

## REVIEW PAPER

# Improving support for heart failure patients: a systematic review to understand patients' perspectives on self-care

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## Abstract

**Aims.** This systematic review aimed to generate patient-focussed recommendations to enhance support of heart failure self-care by examining patients' experiences, perspectives and self-care behaviours.

**Background.** Despite increased recognition of the importance of heart failure self-care, patients' knowledge and practices around this self-care and interventions to improve it are inconsistent. Consequently, current guidelines focus on what the domains of heart failure self-care are, more so than the ways to improve this care.

**Design.** Systematic review and qualitative interpretive synthesis.

**Data sources.** A systematic, comprehensive and detailed search of 11 databases was conducted until March, 2012 for papers published 1995–2012: 37 studies were included (1343 patients, 75 caregivers, 63 health care professionals) that contained a qualitative research component and data on adult patients' heart failure self-care.

**Review methods.** This interpretive synthesis used a recognized approach consisting of a multi-stage analytic process; in addition, the included studies underwent quality appraisal.

**Results.** Findings indicate that while patients could often recall health professionals' self-care advice, they were unable to integrate this knowledge into daily life. Attempts to manage HF were based on how patients 'felt' rather than clinical indicators of worsening symptoms. Self-efficacy and learning from past management experiences facilitated favourable outcomes – these enabled patients and caregivers to adeptly apply self-care strategies into daily activities.

**Conclusions.** Addressing common but basic knowledge misconceptions regarding the domains of HF self-care is insufficient to increase effective HF self-care; this should be supplemented with strategies with patients and family members to promote self-efficacy, learning and adaptation/application of recommendations to daily life.

**Keywords:** chronic disease management, complex interventions, literature review, meta-synthesis, nursing, qualitative, self-management

#### Why is this research or review needed?

- Interventions to improve heart failure self-care have had mixed and inconsistent results and few heart failure self-care interventions incorporate previous qualitative research with heart failure patients in trial design.
- A large body of qualitative studies of heart failure patients' experiences of self-care exists which may provide valuable insights for future self-care interventions.

#### What are the key findings?

- Patients' knowledge of the domains of heart failure self-care remains low, particularly with respect to medication, diet, fluid management and timely help-seeking.
- Learning from past heart failure management experiences better enabled patients to integrate self-care recommendations into their daily lives and activities.

#### How should the findings be used to influence policy/practice/research/education?

- Healthcare professionals should harness patients' experiences with managing heart failure and fostering a sense of control and self-efficacy.
- Further research should evaluate the utility of co-constructing 'decision aids' to assist patients in navigating key stages in decision-making processes around heart failure self-care.
- Future heart failure self-care interventions should deliver content that is adaptable to patients' contexts and move away from seeing self-care as purely a knowledge-based issue.

## Introduction

There is still much to learn about heart-failure (HF) self-care to improve interventions and outcomes (Clark & Thompson 2008). The centrality of HF self-care to effective clinical management, efficient care and sustainable health systems has been recognized by guidelines since 2006 (Heart Failure Society of America 2006a,b): it is recommended that all HF patients receive 'patient education and reinforcement regarding HF and self-care' (Arnold *et al.* 2006, p. 34). Yet, clinical guidelines focus predominantly on what the domains of HF self-care are (McMurray *et al.* 2012) and the relative merits of different care delivery mechanisms, such as disease management programs for information on HF self-care (McMurray *et al.* 2012).

## Background

Although there has been some acknowledgement that HF self-care 'might' be influenced by factors other than infor-

mation (Lainscak *et al.* 2011), what should be done to improve HF patients' willingness and capacity to self-care effectively has received comparatively much less focus. Knowledge proliferates on what the domains of HF self-care are, while how to affect HF self-care remains far less apparent or subject to research. Despite many studies indicating basic deficiencies in patient and families' knowledge and practices around HF self-care (Chaudhry *et al.* 2010) (suggesting that there is both widespread patient need and considerable scope for improvement), it is not surprising that programs and interventions to improve HF self-care have had mixed results (Clark *et al.* 2002, 2005, Reid *et al.* 2006). More and better knowledge of how to improve HF self-care could be harnessed by future interventions. Prior to being evaluated in trials, non-pharmacological interventions can and should incorporate insights from past research into design and components (Craig *et al.* 2008). Yet, very few interventions in the field of HF self-care have done so to date (Riegel *et al.* 2009).

