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# The importance of interactions between patients and healthcare professionals for heart failure self-care: A systematic review of qualitative research into patient perspectives

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Kay Currie<sup>1</sup>, Patricia H Strachan<sup>2</sup>, Melisa Spaling<sup>3</sup>, Karen Harkness<sup>2</sup>,  
David Barber<sup>1</sup> and Alexander M Clark<sup>4</sup>

## Abstract

**Background:** Effective heart failure (HF) self-care can improve clinical outcomes but is dependent on patients' undertaking a number of complex self-care behaviors. Research into the effectiveness of HF management programs demonstrates mixed results. There is a need to improve understanding of patient perspectives' of self-care need in order to enhance supportive interventions.

**Aim:** This paper reports selected findings from a systematic review of qualitative research related to HF self-care need from the patients' perspective. The focus here is on those facets of patient-healthcare professional relationships perceived by patients to influence HF self-care.

**Method:** We searched multiple healthcare databases to identify studies reporting qualitative findings with extractable data related to HF self-care need. Joanna Briggs Institute systematic review methods were employed and recognized meta-synthesis techniques were applied. Critical realist theory provided analytical direction to highlight how individual and contextual factors came together in complex ways to influence behavior and outcomes.

**Results:** Altogether 24 studies (1999–2012) containing data on patient-healthcare professional relationships and HF self-care were included. Interaction with healthcare professionals influenced self-care strongly but was notably mixed in terms of reported quality. Effective HF self-care was more evident when patients perceived that their healthcare professional was responsive, interested in their individual needs, and shared information. Poor communication and lack of continuity presented common barriers to HF self-care.

**Conclusion:** Interactions and relationships with clinicians play a substantial role in patients' capacity for HF self-care. The way healthcare professionals interact with patients strongly influences patients' understanding about their condition and self-care behaviors.

## Keywords

Communication, professional-patient relationship, heart failure, self-care, systematic review, qualitative research

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## Introduction

Relationships between patients and healthcare professionals are integral to effective healthcare but research into healthcare interventions mostly focuses on the nature and effects of intervention components and content. Interactions between the patients and healthcare professionals involved in interventions are comparatively neglected, despite policy and research suggesting these

<sup>1</sup>School of Health and Life Sciences, Glasgow Caledonian University, Scotland

<sup>2</sup>School of Nursing, McMaster University, Canada

<sup>3</sup>Faculty of Nursing, University of Alberta, Canada

<sup>4</sup>University of Alberta, Canada

### Corresponding author:

Alexander M Clark, University of Alberta, 4th Floor Clinical Sciences Building, Edmonton, Alberta, T6G 2G3, Canada.

Email: alex.clark@ualberta.ca

are important. This imbalance in focus is typified in relation to interventions to promote self-care in patients with one of the most burdensome of chronic health conditions: heart failure (HF).

HF is a common and severe condition in high-income countries: it affects 6–10% of the over 65 population, with rates set to increase by 25% by 2030.<sup>1</sup> Whilst HF is associated with high health care costs in high-income countries, it also severely reduces patients' quality of life.<sup>2</sup> International guidelines reiterate the importance of education and support for HF self-care to enable patients to monitor and manage the syndrome at home, maximize wellbeing, reduce mortality and minimize avoidable hospital readmission.<sup>3–7</sup>

Physiological research has identified which health behaviors can reduce demands on the heart and improve its performance during HF.<sup>6</sup> These include smoking cessation, fluid/weight management and monitoring, salt and alcohol restriction, and regular moderate physical activity. Evidence-based prescribing practices and adherence with key medications can also significantly lengthen and improve patients' lives.<sup>5,8</sup> However, patients often find it challenging to engage in numerous self-care behaviors that require ongoing commitment, alongside coping with comorbidities and daily living.

Many interventions have been designed to improve HF self-care and its outcomes. Most commonly, these have been disease management programs delivered by multi-disciplinary healthcare teams, with patient education to support self-care often provided by specialist nurses in clinics or the home. However, despite knowledge of what behaviors are needed for HF self-care, a comparatively large number of interventions and some encouraging early results, recent systematic reviews indicate that the evidence for the effectiveness of these programs is equivocal,<sup>9,10</sup> with Lainscak et al.<sup>7</sup> concluding there is limited strong evidence that self-care interventions can improve symptoms or prognosis.

