publication Type] OR “Heart-Assist Devices”[Mesh] OR “Pediatrics”[Mesh] OR “Child”[Mesh] OR “Critical Care”[Mesh] OR “Intensive Care Units”[Mesh] OR protocol [Title] OR pediatric [Title] OR home care workers [Title] OR health care workers [Title] OR home health aides [Title] OR “Skilled Nursing Facilities” [Mesh]

#1 AND #2 NOT #3= 614 with filters English language and 2012 to present applied

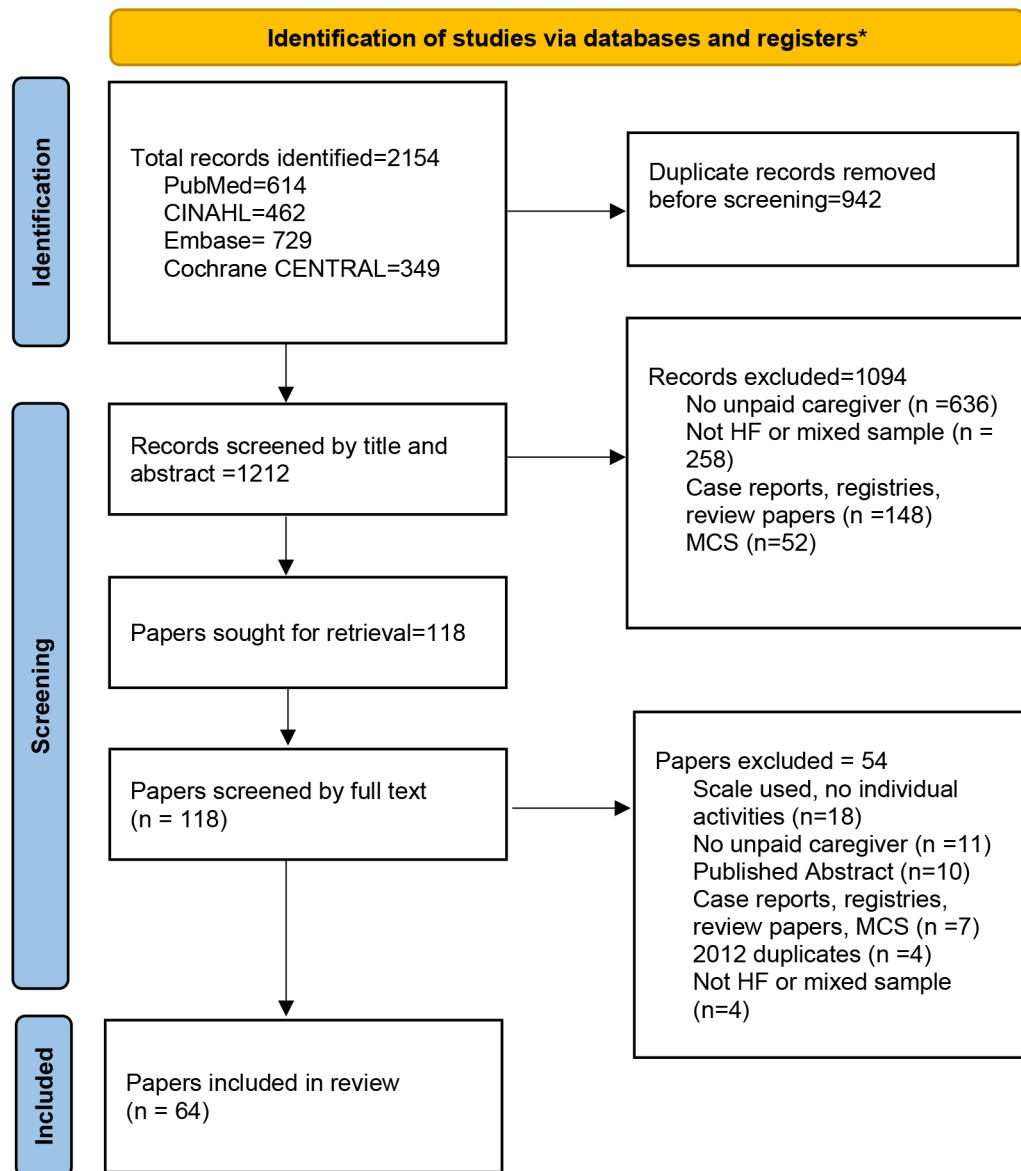


Figure 1.
PRISMA Flow Diagram
*No automation tools were used
HF- heart failure, MCS – mechanical circulatory support.

Table 1.