This paper reports a sub-set of papers included in a 'parent' systematic review on patient and caregivers' perceptions of effective heart failure self-care (Clark *et al.* 2014). While other papers in the series focus exclusively on the role of context (Strachan *et al.* 2014), patient-provider interactions (Currie *et al.* 2014) or strategies for heart failure self-care (Harkness *et al.* 2014), this paper is unique in its focus specifically on knowledge and its exploration of the ways where knowledge and learning are complex, inter-related factors that affect patients' abilities to skilfully perform various aspects of HF self-care. The following paper provides strong empirical support for the need to 'bridge' conceptual and actual HF self-care and offers multiple, specific tips on how health professionals may do so, including the use of decision aids to promote management of HF, which have not been widely or thoroughly discussed previously in the context of heart failure self-care.

## The review

### Aims

This review aims to identify patients' experiences of HF self-care and generate patient-focussed recommendations for enhancing strategies and interventions to improve HF self-care by synthesizing knowledge from a large evidence base of studies into accounts of HF self-care from the perspective of patients, their caregivers and health professionals. These studies are ostensibly focused on patient and/or caregiver 'experiences', perspectives or behaviour, but often contain data on HF self-care.

## Design

As this review was focussed on the complex interplay of factors and process (e.g. perceptions of self-care, learning how to self-care, patients' contexts) that influenced self-care rather than pre-identified predictors or correlates of self-care (e.g. age, socioeconomic status), qualitative research studies were the focus of this review. In particular, this systematic review used the qualitative meta-synthesis approach (Walsh & Downe 2005), which is based on Noblit and Hare's (1988) seminal work, to review and produce findings. This approach has been used to understand various aspects of disease management (Britten *et al.* 2002, Campbell *et al.* 2003, Pound *et al.* 2005) and is well established in cardiac research (Clark *et al.* 2012a,b) as a valid method to harness the perspectives of health service users and providers to inform care and intervention design.

## Search methods

The comprehensive search strategy was developed by a health sciences information specialist and combined over 100 general and specific terms relating to HF and qualitative design, such as 'self-care', 'congestive heart failure' and 'qualitative method'. The following databases were searched until March 19, 2012 for papers published 1995–2012: Ovid MEDLINE, Ovid EMBASE, Ovid PsycINFO, CSA Sociological Abstracts, Ovid AARP Ageline, EBSCO Academic Search Complete, EBSCO CINAHL, EBSCO SocINDEX, ISI Web of Science, Scopus and Proquest Dissertations and Theses. Inclusion criteria were developed prior to commencing the search. Studies were included if they reported primary qualitative data wholly or as part of mixed-methods designs, contained population-specific data or themes pertaining to HF self-care, sampled adults (18+ years) and were published after 1995 as a full English paper or thesis. Studies were excluded if they sampled patients with heart conditions in addition to or other than HF (e.g. coronary artery disease) as these patients are likely to have different self-care needs from those of patients with HF. Publications prior to 1995 were excluded due to likely differences in pharmacological and non-pharmacological HF care prior to this date.

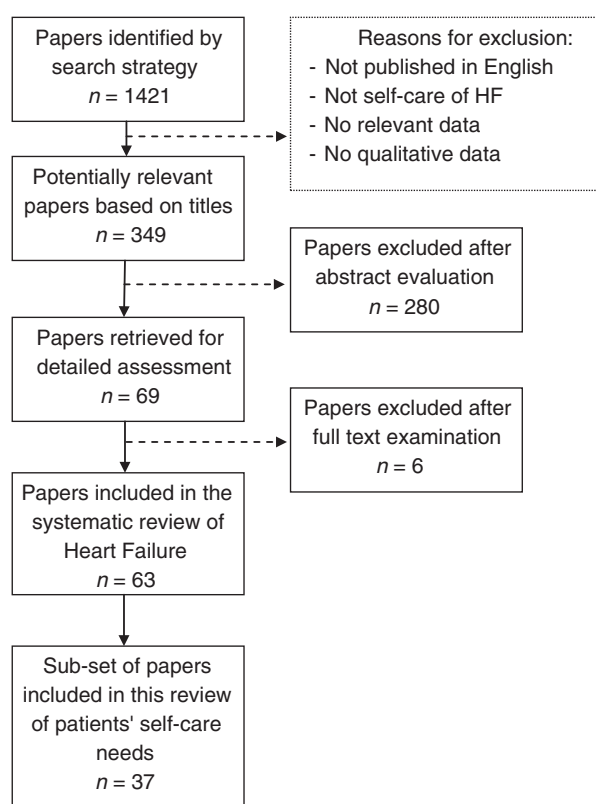
## Search outcome

The systematic search yielded 1,421 papers after removal of duplicates (Figure 1). The titles and abstracts of all identi-

fied papers were initially screened against the inclusion criteria by two independent reviewers (KC, AMC) who discussed the results of the initial screening process to achieve consensus. At this stage, papers were primarily excluded because they were not published in English and/or did not contain a qualitative component. Studies appearing to be potentially relevant ( $n = 69$ ) were full-text reviewed against the inclusion criteria by two independent reviewers (KC, AMC) to determine the cohort of studies included in the meta-synthesis. Six studies were excluded at this stage as they did not contain any data pertaining to the self-care of HF.