Responding to this, Clark and Thompson<sup>11</sup> argued that a new theoretical paradigm for research into interventions is required which acknowledges the complexity of interventions and their effects, recognizing that components and content are not the sole determinants of outcomes.<sup>12</sup> Rather, outcomes can be influenced by the people providing the intervention, its recipients, and the processes through which these parties interact. This recognition is echoed in health policy via the growing emphasis on the importance of person-centered care and shared decision-making.<sup>13–15</sup> This approach encourages healthcare professionals to be responsive to patient preferences, needs and values, and to share responsibility for care and its outcomes. Yet, despite these policy directives, a recent review<sup>16</sup> indicated that poor patient-provider communication, collaboration, and lack of patient

access to information are common. These lead to ineffective self-care, avoidable patient suffering, and wasted resources. Crucially, research is needed that moves beyond simplistic views of intervention outcomes to address the complex links between interventions, their effects, context, and patient-provider processes and relationship.<sup>16,17</sup> Particularly, barriers and facilitators of effective HF self-care need to be identified.

To respond to these issues, and having identified that no comparable systematic review was already published, we conducted a meta-synthesis of qualitative research,<sup>18</sup> to understand HF self-care in terms of patients' own self-care management techniques and how elements of context affect HF self-care, identifying barriers and facilitators of self-care actions.

The objective of the systematic review was to identify and synthesize evidence on HF self-care needs from the perspective of patients who experience this condition. Subsequently, meta-synthesis highlighted a significant category of data related to the patient experience of interactions with healthcare professionals. The findings reported here relate to a subset of the data from the main study and focus on factors associated with patient-healthcare professional interactions.

## Methods

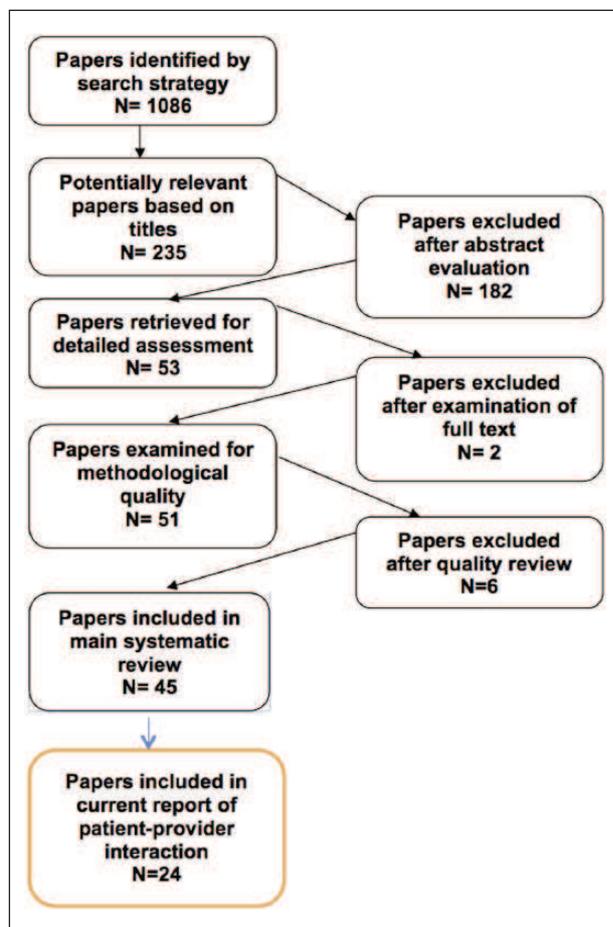
Our inclusion criteria sought studies reporting primary qualitative data from full papers/theses and contained specific data from adults  $\geq 18$  years related to self-care needs in HF, defined by the research team as 'findings related to any process, phenomena or construct that pertains to meeting the self-care needs of HF in patients.'