CASP Ratings for All Studies

Author	Qualitative			Quantitative			Quality Rating
	Valid ^a	Qualitative Results ^b	Valuable ^c	Valid ^d	Quantitative Results ^e	Valuable ^f	*Risk of bias legend in note below
Aamodt et al. (2022) ²²	Yes	Yes	Yes	--	--	--	High
Ahmad et al. (2016) ⁴⁰	Yes	Yes	Yes	--	--	--	High
Al-Rawashdeh et al. (2020) ⁵³	Yes	Yes	Yes	--	--	--	High
Bahrami et al. (2014) ⁵⁴	Yes	Yes	Yes	--	--	--	High
Barello et al. (2015) ⁵⁵	Yes	Yes	Yes	--	--	--	High
Blanck et al. (2021) ⁴¹	Yes	Yes	Yes	--	--	--	High
Buck et al. (2018) ⁵⁶	Yes	Yes	Yes	--	--	--	High
Burke et al. (2014) ⁵⁷	Yes	Yes	Yes	--	--	--	High
Butcher et al. (2022) ⁵⁸	Yes	Yes	Yes	--	--	--	High
Cameron et al. (2016) ⁵⁹	Yes	Yes	Yes	--	--	--	High
Choi et al. (2021) ⁶⁰	Yes	Yes	Yes	--	--	--	High
Clements et al. (2022) ⁶¹	--	--	--	Yes	Yes	Yes	High
Cross et al. (2022) ⁶²	Yes	Yes	Yes	--	--	--	High
Davidson et al. (2013) ⁶³	--	--	--	Yes	Yes	Yes	High
Durante et al. (2019) ²³	Yes	Yes	Yes	--	--	--	High
El-Dassouki et al. (2022) ²⁴	Yes	Yes	Yes	--	--	--	High
Etemadifar et al. (2015) ⁶⁴	Yes	Yes	No [*]	--	--	--	Moderate [*]
Farmer et al. (2016) ⁶⁵	Yes	No ^{**}	No ^{**}	--	--	--	Low ^{**}
Grant & Graven (2019) ¹⁹	Yes	Yes	Yes	--	--	--	High
Gusdal et al. (2016) ⁶⁶	Yes	Yes	Yes	--	--	--	High
Hamilton (2016) ⁶⁷	Yes	Yes	Yes	--	--	--	High
Hayashi et al. (2021) ²¹	--	--	--	No [*]	Yes	Yes	Moderate [*]
Heo et al. (2021) ⁶⁸	Yes	Yes	Yes	--	--	--	High
Holden et al. (2017) ⁴²	No [*]	Yes	Yes	--	--	--	Moderate [*]
Hopp et al. (2014) ⁶⁹	No [*]	Yes	Yes	--	--	--	Moderate [*]
Jose et al. (2020) ⁷⁰	Yes	Yes	Yes	--	--	--	High
Kennedy et al. (2017) ²⁵	Yes	Yes	Yes	--	--	--	High
Kim et al. (2020) ⁷¹	Yes	Yes	Yes	--	--	--	High
Kitko et al. (2015) ⁷²	Yes	Yes	Yes	--	--	--	High
Kitko & Hupcey (2013) ²⁶	Yes	Yes	Yes	--	--	--	High
Kumari et al. (2020) ²⁷	Yes	Yes	Yes	--	--	--	High
Lauvli et al. (2016) ³⁵	Yes	No [*]	Yes	--	--	--	Moderate [*]

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	Qualitative			Quantitative			Quality Rating
Author	Valid ^a	Qualitative Results ^b	Valuable ^c	Valid ^d	Quantitative Results ^e	Valuable ^f	*Risk of bias legend in note below
Liljeroos et al. (2015) ⁷³	--	--	--	Yes	Yes	Yes	High
McHorney et al. (2021) ⁷⁴	Yes	Yes	Yes	--	--	--	High
Mickelson et al. (2015) ⁷⁵	Yes	Yes	Yes	--	--	--	High
Mickelson et al. (2016) ²⁸	Yes	Yes	Yes	--	--	--	High
Mickelson & Holden (2018) ⁷⁶	Yes	Yes	Yes	--	--	--	High
Nwosu et al. (2022) ⁷⁷	Yes	Yes	Yes	--	--	--	High
Östman et al. (2019) ⁷⁸	Yes	Yes	Yes	--	--	--	High
Pearson et al. (2022) ¹⁵	Yes	Yes	Yes	--	--	--	High
Petruzzo et al. (2017) ⁷⁹	Yes	Yes	Yes	--	--	--	High
Piette et al. (2015) ⁸⁰	--	--	--	Yes	Yes	Yes	High
Risbud et al. (2022) ⁸¹	Yes	Yes	Yes	--	--	--	High
Sampaio et al. (2019) ⁸²	Yes	Yes	Yes	--	--	--	High
Schutz & Walthall (2022) ³¹	No **	No **	Yes	--	--	--	Low **
Sebern et al. (2018) ³²	Yes	Yes	Yes	--	--	--	High
Sedlar et al. (2020) ⁸³	Yes	Yes	Yes	--	--	--	High
Shahrbabaki et al. (2016) ⁸⁴	Yes	Yes	Yes	--	--	--	High
Slightam et al. (2022) ⁴⁹	Yes	Yes	Yes	--	--	--	High
Stamp et al. (2016) ⁸⁵	--	--	--	No *	Yes	Yes	Moderate *
Strøm et al. (2015) ³⁶	Yes	Yes	Yes	--	--	--	High
Sullivan et al. (2016) ¹⁶	Yes	Yes	Yes	--	--	--	High
Tavakoli et al. (2018) ³⁸	Yes	Yes	Yes	--	--	--	High
Wingham et al. (2015) ¹⁸	Yes	Yes	Yes	--	--	--	High
Wingham et al. (2017) ⁸⁶	Yes	Yes	Yes	--	--	--	High
Wooldridge et al. (2019) ⁸⁷	Yes	Yes	Yes	--	--	--	High
Wu et al. (2019) ⁸⁸	--	--	--	Yes	Yes	Yes	High
Mixed Methods							
	Qualitative			Quantitative			Quality Rating
Author	Valid ^a	Qualitative Results ^b	Valuable ^c	Valid ^d	Quantitative Results ^e	Valuable ^f	
Baik et al. (2022) ⁸⁹	Yes	Yes	Yes	No *	Yes	Yes	Moderate *
Bangerter et al. (2019) ³⁹	Yes	Yes	Yes	Yes	Yes	Yes	High
Chi et al. (2018) ³⁷	Yes	Yes	Yes	Yes	Yes	Yes	High
Holden et al. (2015) ⁹⁰	No **	Yes	Yes	No **	No **	Yes	Low **
Näsström et al. (2017) ²⁹	Yes	Yes	Yes	Yes	Yes	Yes	High
Piamjariyakul et al. (2013) ³⁰	Yes	Yes	No **	Yes	Yes	No **	Low **

Author	Qualitative			Quantitative			Quality Rating
	Valid ^a	Qualitative Results ^b	Valuable ^c	Valid ^d	Quantitative Results ^e	Valuable ^f	*Risk of bias legend in note below
Wingham et al. (2019) ⁵⁰	Yes	Yes	Yes	Yes	Yes	Yes	High

Notes.