## Quality appraisal

The quality of each included study was independently assessed by two reviewers (KC, MS) using the criteria from the validated Critical Appraisal Skills Programme (CASP) Qualitative Appraisal Tool (NHS Learning and Development 2007). The CASP Tool consists of ten questions to appraise qualitative studies. Based on these 10 questions and two further questions added by the authors, studies were ranked as low, moderate or high quality, but were not excluded on the basis of low quality (Supplemental File S2).



**Figure 1** Flow of studies from identification to inclusion.

Disagreements in overall quality scores were discussed and resolved by consensus.

### Data abstraction

In accordance with the processes described by Walsh and Downe (2005), a multi-stage analytic process was used to synthesize findings. It should be noted that papers were analyzed in the order the full-text manuscript was retrieved. First, verbatim findings or themes pertaining to the self-care of HF were extracted from each of the included studies and imported into an analytic matrix (note: the included studies were not abstracted in any particular order). Secondly, these verbatim themes findings were read and re-read in light of each other to create categories which captured the data presented in the included papers. Sample categories included the domains of HF self-care (such as findings related specifically to fluid restriction, exercise capacity, etc.) and other prominent ideas identified in the included papers, such as the role of caregiver support and adherence in managing HF self-care.

### Synthesis

A preliminary set of abstracted themes of the whole dataset was developed and refined by KC, AMC and MS. The initial categories were read, reorganized and compared to generate lower order themes, which were discussed and agreed on by the team. The lower-order themes were reanalysed in the light of the included studies and the data reorganized to search for further supporting evidence. In all cases, the team examined the data for instances where the data did not support the lower-order or higher-order themes, leading in some cases, to further synthesis of the data and redefinition of the themes. As an example of the analysis process, it became apparent during the synthesis that across numerous categories (such as medication, fluid restriction, dietary sodium intake, etc...), studies consistently referred to patients' poor knowledge of HF self-care. This led to the creation of lower-order themes such as 'patients' poor knowledge of medications' and 'struggles with dietary sodium restrictions'; the data were then re-categorized accordingly to search for further congruency (and discrepancy) among the data. These lower order themes were translated into the final, higher-order theme presented in this paper 'low patient knowledge of HF' with supporting evidence arranged according to the specific clinical domains of HF management. This article presents a sub-set of these higher-order themes, which focus specifically on patients HF self-care needs as defined below. It is possible that

based on these definitions, potentially relevant papers were excluded from this paper.

Throughout the review, HF self-care was defined as: 'the decisions and strategies undertaken by the individual in order to maintain life, healthy functioning and well-being' (Jaarsmaa *et al.* 2003). To support consistent interpretation among the team, data or themes were interpreted to be relevant if: 'findings related to any process, phenomena or construct that pertains to the self-care of HF in patients or support of self-care by lay caregivers'.

## Results

### Search results

Of 1421 papers identified (Figure 1), 37 met the criteria for inclusion in this review of patients' self-care needs (Table 1). Included studies involved: 1343 patients (549 female, 565 male, 229 sex not reported; mean age 66.1 years; range 25-98 years), 75 caregivers and 63 health-care providers. With some exceptions, populations were predominantly Caucasian and urban dwelling. The majority of studies were conducted in the USA ( $n = 24$ ). Overall, study quality was moderate ( $n = 19$ ) with common study weaknesses being superficial themes, over-reliance on convenience sampling and insufficient description of sample characteristics (Supplemental File S1).

### Results of the review

#### *Low patient knowledge of HF*

Across studies, patients often believed they were engaged in HF self-care yet lacked the basic knowledge to do so effectively. Reports of such poor knowledge were pervasive across the included studies and pertained to all clinical domains of HF management.

#### *Medication*

Despite the central role that medication adherence has in effective HF self-care, patients reported lacking a detailed knowledge of how medication influenced HF (Reid *et al.* 2006, Wu 2007, Jowsey *et al.* 2009, van der Wal *et al.* 2010). No studies reported that patients had a high, deep or sophisticated knowledge of medicines or understood their purpose or how they helped HF. Medicines were seen by patients to be effective in some studies, (Wu 2007, Kaholokula *et al.* 2008, Macabasco-Oconnell *et al.* 2008, Wu *et al.* 2008, Rerkluenrit *et al.* 2009, Ming *et al.* 2011) but not in others, (Rogers *et al.* 2002, Clark *et al.* 2005, Jowsey *et al.* 2009) with patients being particularly vague