Due to marked changes in the management of HF since 1995, the search was limited to papers published after 1995. Only papers reported in English were reviewed due to limitations in translation resources. The search was completed in March 2012. Our search strategy used an extensive qualitative research design filter containing over 100 terms to combine general and specific terms in relation to HF and self-care to search multiple health related databases. Reference lists of relevant papers were manually searched for additional sources. Identified papers were screened for relevancy first by their titles/abstract. Papers which appeared to be potentially relevant were then full-text screened against the inclusion criteria.

The systematic review was managed using the Joanna Briggs Institute 'Qualitative Assessment and Review Instrument' (JBI-QARI) ([www.joannabriggs.edu.au](http://www.joannabriggs.edu.au)). The quality of all included studies was assessed using the JBI-QARI critical appraisal tool. Title, full-text screening, and quality appraisal involved independent assessment by two reviewers, with any disagreements resolved by consensus

**Table 1.** Overview of findings: barriers and facilitators of heart failure self-care based on patients' experiences of interactions with healthcare providers.

Contextual category: healthcare provider	Themes	Included studies (first author name)
<b>Barriers to self-care</b>	Poor communication	Mead, <sup>20</sup> Granger, <sup>21</sup> Scotto, <sup>22</sup> Wu, <sup>23</sup> Boren, <sup>24</sup> Kaholokula, <sup>25</sup> Glassman, <sup>26</sup> Stromberg, <sup>27</sup> Riegel, <sup>28</sup> Clark, <sup>29</sup> Helleso <sup>30</sup>
	Lack of information or explanation	Mead, <sup>20</sup> Wu, <sup>23</sup> Boren, <sup>24</sup> Kaholokula, <sup>25</sup> Glassman, <sup>26</sup> Clark, <sup>29</sup> Rodriguez, <sup>31</sup> Schnell, <sup>32</sup> Weierbach, <sup>33</sup> Riegel, <sup>34</sup> Tully, <sup>35</sup> Clark, <sup>36</sup> Ming <sup>37</sup>
	Poor continuity of care	Mead, <sup>20</sup> Boren, <sup>24</sup> Tully, <sup>35</sup> Brannstrom, <sup>38</sup> Falk, <sup>39</sup> Horowitz, <sup>40</sup> Mahoney <sup>41</sup>
<b>Facilitators of self-care</b>	Effective listening and respect	Mead, <sup>20</sup> Scotto, <sup>22</sup> Wu, <sup>23</sup> Boren, <sup>24</sup> Glassman, <sup>26</sup> Riegel, <sup>28</sup> Clark, <sup>29</sup> Schnell, <sup>32</sup> Riegel, <sup>34</sup> Tully, <sup>35</sup> Ming, <sup>37</sup> Brostroem <sup>42</sup>
	Interventions, information and support	Mead, <sup>20</sup> Boren, <sup>24</sup> Glassman, <sup>26</sup> Crowder <sup>43</sup>

**Figure 1.** Selection process.

among the research team. Figure 1 presents a flow chart of the selection process.

Qualitative data were extracted, categorized and synthesized by re-assembling the findings on the basis of similarity in meaning. Verbatim findings pertaining to HF self-care were first imported into an analytical matrix

from all included studies. Recognised meta-synthesis approaches were applied<sup>19</sup> whereby findings were re-read in a multi-stage process in light of each other, reorganized via an inductive process (i.e. no pre-determined analytical framework at this stage) and compared to generate novel lower-order themes, agreed by the research team. As meta-synthesis involves data being re-analyzed to produce new theory or knowledge, no study was excluded based on appraised quality alone, if adequate data was provided to illustrate authors' interpretation of findings. Emergent themes and synthesized categories were discussed by all team members to ensure continued focus on the review aim. Critical realist theory was applied to guide development of the final synthesis, in terms of how individual and contextual factors came together in complex ways to influence human behavior and outcomes.<sup>12</sup> One such synthesized contextual category was 'healthcare professionals', the findings of which are presented in this paper.

## Findings

### Review results

Twenty-four papers published between 1999–2012 met the criteria for inclusion in the review and synthesis of patient experiences and reactions to healthcare professionals (see Appendix 1). Studies involved a total of 699 patients (range: 5–387 participants; gender balance undetermined; age range: 28–93 years), 42 caregivers and 21 healthcare professionals; we focus here on findings reflecting the patient perspective. With some exceptions, populations were predominantly Caucasian and urban dwelling. Studies were conducted in North America (16), Scandinavia (5), the UK (2), and Malaysia (1). Study quality was variable with common weaknesses being superficial analyses of themes, over-reliance on convenience sampling, and inadequate inclusion of participant voices/illustrative quotations.