a: CASP qualitative validity questions: Are the results of the study valid? (Sub-questions: Was there a clear statement of the aims of the research?, Is a qualitative methodology appropriate? Is it worth continuing? Was the recruitment strategy appropriate to the aims of the research? Was the data collected in a way that addressed the research issue? Has the relationship between research and participants been adequately considered?);

b: CASP qualitative result questions: What are the results? (Sub-questions: Have ethical issues been taken into consideration?, Was the data analysis sufficiently rigorous? Is there a clear statement of findings?);

c: CASP qualitative value questions: Will the results help locally? (Sub-question: How valuable is the research?);

d: CASP quantitative validity questions: Are the results of the study valid? (Sub-questions: Did the study address a clearly focused issue? Was the sample recruited in an acceptable way? Is it worth continuing? Was the exposure accurately measured to reduce bias? Was the outcome accurately measured to minimize bias? Have the authors identified all important confounding factors? Have they taken into account of the confounding factors in the design and/or analysis? Was the follow up of subjects complete enough? Was the follow up of subjects long enough?);

e: CASP quantitative results questions: What are the results? (Sub-questions: What are the results of this study? How precise are the results? Do you believe the results?);

f: CASP quantitative value questions: Will the results help locally? (Sub-questions: Can the results be applied to local populations? Do the results of this study fill with other available evidence? What are the implications of this study for practice?);

* denotes moderate risk of bias present,

** denotes high risk of bias present

Table 2.

Study Sample, Purpose, Findings and Limitations

Author	Sample (Male, Female, Mixed Sample (%female) Mean age (+/- SD) or Median/Range	Purpose*	Findings (Qualitative Themes, Quantitative Summary)	Limitations
Aamodt et al. (2022) ²²	n=9 Mixed sample (% unknown) Age unknown	Explore informal caregivers' experiences with performing non-invasive telemonitoring	Themes: 1) Access to support 2) Towards routinizing 3) Mastering	Sample
Ahmad et al. (2016) ⁴⁰	Patients (n=58); Caregivers (n=32); Clinicians (n=67) Mixed sample (66%) Age 54/27 – 80	Characterize the patient and caregiver experience of managing at home	Themes: 1) Staying healthy at home 2) Challenges to home heart failure management 3) Reasons for hospital admission	Single site
Al-Rawashdeh et al. (2020) ⁵³	n= 59 Mixed sample (80%) Age 45 (+/- 12)	Explore and describe the views and lived experiences of family caregivers providing home care	Themes: 1) Caregiving as a mandatory responsibility, 2) Caregiving as a positive experience 3) Caregiving as a negative experience 4) Factors influencing the caregiving experience	Sample
Bahrami et al. (2014) ⁵⁴	n=19 Mixed sample (79%) Age 20 – 30 (26.31%), 31 – 40 (31.57%), 41 – 50 (42.10%)	Explore the informational needs and related problems of family caregivers	Themes: 1) Lack of care-related knowledge 2) Inaccessibility to responsible source of information 3) Lack of guidance from healthcare team 4) Caring with ambiguity due to unpredictable nature of the disease	Analytic methods unclear
Baik et al. (2022) ⁸⁹	n=13 Mixed sample (85%) Age 70 (+/- 5.5)	Qualitative: Explore the experiences of older caregivers Quantitative: Examine levels of caregiver burden, psychological distress, self-efficacy and QoL	Qualitative: Themes: 1) Impact of Being a Caregiver 2) Managing Caregiver Distress 3) Embracing the Caregiver Role Quantitative: Summary: Reported low levels of caregiver burden, psychological distress, and high levels of caregiving self-efficacy and QoL	Sample
Bangerter et al. (2019) ³⁹	Qualitative: n=16 Mixed sample (88%) Age 66 (+/- 10) Quantitative: n=108 Mixed sample (83%) Age 66 (+/- 14)	Qualitative/ Quantitative: Explore self-gain and positive aspects of family caregivers	Qualitative: Themes: 1) Caregiving as a means to enhancing relationships 2) Success in negotiating care and healthy behaviors with people with HF 3) Caregiving as a means of preparing caregivers for the future Quantitative: Summary: Spousal caregivers, and caregivers with higher preparedness and higher mastery had greater odds of reporting high self-gain	None noted
Barello et al. (2015) ⁵⁵	n=4 Mixed sample (25%) Age ><50 years	Investigate the features and levers of the HF patient engagement process	Themes reflect patient process not caregiver process	Sample

Author	Sample (Male, Female, Mixed Sample (%female) Mean age (+/- SD) or Median/Range)	Purpose*	Findings (Qualitative Themes, Quantitative Summary)	Limitations
Blanck et al. (2021) ⁴¹	n= 12 Female sample (100%) Age 63 (+/- 9)	Elucidate the meaning of support given and received by carers	Themes: 1) Being there for someone 2) Being in partnership with one's relative 3) Meeting the unpredictable healthcare system	Sample
Buck et al. (2018) ⁵⁶	n=27 Mixed sample (74%) Age 64 (+/-14)	Examine how patient/informal caregiver dyads mutually engage in managing at home	Themes: 1) Maintaining established routines or patterns 2) Changing routines or patterns day to day or based on symptoms 3) Mobilizing support from third party	Focus on dyad not just caregiver
Burke et al. (2014) ⁵⁷	n=20 Mixed sample (95%) Age 59/59-74	Understand what roles caregivers perceive and desire for themselves	Themes: 1) Health Manager/Care Plan Enforcer 2) Advocate for Improved Quality of Life, 3) Expert in the Lived Experience of HF 4) Expressions of Role Conflict and Role Strain	Sample
Butcher et al. (2022) ⁵⁸	n= 39 Mixed sample (93%) Age >70	Evaluate an 8-week program of education and support	Themes: 1) Becoming stronger 2) Altered outcome for the future 3) Connection through knowledge	High rate of refusal to participate
Cameron et al. (2016) ⁵⁹	n= 12 Mixed sample (75%) Age 67/50-82	Examine carers' views to identify factors that facilitated, or hindered, patient	Themes: 1) Hinderance to engagement 2) Roles and Relationships 3) Social Support 4) Community engagement and competency	Sample
Chi et al. (2018) ³⁷	n= 28 Mixed sample (79%) Age 60 (+/-10)	Qualitative/Quantitative Explore challenges that family caregivers faced	Qualitative: Themes: 1) Difficulty in supporting patient care and activities of daily living 2) Inadequate social support 3) Communication issues 4) Financial concerns. Quantitative: Summary: Caregivers were mildly anxious and had worse financial and physical quality of life than their social and emotional quality of life.	Secondary analysis
Choi et al. (2021) ⁶⁰	n=53 Mixed sample (89%) 63 (+/-14)	Explore the caregiving experiences	Themes: 1) Accumulating Knowledge and Skills for Caregiving 2) Losing a Sense of Control 3) Balancing an Unstable Life 4) Constructing Illness Memory 5) Centering the Patient in Daily Life 6) Accepting the Loss of a Family Member 7) Coping with Grief by Drawing on Social Support 8) Facing Financial Responsibility 9) Rethinking Hospice Care	Secondary analysis
Clements et al. (2022) ⁶¹	n= 74 Mixed sample (78%) Age 49 (+/-11)	Evaluate effectiveness of a caregiver-only educational intervention	Quantitative Summary: Significant improvement in patient self-care maintenance and management, cardiac readmission, and caregiver perceived control	Sample
Cross et al. (2022) ⁶²	n=113 Mixed sample (89%) Age 51(+/-13)	Examine the impact of the COVID-19 pandemic on family caregivers	Themes: 1) Social isolation was real 2) Change in everyday routines 3) Keeping or making appointments was challenging	Pandemic focus may have skewed results

Author	Sample (Male, Female, Mixed Sample (%female) Mean age (+/- SD) or Median/Range	Purpose*	Findings (Qualitative Themes, Quantitative Summary)	Limitations
			4) Masks and precautions were necessary 5) There was added fear, anxiety, and worry	
Davidson et al. (2013) ⁶³	n=84 Mixed sample (% unknown) Age 56 (+/-15)	Describe the characteristics of caregivers for people at the end of life	Quantitative Summary: People caring for those with HF were far less likely to access specialist palliative care services despite having much greater levels of unmet needs for physical care.	Potential recall bias from post-hoc survey
Durante et al. (2019) ²³	n=40 Mixed sample (83%) Age 54 (+/- 16)	Describe caregivers' contributions to self-care maintenance and management	Themes: 1) Caregivers contributed to self-care maintenance and management using strategies that they learned from others along with the support of trusted sources 2) Caregivers lacked confidence in symptom management, which often led to delayed symptom response and increased use of emergency departments	None noted
El-Dassouki et al. (2022) ²⁴	n= 20 Mixed sample (85%) Age 63 (+/-8)	Characterize how technology might support caregivers to optimize caregiving practices and improve shared outcomes	Themes: 1) Caregiver experiences with caregiving activities 2) The role of technology facilitating caregiving activities within a dyad	Technology focus may have skewed results
Etemadifar et al. (2015) ⁶⁴	n=21 Mixed sample (76%) Age 41/20-50	Explore the experiences of family caregivers	Themes: 1) Caregiver uncertainty 2) Lack of familial and organizational support 3) Allah-centered caring	Sample
Farmer et al. (2016) ⁶⁵	n=20 Mixed sample (64%) Age 68 (+/-14)	Identify factors underlying hospitalization	Themes: 1) Factors reported to influence adherence 2) Factors related to the patient-provider relationship 3) System-level factors 4) Environmental factors	Sample
Grant & Graven (2019) ¹⁹	n=530 Mixed sample (49%) Age 41(+/-10)	Identify problems experienced by caregivers	Themes: 1) Performing multifaceted activities and roles evolving around daily HF demands 2) Maintaining caregiver well-being 3) Providing unending care	None noted
Gusdal et al. (2016) ⁶⁶	n=14 Mixed sample (79%) Age 71/50-88	Explore experiences and needs of caregivers	Themes: 1) Living in a changed existence 2) Struggling and sharing with healthcare	Sample
Hamilton (2016) ⁶⁷	n=10 Mixed sample (60%) Age 46(+/-15)	Describe the lived experience of African American caregivers	Themes: 1) Layers of support 2) Realization of self-neglect 3) Experiencing the "blues" 4) Connecting with the healthcare provider 5) Unmet financial needs 6) Perceptions of nonadherence	Sample
Hayashi et al. (2021) ²¹	n=126 Mixed sample (72%) Age 64(+/-14)	Describe the role and burden of caregiving	Quantitative Summary: Meal preparation was most frequently reported activity; 24% found this burdensome. Feeling physically tired and emotionally worrying about the patient were the most frequent consequences of caregiver. Approximately half of caregivers felt caregiving impacted their lifestyle.	Sample
Heo et al. (2021) ⁶⁸	n=21 Mixed sample (61%)	Explore experiences of dietary sodium adherence	Themes: 1) Lack of adherence to a low sodium diet 2) Several barriers to dietary sodium	Sample