Analysis of data within the contextual category 'healthcare professionals' identified a range of themes related to self-care support as voiced by patients, emerging broadly as either barriers or facilitators (Table 1). The included studies consistently reported the influence of the quality of healthcare professional interactions on self-care and its outcomes. Generally, effective communication provided support for patient adherence to self-care recommendations. Conversely, perceived lack of support arising from poor communication from healthcare professionals was seen to harm HF self-care.

### Barriers to effective self-care

The contextual category of 'Barriers to effective self-care' encompassed three themes; poor communication; lack of information or explanation; poor continuity of care.

Twenty-two studies highlighted various aspects of perceived poor interactions with healthcare professionals, seen to alienate patients from participating in their own care<sup>20</sup> and contribute to low adherence to prescribed regimen.<sup>21–23</sup> Patients cited a range of examples of poor communication, including that which was seen to be impersonal,<sup>24,25</sup> indifferent to the individual patient,<sup>26,27</sup> overly 'clinical',<sup>28</sup> 'one-way',<sup>20</sup> and lacking in patient support,<sup>22,29</sup> or respect.<sup>30</sup>

*I felt at times that I would go to my doctor and I said 'I am not coping well with this or that.' He said 'Well, what do you expect? You have got a bad heart.' And before I knew it, I was out the door. I said (to myself) 'Wait a minute I didn't even get a chance to ask him anything!' I could have done with a bit more advice on how to cope (p.455).<sup>29</sup>*

*I wanna tell my doctor 'this is how I feel and it's important to listen to how I feel.' You don't only have to be competent, you have to be caring (p.73).<sup>20</sup>*

Inadequate explanation of pertinent information was noted as problematic, specifically around: the nature of HF,<sup>24,25,29,31,32</sup> HF medications and their side effects<sup>20,23,25,26,29,33</sup> and dietary sodium intake,<sup>34</sup> e.g.

*I wish someone would have told me how it was going to be. I wish they had told me more about it. All that I went through, I didn't know anything about that... I was constantly in the hospital... every two to three days... and it was frightening... scary (p.90).<sup>24</sup>*

Poor information regarding commonly prescribed medications was especially challenging for patients. Inadequate understanding contributed to low adherence to the medication regimen and patients struggled to work out the effects of their medication.<sup>26</sup> Even when patients received information leaflets, they did not feel adequately informed<sup>35</sup> and reported preferring to discuss medications rather than rely on reading materials.<sup>20,26</sup>

*My heart is not going fast enough to pump the water away and I wasn't taking my water pills the way I should have. I didn't realize how important the water pills were... Nobody explained how important it was to me. I just got fed up taking them, running to the toilet. If I had realized how important it was, I wouldn't have stopped it. I just didn't bother because nobody else was bothering (p.455).<sup>29</sup>*

Lack of continuity of care was also identified as a barrier to self-care. Frequent changes of healthcare provider or conflicting advice between hospital and family medical services led to treatment plans and instructions being seen by patients as inconsistent.<sup>20,24,35,38–41</sup> Patients also experienced problems obtaining adequate access to providers<sup>20</sup> due to limited consultation times and difficulties making appointments.<sup>24,35</sup>

Ultimately, patients viewed healthcare professionals as responsible for the quality of information provided. However, patients could adversely affect the quality of interactions by deliberately avoiding asking questions, despite wanting clarification, or not sharing relevant information with healthcare professionals.<sup>24–26,36</sup> Such behaviors may be considered characteristic of 'passive' patients, or those who simply choose to 'trust' their physicians.<sup>37</sup> Alternatively, they may reflect over-riding patient preconceptions, for example, that doctors are too busy or patients are unqualified to ask questions.<sup>24,36</sup>

*I have a hard time asking questions... I guess I really and truly didn't want to inconvenience them if there was nothing wrong. I thought maybe they would tell me it was all in my head (p.88–89).<sup>24</sup>*

*I have a problem with different doctors. You come in and get one doctor and then you come again and get another one. One doctor prescribes something and then another doctor says, 'Oh no, why'd he prescribe this?' (p.72).<sup>20</sup>*

### Facilitators of self-care

The contextual category of 'Facilitators to effective self-care' encompassed two themes; effective listening and respect; interventions, information and support.