Author	Sample (Male, Female, Mixed Sample (%female) Mean age (+/- SD) or Median/Range)	Purpose*	Findings (Qualitative Themes, Quantitative Summary)	Limitations
	Age 52(+/-16)		adherence 3) A few facilitators of dietary sodium adherence 4) Distorted perceptions of dietary education from healthcare providers	
Holden et al. (2015) ⁹⁰	n=14 Sample not reported Age not reported	Understand the nature and prevalence of barriers to self-care performance	Qualitative Themes: 1) Person barriers 2) Task barriers 3) Tool barriers 4) Context barriers Quantitative Summary: Person-patient barriers arose from stable patient characteristics. Task barriers arose from self-care activity characteristics. Tool and technology barriers were related to the availability, design, or consequence of use in the course of self-care. Physical-spatial, social-cultural, and organization context barriers were common.	Sample
Holden et al. (2017) ⁴²	Study A n=10 Sample not reported Age 34(+/-11) Study B n=10 interviews; 9 focus groups Sample not reported Age not reported Study C n=35 Sample not reported Age 73(+/-7)	Specify the role of macroeconomic factors in the patient work system	Themes: 1) Person-task-tools 2) Physical context factors 3) Social context factors 4) Organizational context factors	Mixed three studies that do not all focus on HF caregivers
Hopp et al. (2014) ⁶⁹	n=35 (11 patient/caregiver dyads) Sample not reported Age 23–52	Explore perception of African Americans patients and caregivers concerning hospitalization	Themes: 1) Differing expectations of going to the hospital between patient and caregiver 2) Reasons for going to the hospital 3) Patient-caregiver distinct communication style	Sample
Jose et al. (2020) ⁷⁰	n=9 (caregivers), 22 (patients), 13 (healthcare providers) Mixed sample (89%) Age not reported	Understand barriers and facilitators to high-quality care	Themes: 1) Motivation to improve patient lifestyle behavior post-diagnosis 2) Follow-up calls from hospital staff helping patients 3) Emotional stress 4) Lack of clear detailed care plans for self-management 5) Caregiver support 6) Advice on substance use 7) Availability of experienced nursing staff 8) Perceived value and usage of Guideline Directed Medical Therapy in clinical practice 9) High patient caseload	Sample
Kennedy et al. (2017) ²⁵	n=22 (caregivers), 60 (patients), 11 (healthcare providers)	Describe perceived and desired roles of patients' and caregivers' and	Themes: 1) Education on disease specifics 2) Guidance to enhance quality of life	Sample

Author	Sample (Male, Female, Mixed Sample (%female) Mean age (+/- SD) or Median/Range	Purpose*	Findings (Qualitative Themes, Quantitative Summary)	Limitations
	Mixed sample (73%) Age 18–35 (18%), 36–55 (45%), 56–65 (27%), >65 (9%)	compare with healthcare provider perceived roles	3) Learning to cope with HF 4) Future outlook and care decisions	
Kim et al. (2020) ⁷¹	n =16 (caregivers), 15 (patients) Mixed sample (88%) Age 59(+/-12)	Understand the cognitive and emotional experience of patient and family managing HF	Themes: 1) Dyad health beliefs characterized by acceptance, optimism, and pessimism 2) Negative emotions influenced the dyadic experience 3) Interpersonal relationship closeness influenced contributions to managing HF	None noted
Kitko et al. (2015) ⁷²	n= 47 dyads Mixed sample (n=39) Age 62/28–88	Determine the prevalence and areas of incongruence between dyads, and the impact on the dyadic relationship	Themes: 1) Illness management 2) Health care issues 3) End of life decisions	Sample
Kitko & Hupcey (2013) ²⁶	N=20 (caregivers), 20 (patients) Mixed sample (70%) Age 68/46–78	Describe the type of work in long-term spousal caregiver across the progressive course of HF	Themes: 1) Providing care 2) Navigating the system 3) Maintaining self 4) Managing the household 5) Vigilance 6) Normalcy	Sample
Kumari et al. (2020) ²⁷	n=12 (caregivers), 15 (patients), 4 (doctors), 10 (nurses) Mixed sample (58%) Age 45(+/-15)	Explore patient self-management practice, caregiver home management, and healthcare provider hospital management	Themes: 1) Caregiver as a partner in care 2) Symptoms of patients and their home management 3) Deciding management of emergency conditions 4) Knowledge regarding lifestyle modifications 5) Awareness about mandatory aspects of care 6) Effect of illness on daily life of caregivers 7) Need of specialized care	Sample
Lauvli et al. (2016) ³⁵	n= 19 Mixed sample (89%) Age 45(+/-15)	Explore experiences and views of caregivers about needs for knowledge, support, and collaboration with healthcare professionals	Themes: 1) Involvement, willingness to assume responsibility and desire for knowledge 2) Unclear responsibility and insufficient flow of information 3) Available and competent supporters	Sample
Liljeroos et al. (2015) ⁷³	n=155 dyads Mixed sample (69% intervention, 19% control) Age 67(+/-12, intervention), 70(+/-11, control)	Determine 24-month effects of a psych-education support intervention dyads	Quantitative Summary: No 24-month intervention effects on health, depressive symptoms, or perceived control among dyads.	High attrition, underpowered analysis
McHorney et al. (2021) ⁷⁴	n=26 (caregivers), 63 (patients) Mixed sample (52%) Age 56(+/-11)	Present symptom and symptom-impact experiences of patients and caregivers	Themes: Cardinal Symptoms and Impacts, and Elicitation of Non-cardinal Symptoms and Impacts Medication Adherence Self-management Quality of Care	Sample

Author	Sample (Male, Female, Mixed Sample (%female) Mean age (+/- SD) or Median/Range)	Purpose*	Findings (Qualitative Themes, Quantitative Summary)	Limitations
Mickelson et al. (2015) ⁷⁵	n=14 (caregivers) n=30 (patients) Sample not reported Age not reported	Use a human factors perspective to examine how older adults use cognitive artifacts for medication management	Themes: Not reported. Fifteen cognitive artifact types identified that supported medication management	Sample, Secondary data analysis
Mickelson et al. (2016) ²⁸	n=30 (caregivers) n= 61 (patients) Sample not reported Age not reported	Describe and analyze medication management work process using a macrocognitive workflow framework	Themes: 1) Sensemaking 2) Planning 3) Coordination 4) Monitoring 5) Decision making	Sample
Mickelson & Holden (2018) ⁷⁶	n=31 (caregivers) n= 61 (patients) Sample not reported Age not reported	Investigate medication safety through the analysis of non-adherence events described by older patients	Themes: Not reported. Seventy non-adherence events were identified, described, and analysed for performance shaping factors. Half were classified as errors and half as violations. Performance shaping factors included elements of the person or team (e.g. patient limitations), task (e.g. complexity), tools and technologies (e.g. tool quality) and organisational, physical, and social context (e.g. resources, support, social influence).	Sample, Secondary data analysis
Näsström et al. (2017) ²⁹	n=15 Mixed sample (73%) Age 77/52–92	Describe the partners' perspectives on participation in the care for patients receiving home care	Themes: 1) Adapting to the caring needs and illness trajectory 2) Coping with caregiving demands 3) Interacting with healthcare providers 4) Need for knowledge to comprehend the health situation Quantitative Summary: Partners scored practical and treatment-related tasks high. Partner tasks in connection with personal care scoring was low.	Sample
Nwosu et al. (2022) ⁷⁷	n=21 (caregivers) n=13 (patients) Mixed sample (71%) Age 57/19–80	Capture patients' and carers perspectives, the impact on their health reported quality of life, and factors associated with poor health outcomes	Themes: 1) Change "impact" in lifestyle 2) Managing ongoing health or adjusting to HF diagnosis 3) Psychological/mental health impact of HF	Sample
Östman et al. (2019) ⁷⁸	n=15 Mixed (67%) Mean age 68/33–82	Describe continuity of care as perceived by the next of kin	Themes: 1) Want to be involved without being in charge 2) Want to be in control without acting as the driving force in the care situation 3) A need for sustainability without being overlooked 4) Focusing on making life meaningful while being preoccupied with caregiving activities	Sample
Pearson et al. (2022) ¹⁵	n=17 (caregivers) n=21 (patients) Mixed (64%) Mean age 68	Explore the role and experiences of informal carers	Themes: 1) The complex nature of informal caregiving ('spinning plates') 2) The barriers to caregiving ('the spinning falters') 3) The facilitators of caregiving ('keeping the plates spinning')	Dyads interviewed together
Petruzzo et al. (2017) ⁷⁹	n=30 Mixed (63%) Age 53 (±14.36)	Describe the lived experience of the caregivers	Themes: 1) Fear and worry related to the illness 2) Life changes and restrictions 3) Burden due to caregiving 4) Uncertainty about illness management	Sample

Author	Sample (Male, Female, Mixed Sample (%female) Mean age (+/- SD) or Median/Range	Purpose*	Findings (Qualitative Themes, Quantitative Summary)	Limitations
			5) Helping patients to cope with the illness 6) Love and affection towards the patient	
Piamjariyakul et al. (2013) ³⁰	n=12 Mixed (75%) Age 63 (±14)	Determine feasibility and evaluate helpfulness and costs of a coaching program for family caregiver	Qualitative Themes: 1) Use of coaching strategies in delivering the program was valuable to caregivers 2) The program provided caregivers with specific information 3) Program content and materials were helpful to caregivers 4) The coaching program was easily delivered via telephone Quantitative Summary: Caregiver burden scores were significantly reduced and raw scores of confidence and preparedness for HF home management improved 3 months after the intervention.	Sample
Piette et al. (2015) ⁸⁰	n=369 dyads Mixed (65%) Age 47 (±13)	Determine whether automated feedback to caregivers impacts burden and assistance with self-management	Quantitative Summary: Intervention caregivers were more likely to report attendance at doctor visits than control At 6 months, intervention caregivers were more likely to report some involvement in patients' medication adherence than control At 12 months, 42.5% of intervention caregivers reported some involvement in adherence compared with 32.3% of control	VA sample
Risbud et al. (2022) ⁸¹	n=15 dyads, 1 triad Mixed (78%) Age 59 (±12)	Understand the positive relationship and emotional experiences that lead to perceived success with managing healthcare	Themes: 1) Patient-family dyads with shared care networks experienced positive mindsets about living with HF and health management 2) Dyads who reported strong relationship and love as primary motivators to handle health together perceived good quality of life and success with management 3) Mutual care between individuals in a dyad resulted in cooperative health management and positive outlooks on life with HF	Sample
Sampaio et al. (2019) ⁸²	n=10 Mixed (100%) 70/50-85	Explore meaning of being a family caregiver their own home and to gain an understanding of how dignity is upheld	Themes: 1) Struggle between inner force and sense of duty 2) Struggle between feelings of burden and security	Sample
Schutz & Walthall (2022) ³¹	n=17 no demographic data collected	Explore the experiences and needs of caregivers	Themes: 1) Taking on the role of caregiver 2) Getting to grips with being a caregiver 3) Impact on own health and wellbeing 4) Need for information and support	Sample
Sebern et al. (2018) ³²	n=32 (caregivers) n=58 (patients) n=67 (clinicians) Mixed sample (75%) Age 72 (±5)	To conduct a formative evaluation of the iPad-Enhanced Shared Care Intervention for Partners (iSCIP)	Themes: 1) Self-management education (shared burden, fatigue, depression, anxiety, need for nutritional guidance) 2) Shared care (shared communication) 3) Shared values (value not being a burden, value autonomy, value activities with family and friends) 4) Care preferences (shared activities, shared symptoms monitoring, barriers to mobilizing family and paid resources) 5) Care planning (vulnerability of both care partners, communication with family) 6) Palliative care (request for information about palliative care & prognosis, preference	Sample