In contrast to the barriers presented above, high quality interactions were seen to support self-care in thirteen studies. Ready access to healthcare professionals,<sup>20,23</sup> effective listening and respect enabled patients to participate in their self-care. This was evident in patient descriptions of the patient-healthcare professional relationship as an 'active partnership'.<sup>22,24,26,28,34,35,37,42</sup>

*They listen... like my input... I feel so much better. They don't argue with me... respect me as a person. That is really, really important to me... they are interested in me (p.91).<sup>24</sup>*

Patients especially valued healthcare professionals who were perceived to openly share information<sup>24,37,42,43</sup> and

provided a range of options, yet respected patients' choices.<sup>28,32,34</sup>

*The approach of doctors in Penang is very different from the doctors in U.S. The doctors in U.S. will come and talk to me, tell me about my condition and what they plan to do. They will also ask my opinion (p.573).<sup>37</sup>*

Although reported in only one study, pharmacists were seen to promote self-care adherence by supporting patient capacity for medication management.<sup>29</sup>

Disease management programs or support groups were cited as positive and safe learning environments for patients, providing effective and consistent information.<sup>20,24,26,43</sup> Programs were perceived to enhance self-care,<sup>24,26</sup> through increased formal knowledge of HF, particularly of medications<sup>26</sup> and informal knowledge, particularly through development of skills relevant to the patient's personal context.<sup>43</sup> Notably, programs appeared to bridge the gap between knowledge and action, particularly among women who reported learning to perceive symptoms as meaningful and connected to HF.<sup>24</sup> Patients also reported learning strategies to improve both communication with healthcare professionals and confidence during consultations.<sup>26</sup> In this way, the didactic knowledge provided by programs was made understandable, meaningful, and *useable* to patients.

*If I hadn't gone to the HF clinic, I wouldn't be here. I'm convinced of that because even though I had finally gotten diagnosed with HF before I went, I didn't get the education on how to live with HF. I was still killing myself, not on purpose, I just didn't know (about salt and fluid restriction). Now I have learned to maintain a proper diet, to control liquids and sodium (p.32).<sup>43</sup>*

## Discussion

To our knowledge this is the first systematic review exploring patient perspectives of self-care need in HF, specifically reporting on those aspects of interactions with healthcare professionals which patients report as helpful or hindering. Adopting Clark and Thompson's<sup>11</sup> recommendations for a new paradigm of research into HF programs, this synthesis points to the importance of complex individual and contextual factors which influence patient-professional interactions and subsequent patient self-care. Effective communication and high continuity of care to promote high levels of patient knowledge are central aims of healthcare professional practice. Yet, despite these aims, many patients in the studies reviewed reported basic deficits around these elements. Effective self-care was consistently supported when patients perceived healthcare professionals to be accessible, listening, respectful and collaborative in their approach. Conversely, the detrimental impact of inconsistent advice, poor communication,

lack of empathy or personal regard for patients who are juggling the demands of self-care with other social roles and personal values is clear. Whilst the studies included in this review were published over a significant time-frame and carried out in a range of geographical contexts, the consistency of these barriers and facilitators of self-care was notable.

International guidelines for management of HF<sup>3-7</sup> highlight the importance of patient education for self-care. Findings from this review endorse these recommendations but show that this care is often lacking. Further, our synthesis offers new and useful insights into patients' perspectives of what makes interaction with healthcare professionals more, or less, effective in supporting HF self-care. Interactions between patients and healthcare professionals are potentially as important to outcomes as program content, highlighting the need to focus on a more complex inter-play of factors in the design and delivery of HF programs. An important element of HF support in this context is not necessarily then what providers think the content of interventions should be, rather how does the intervention support effective patient-healthcare professional relationships, aiming to enhance communication and thus patient learning.