Author	Sample (Male, Female, Mixed Sample (%female) Mean age (+/- SD) or Median/Range)	Purpose*	Findings (Qualitative Themes, Quantitative Summary)	Limitations
			for information about prognosis, complex decision)	
Sedlar et al. (2020) ⁸³	n=21 Mixed sample (81%) Age 60 (±14)	Explore the views about personal experiences, perceived needs, and barriers to optimal management	Themes: 1) Impact of HF on everyday life 2) Barriers to HF self-care 3) Psychological and social support difficulties 4) Barriers to effective healthcare in HF clinic	Sample
Shahrbabaki et al. (2016) ⁸⁴	n=3 (caregivers); n=11 (patients) n=6 (clinicians) Female (100%) Age 64	Explore obstacles to coping related to support	Themes: 1) Inadequate family performance 2) Lack of emotional support 3) Lack of physical care 4) Lack of knowledge	Sample
Slightam et al. (2022) ⁴⁹	n=14 dyads Female (100%) Ages not reported	Understand and identify shared recommendations to improve self-care	Themes: 1) Couples and clinicians believe that improvements are still needed to existing HF education, especially the need to be tailored to learning style and culture 2) Couples and clinicians believe that technology can facilitate better HF care 3) Couples and clinicians believe that caregiving partners are part of the self-management team and should be involved in care management to support the person with HF 4) Caregiver role reversal (the spouse is sicker than the person with HF) 5) Relationships with poor or ineffective communication (e.g., a 'nagging' spouse)	VA sample
Stamp et al. (2016) ⁸⁵	n=117 dyads Caregiver gender not reported Caregiver ages not reported	Examine the association of family functioning, confidence and motivation and determine if a family partnership intervention would promote higher levels of perceived confidence and treatment self-regulation (motivation)	Quantitative summary: The family partnership intervention group significantly improved confidence and motivation at four months. High perceived confidence increased significantly at four months. There were no group or time effects for perceived confidence in diet when compared with a control group	Missing information on sample. High attrition rate
Strøm et al. (2015) ³⁶	n=19 Mixed (89%) Age 63/45–83	Explore next of kin's experiences of invisible care and the inherent responsibilities in caring for a relative	Themes: 1) "Being on the alert", refers to staying alert day and night whether the next of kin is with the CHF patient or not and whether the necessity for vigilance is real or assumed 2) "Being a forced volunteer"	Sample
Sullivan et al. (2016) ¹⁶	n=63 (caregivers) n=63 (patients) Mixed (76%) Age 60	Gain a deeper understanding of the caregiving experience and describe the needs and concerns expressed by caregivers	Themes: 1) Competence concerns about performance of caregiving tasks 2) Compassion maintenance 3) Vigilance behaviors 4) Regulating patient activities 5) Providing emotional support 6) Caring for self; having multiple responsibilities 7) "Addressing practical things like power of attorney and a will"	Data collected from 2005–2007
Tavakoli et al. (2018) ³⁸	n=7 (caregivers) n=3 (patients) n=4 (clinicians) Mixed (86%) Age 43/33–51	Obtain a deep understanding of the educational needs caregivers to empower them to carry out proper caregiving and describe	Themes: 1) Need basic care management education to meet patients' basic needs, manage their critical situations, and help them achieve a higher quality of life 2) Care with dignity: respecting patients, empathy, and caregivers' accountability	Sample

Author	Sample (Male, Female, Mixed Sample (%female) Mean age (+/- SD) or Median/Range)	Purpose*	Findings (Qualitative Themes, Quantitative Summary)	Limitations
		strategies needed to continue care	3) Resilience development: Maintaining the physical and psychosocial health of the caregivers, challenge management using internal and external resources, promoting participatory care, motivation & not getting burnt out, and vigilance	
Wingham et al. (2015) ¹⁸	n=26 Mixed (73%) Mean age 66/39–84	Identify the needs of caregivers to inform the development of a caregiver resource to be used as part of a home-based self-management program	Themes: 1) Providing support, including coping with uncertainty, what to do in an emergency, hypervigilance 2) Transition to becoming a caregiver, including sense making, experimenting to find what works and what doesn't, communication with health professionals, managing own mental and physical health, and managing home and work 3) Engaging help, including concern of being a burden, need to develop skills to engage social support, voluntary and formal services	
Wingham et al. (2017) ⁸⁶	n=22 Mixed (73%) Age range 39–84 (only age range provided)	Identify factors that contribute to the experience of anguish and understand how caregivers learn to live with what is frequently a challenging and demanding role	Themes: 1) Emotional impact, including fear for the future, uncertainty, and anticipatory grieving 2) Role definition and psychological adjustment to new role, including reduced resilience, physical care through the day and night, learning care skills, complex and ever-changing medication regime, role conflict, caregivers with their own serious health needs 3) Exclusion by the cared-for person and by health professionals 4) Ignoring one's own health	Secondary data analysis
Wingham et al. (2019) ⁵⁰	n=44 caregivers in the control group n=53 in intervention n=20 in the qualitative interviews Mixed (78%) Age 63 (+/-15) intervention group 68 (+/-11) years control group	Compare the caregiver outcomes between the REACH-HF and control groups and to report views and perceptions of caregivers on their experience of using the intervention	Qualitative: Themes: Most caregivers who received the intervention made positive changes to how they supported the patient, and perceived they had increased confidence in the caregiver role over time Quantitative: Summary: Intervention group had a higher mean CC-SCHFI confidence score at 12 months. No significant between group differences were seen in other caregiver outcomes	Patients not caregivers were randomized. Sample size powered patients.
Wooldridge et al. (2019) ⁸⁷	n=27 dyads Mixed (93%) Age 62 (±12)	Examine communal coping among patient-caregiver dyads	Themes: 1) Collaboration depends on the specific self-management behavior 2) Collaboration extends beyond HF and includes managing the health of both patients and caregivers 3) Collaboration varies by whether dyads agree that HF is a shared problem	Secondary data analysis
Wu et al. (2019) ⁸⁸	n=43 dyads Mixed (71%) Age 55 (±15)	Test the efficacy of a multi-component, family-focused, literacy-sensitive (FamLit) intervention on medication adherence in HF patients	Quantitative Summary: At 3-months, intervention had significantly better medication adherence than control At 6 months, intervention effect on adherence was sustained and decreased in the control Significant interaction for group by time, non-significant trend toward improvement in care partner attitudes/knowledge, perceived behavioral control, perceived support, but little or no change, or lower scores in control group from baseline to 6 months	Sample

Table 3.

Study Demographics

	Qualitative	Quantitative	Mixed Methods
Number of Studies	50 ^{15,16,18,19,22-28,31,32,35,36,38,40-42,49,53-60,62,64-72,74-79,81-84,86,87}	7 ^{21,61,63,73,80,85,88}	7 ^{29,30,37,39,50,89,90}
Publication years	2013–2022	2013, 2015–2016, 2018–2019, 2021–2022	2013, 2015, 2017, 2019, 2022
Country of Origin (# of studies)	Australia (1) ⁵⁹ Canada (2) ^{19,24} India (2) ^{27,70} Iran (4) ^{38,54,64,84} Italy (3) ^{23,55,79} Jordan (1) ⁵³ Lithuania (1) ²² Norway (3) ^{22,35,36} Portugal (1) ⁸² Slovenia (1) ⁸³ South Korea (1) ⁶⁸ Sweden (3) ^{41,66,78} United Kingdom (7) ^{15,18,19,31,58,77,86} United States (22) ^{16,19,25,26,28,32,40,42,49,56,57,60,62,65,67,69,72,74-76,81,87} Not specified (1) ⁷¹	Australia (1) ⁶³ Japan (1) ²¹ Sweden (1) ⁷³ United States (4) ^{61,80,85,88}	Sweden (1) ²⁹ United Kingdom (1) ⁵⁰ United States (5) ^{30,37,39,89,90}
Sample Size (range of # of participants)	Caregivers (3 – 530) Patients (4 – 221) Dyads (11 – 47) Other* (5 – 67)	Caregivers (43 – 126) Patients (43) Dyads (37 – 369)	Caregivers (13 – 72) Patients (30)
Caregiver Relationship (# of studies)	Spouse/Partner (42) ^{15,16,18,19,22,24-26,28,31,32,35,36,38,41,49,53-58,60,64,66-69,71,72,74-79,81-84,86,87} Daughter/Son (36) ^{15,18,19,22,24,28,31,35,36,38,41,53-58,60,64,66-69,71,72,74-79,81-84,86} Daughter-In-Law/Son-In-Law (3) ^{53,83,84} Mother/Father (5) ^{22,24,60,72,81} Sibling (4) ^{60,71,74,81} Grandchildren (5) ^{28,31,69,77,83} Family Members (7) ^{19,41,54,56,57,64,74} Friends (10) ^{19,24,28,56,67,69,71,74,81,83} Other, Not specified (4) ^{53,68,74,79} Not reported (8) ^{23,27,40,42,59,62,65,70}	Spouse/Partner (4) ^{21,61,73,85} Daughter/Son (3) ^{21,61,85} Daughter-In-Law/Son-In-Law (1) ⁸⁰ Mother/Father (1) ⁶¹ Sibling (3) ^{21,61,85} Family members (2) ^{21,80} Friends(2) ^{21,80} Other, Not specified (3) ^{21,61,85} Not reported (2) ^{63,88}	Spouse/Partner (7) ^{29,30,37,39,50,89,90} Daughter/Son (2) ^{30,37} Daughter-In-Law/Son-In-Law (1) ³⁹ Mother/Father (1) ³⁰ Sibling (1) ⁸⁹ Family members (1) ⁵⁰ Friends (1) ⁵⁰ Other, Not specified (3) ^{30,37,39} Not Reported (1) ⁹⁰

Note. *Physicians, nurses

Table 4.

Categories of Caregiver Activities Supporting HF Self-Care

Activities	Self-Care Domains		
	Domain-specific examples (# of studies)		
	Maintenance (n=58)	Monitoring (n=35)	Management (n=30)
Physical Activity	Engaging in or promoting exercise 16,18,23–25,27,32,37,40,41,62,67,72,79,87,89,90	Monitoring for safety 37	
Diet + Fluids	Planning, shopping, preparing, and tracking meals 15,16,19,21,23,25,27,29,32,37,39,40,42,49,55,56,61,64,67,68,70,79,81–85,87,90		
Medications	Obtaining, organizing, observing administering, tracking 15,18,19,21,23–32,35–37,42,49,50,53–55,57,61–63,67,70,75–78,80–88	Monitoring side effects and medication lists 28,29,53	
Medication Administration	Routine medications 23,25,28,54,76		In response to symptoms (e.g., extra diuretic dose with ankle edema) 18,23,27,37,61
Motivational/ Emotional Support	16,18,19,22,23,27,29,32,55,57,59,62,65,71,72,79,83	15,18,22	81
Medical Appointments	Coordinating and attending routine appointments, advocacy 15,18,23,24,29–31,35,38,41,53,55,57,62,77,78,80,81,87		In response to symptoms, advocacy 22,23,39,41,54,66,81,82
Symptom monitoring		Body monitoring, signs/symptoms, weight, vigilance, comorbidities 15,16,18,19,22,23,25–32,35,36,41,49,50,54,56,57,61,65,71,74,79,81,82,84,86	Adapting symptom monitoring in response to ankle edema, caregiver changes routine in response to symptoms 23,26
Monitoring blood pressure and heart rate		19,24,25,27,28,30,89	
Communication with healthcare providers		Sharing tracked information during appointments, sending information using portals/ telemonitoring systems/ apps 22,24,27,28,31,41,49	In response to signs/symptoms, managing telemonitoring apps 18,24,25,27,29,31,49,64,66,67,79
Tracking clinical data		Vital signs, weight, urine output, symptoms 22,24–27,29,30	24,25
Training/ Mastery		Developing strategies, overseeing devices 22–24	
Patient education		To do monitoring, to recognize signs/symptoms 23,79	
Symptom Management			Treatment implementation, making care decisions, managing comorbidities, managing psychologically distressing factors, seeking emergency care, CPR 18,19,22–24,27,37,38,56,58,60,63,69,72,73

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