The finding that processes around communication and relationships contribute to effective self-care has precedents. The positive impact of effective communication on the patient-provider relationship is supported by Fuertes et al.<sup>44</sup> study of the cognitive-emotional aspects (or 'working alliance') of the physician-patient relationship endorsed in a range of chronic conditions. They found that the working alliance relationship is stronger when patients have higher perception of the usefulness of the treatment, believe they can adhere to the treatment plan, and are satisfied with the relationship. Fuertes et al.<sup>44</sup> determined that the 'working alliance' is associated with higher levels of patient satisfaction and adherence to treatment. Similar conclusions were reached by Haskard and DiMatteo<sup>45</sup> whose meta-synthesis of 127 studies found significant positive correlations between healthcare professional-patient communication and adherence to treatment regimens. Physicians who had received communication training achieved 'substantial and significant improvements in patient adherence (p.826).

The importance of communication skills is recognized more broadly in various aspects of the management of long term conditions. Jagosh et al.<sup>46</sup> conducted a qualitative study involving 58 patients who experienced a variety of long term conditions, highlighting the importance of physician 'listening' as a means of fostering and strengthening the doctor-patient relationship. Similarly, in a systematic review of factors influencing self-care in diabetes, Wilkinson et al.<sup>47</sup> report themes of 'respectful communication' where both patient and provider opinions were valued, and 'disrespectful communication', perceived as

'rude, creating the perception that the opinion and experience of the individual are of little value' (p.6). Their conclusions echo a key finding from our meta-synthesis in relation to the need for reciprocal, respectful relationships based on effective listening to understand patients' needs.

Other work has provided insights into how healthcare professionals can harness supportive relationships to improve self-care. The study of Kosmala-Anderson et al.<sup>48</sup> involved a cross-sectional survey of 482 clinicians and longitudinal cohort survey of 114 clinicians using self-determination theory to explore factors influencing healthcare professionals' engagement in support for self-care. They found that professionals who felt competent and confident to deliver support, possibly after training, and those who had some degree of autonomy to decide how they would offer support, were most likely to engage in this type of activity.

Whilst patients in the studies we reviewed indicated that lack of continuity of care or other system constraints such as difficulties making appointments or feeling rushed were problematic, Legare et al.'s<sup>15</sup> systematic review of barriers and facilitators to shared decision-making noted that healthcare professionals also reported lack of time as a barrier to shared decision-making. Thus, a combination of interpersonal and organizational factors can impede effective support for patient learning in self-care.

This meta-synthesis is inevitably limited by the quality of the data incorporated into the systematic review. We incorporated all substantiated data within our analysis, regardless of the quality appraisal of the original study. Some studies were methodologically strong, others less so. Philosophical perspectives were evident and coherent in some works, again less so in others. This may have influenced the findings of these individual studies and therefore the data incorporated within our meta-synthesis. Similarly, due to translation constraints, we sought only studies published in English, and others may have been excluded. Despite these limitations, we feel that the findings remain valid in relation to our original aim; to synthesize qualitative evidence on HF self-care needs from the perspective of patients.

Finally, the research studies reviewed here tended to focus on physician-patient interactions. As much of the patient education and ongoing support for self-care in HF is provided by specialist nurses, further research investigating nurse-patient interaction in this context is recommended.

## Conclusions

The nature of the patient-healthcare professional relationship is pivotal to enhancing the patient experience of support for self-care. Our findings endorse the need for healthcare professionals to develop and apply effective communication skills in order to establish the types of reciprocal relationships that foster patient confidence.

Organizational structures exert a powerful contextual influence on the ability of healthcare professionals to establish the type of beneficial relationships necessary to support self-care effectively. Lack of continuity of care by frequent changes of practitioner and time constraints on consultations present significant barriers to relationship formation. Models of care where members of specialist teams are consistently available and able to provide information and regular support, were highly valued by patients. Managers need to support self-care by ensuring sufficient consultation times to allow supportive relationships to be established.

The growing emphasis on person-centered care and shared decision making means that the need to develop professional knowledge and skills in order to communicate more effectively with patients is ever more pressing. Whilst our findings may appear 'common sense' to some, the patient perspectives highlighted here indicate it is clearly not 'common practice' for many, and important messages for practice remain. This meta-synthesis has provided internationally derived evidence on important dimensions of patient-healthcare professional interactions in the context of support for self-care in HF.

## Implications for practice

- HF interventions should involve the formation of respectful partnerships for patient support.
- Training in listening and questioning skills, to elicit patient concerns and evaluate patient learning, is needed.
- HF patient education should focus not only 'what' the patient needs to know, but 'how' they can apply that learning in the more complex reality of their daily lives.
- Healthcare professionals should review current working practices to provide more tailored, individualized packages of HF support.

## Conflict of interest

The authors declare that there is no conflict of interest.

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**Appendix I.** Quality appraisal and methodological descriptions of included studies (n=24).

First author (study setting)	Quality rank L/M/H	Main strengths (+) and weaknesses (-)	Method/s	Sampling strategy	Sample Pt, HP, Cg (male/female)	Mean age and/or range (sex)
Boren <sup>24</sup> (USA)	H	+ Congruity between research methodology and interpretation of results; strong grounded theory approach - Some inconsistency is where data originates from; Discusses data collected in the study data but also data collected within the author's nurse practice	SSI	Convenience	15 Pt (0/15)	28–76
Brannstrom <sup>38</sup> (Sweden)	M	+ Detailed presentation of themes and sub-themes; participants are adequately represented in the themes/findings - Participants recruited from single site; limited description of data analysis	UI	Convenience	15 HP (11/4)	37–65
Brostroem <sup>42</sup> (Sweden)	M	+ Research methods are well-described; data analysis conducted by two researchers to ensure reliability - some quotes do not appear to support researchers' interpretations/themes	SSI	Purposive	20 Pt (13/7)	55–85 (F); 38–82 (M)
Clark <sup>29</sup> (UK)	M	+ Congruity between the research questions and research design; study participants are adequately represented; quote identifiers are used - Limited information on data analysis, researcher position, caregiver demographics	SSI	Convenience; purposive	50 Pt (33/17) 30 Cg (NR)	68 (F); 67 (M) Pt only
Clark <sup>36</sup> (Canada)	H	+ Congruity between research methodology and methods; participants are adequately represented - characteristics of caregivers in sample is not clear	SSI	Convenience; quota	42 Pt (27/15) 30 Cg (NR)	76 Pt only
Crowder <sup>43</sup> (USA)	M	+ Congruity between data collection and analysis procedures; insightful observations pertaining to patients' motivation for participating in HF clinic - Findings seem generic; paper lacks a theoretical framework	SSI	Convenience	15 Pt (4/11)	70.2 51–89
Falk <sup>39</sup> (Sweden)	M	+ Clear description of data analysis; provides sample data for all main categories - Interview questions not provided; illustrative quotes are sometimes rather mundane	SSI	Purposive	17 Pt (12/5)	72 55–83
Glassman <sup>26</sup> (USA)	M	+ Detailed systematic research approach; use of independent auditor to verify transcripts - Small number of participants; quotes appear to draw from few participants; some data seems repetitive	UI	Convenience; purposive	5 Pt (3/2)	77.2 60–85
Granger <sup>21</sup> (USA)	M	+ Congruity between theoretical framework and interview guide and approach to analysis; unique focus on patient-physician dyads - Findings appear to be congruent with data collection and analysis, however, there is little patient data to substantiate results	SSI	Purposive	6 Pt (5/1) 6 HP (3/3)	58 Pt only
Helleso <sup>30</sup> (Norway)	M	+ Basic interpretive descriptive approach; rationale for data collection approach given - Sample not well described; quote identifiers not used; themes appear superficial	SSI	Convenience	14 Pt (6/8)	79.6 71–93

(Continued)

## Appendix I. (Continued)

First author (study setting)	Quality rank L/M/H	Main strengths (+) and weaknesses (-)	Method/s	Sampling strategy	Sample Pt, HP, Cg (male/female)	Mean age and/or range (sex)
Horowitz <sup>40</sup> (USA)	H	+ Robust theoretical framework; rigorous sampling methods; detailed description of analysis and sample characteristics; recommendations and conclusions appear to flow from the interpretation of the data - None identified	SSI	Purposive	19 Pt (10/9)	52–89
Kaholokula <sup>25</sup> (USA)	L	+ Focus on ethnic minority groups living with HF; rationale for use of pre-determined theoretical model - Not clear, in most cases, whether the findings presented related to patients, carers, or both. No identifiers given to the quotations to determine whether these perceptions were across the breadth of the patient/carer sample or came from a few select participants	FG	Convenience	11 Pt (5/6) 25 Cg (4/21)	65.9 Pt 50.5 Cg
Mahoney <sup>41</sup> (USA)	M	+ Congruity between methods and analysis of data; participants selected from multiple sites; use of a pilot study; - Conclusions appear somewhat simplistic	SSI	Purposive	16 Pt (12/4) 12 Cg (NR) 20 Pt (15/5)	67.7 Pt only
Mead et al., 2010 (USA)	M	+ Congruity between research questions and data collection methods; very large sample size; patients recruited from multiple sites; participants are adequately represented in the data through illustrative quotes - Lack of age or sex-based descriptive analysis	FG	Convenience; purposive	387 Pt (84/198: 105 sex not described)	41% ≥ 65
Ming <sup>37</sup> (Malaysia)	M	+ Sufficient description of sample; patients appear to be adequately represented (via use of supporting quotes from participants) - Theoretical basis not described; the interview guide or sample interview questions are not provided	SSI	Purposive		56.5 27–75
Riegel <sup>28</sup> (USA)	M	+ Basic interpretive descriptive design and approach to analysis - Minimal description or interpretation of quotes provided for themes	Structured interviews; FG	Convenience	26 Pt (17/9)	74.4 59–91
Riegel <sup>34</sup> (USA)	H	+ Congruity between mixed-methods approach and integration and interpretation of qualitative and quantitative data - Findings obtained during motivational interviewing intervention sessions	Motivational interviews conducted as part of a face-to-face intervention	Convenience	15 Pt (6/9)	59.7
Rodriguez <sup>31</sup> (USA)	M	+ Discusses inter-coder reliability; patient sample is representative of whole NYHA spectrum - Sample is largely male & white and was pre-determined (not based on thematic saturation); description of data analysis process lacks details	SSI	Convenience	25 Pt (24/1)	70.4 53–87

## Appendix I. (Continued)

First author (study setting)	Quality rank L/M/H	Main strengths (+) and weaknesses (-)	Method/s	Sampling strategy	Sample Pt, HP, Cg (male/female)	Mean age and/or range (sex)
Schnell <sup>32</sup> (Canada)	L	+ Inclusion of ethnic minority groups; data analysis and report of findings is theoretically guided - The small convenience sample is inadequately described; interview guide development poorly described; coding/thematic analysis not described as to be reproducible	SSI	Convenience	11 Pt (7/4)	64 43–79
Scotto <sup>22</sup> (USA)	H	+ Congruity in methodological approach; clear conceptualization of self-care and sampling rationale - None identified	SSI	Convenience	14 Pt (9/5)	63 42–84
Stromberg <sup>27</sup> (Sweden)	H	+ Congruity between methodology and data collection methods - Interview questions use sophisticated language which may not be understood by participants; superficial examples might have more complex interpretations	SSI	Purposive	25 Pt (17/8)	46–93
Tully <sup>35</sup> (Ireland)	M	+ Explores experiences of patients enrolled in urban and rural services; participants are adequately represented in the results - Sample is mostly male and findings are limited to healthier HF patients as they may be more likely to participate in FG	FG	Convenience	15 PT (12/3)	NR
Weierbach <sup>33</sup> (USA)	M	+ Congruity in research methods, research questions, data analysis, and interpretation of results - Discussion is brief	SSI; Case note review	Convenience	20 Pt (9/11)	74.6 65–90
Wu <sup>23</sup> (USA)	M	+ Clear description of sample and methods; conclusions appear to flow from the analysis / interpretation of data - Limited description of setting and recruitment strategies; reliance on convenience sampling	SSI	Convenience	16 Pt (9/7)	60.4 41–84

Cg: caregiver; FG: focus group; H: high; HP: health professional; L: low; M: moderate; NR: not reported; NYHA: New York Heart Association classification of severity of heart failure; Pt: patient; SSI: semi-structured interview; UI: unstructured interview.