**Table 1** Methodological descriptions of included studies ( $n = 37$ ).

| First author (study setting)                     | Method/s                            | Sampling strategy                        | Sample Pt, HP, Cg (male/female)                | Mean age and/or range (sex)  |
|--|-------------------------------------|--|--|------------------------------|
| Boren (2001)<br>(USA)                            | SSI                                 | Convenience                              | 15 Pt (0/15)                                   | 28-76                        |
| Buetow <i>et al.</i> (2001)<br>(New Zealand)     | SSI                                 | Convenience                              | 62 Pt (NR)                                     | NR                           |
| Clark <i>et al.</i> (2005)<br>(UK)               | SSI                                 | Convenience; purposive                   | 50 Pt (33/17)<br>30 Cg (NR)                    | 68 (F);<br>67 (M)<br>Pt only |
| Crowder (2006)<br>(USA)                          | SSI                                 | Convenience                              | 15 Pt (4/11)                                   | 70.2<br>51-89                |
| Dickson <i>et al.</i> (2008)<br>(NR)             | SSI;<br>survey                      | Purposive                                | 41 Pt (26/15)                                  | 49<br>25-65                  |
| Dickson <i>et al.</i> (2011)<br>(USA)            | SSI;<br>survey                      | Purposive                                | 41 Pt (26/15)                                  | 49<br>25-65                  |
| Dickson <i>et al.</i> (2012)<br>(USA)            | SSI;<br>survey                      | Purposive                                | 30 Pt (18/12)                                  | 59.6<br>26-98                |
| Gary (2006)<br>(USA)                             | SSI                                 | Convenience                              | 32 Pt (0/32)                                   | 68                           |
| Glassman (2007)<br>(USA)                         | UI                                  | Convenience;<br>purposive                | 5 Pt (3/2)                                     | 77.2<br>60-85                |
| Granger <i>et al.</i> (2009)<br>(USA)            | SSI                                 | Purposive                                | 6 Pt (5/1)<br>6 HP (3/3)                       | 58 Pt                        |
| Horowitz <i>et al.</i> (2004)<br>(USA)           | SSI                                 | Purposive                                | 19 Pt (10/9)                                   | 52-89                        |
| Hopp <i>et al.</i> (2012)<br>(USA)               | FG; interviews                      | Convenience                              | 35 Pt (NR)                                     | 74.3<br>> 60-93              |
| Hoyt (1999)<br>(USA)                             | SSI                                 | Convenience                              | 11 Pt (5/6)                                    | 67<br>50-81                  |
| Jowsey <i>et al.</i> (2009)<br>(Australia)       | SSI;<br>survey                      | Purposive for age,<br>medical conditions | 52 Pt (28/24)<br>14 Cg (1/13)<br>63 HP (19/44) | NR                           |
| Jurgens <i>et al.</i> (2009)<br>(USA)            | SSI                                 | Convenience                              | 77 Pt (40/37)                                  | 75.9                         |
| Kaholokula <i>et al.</i> (2008)<br>(USA)         | FG                                  | Convenience                              | 11 Pt (5/6)<br>25 Cg (4/21)                    | 65.9 Pt<br>50.5 Cg           |
| Lough (1996)<br>(NR)                             | SSI                                 | Purposive                                | 25 Pt (12/13)                                  | 71<br>66-91                  |
| Macabasco-Oconnell <i>et al.</i> (2008)<br>(USA) | Structured<br>interviews;<br>survey | Convenience                              | 65 Pt (29/36)                                  | 59                           |
| Mead <i>et al.</i> (2010)<br>(USA)               | FG                                  | Convenience;<br>purposive                | 387 Pt (84/198;<br>105 sex not described)      | 41% $\geq$ 65                |
| Meyerson and Kline (2009)<br>(USA)               | Written<br>anecdotal<br>records     | Convenience                              | 27 Pt (NR)                                     | 75                           |
| Ming <i>et al.</i> (2011)<br>(Malaysia)          | SSI                                 | Purposive                                | 20 Pt (15/5)                                   | 56.5<br>27-75                |
| Reid <i>et al.</i> (2006)<br>(UK)                | SSI                                 | Convenience                              | 50 Pt (33/17)<br>29 Cg                         | 67.1<br>41-80<br>Pt only     |
| Rerkluenrit <i>et al.</i> (2009)<br>(Thailand)   | SSI                                 | Purposive;<br>theoretical                | 35 Pt (19/16)                                  | NR                           |

**Table 1** (Continued).

| First author (study setting)                   | Method/s                   | Sampling strategy      | Sample Pt, HP, Cg (male/female) | Mean age and/or range (sex) |
|--|----------------------------|------------------------|---------------------------------|-----------------------------|
| Riegel and Carlson (2002) (USA)                | Structured interviews; FG  | Convenience            | 26 Pt (17/9)                    | 74.4<br>59-91               |
| Riegel <i>et al.</i> (2006) (USA)              | Face-to-face intervention  | Convenience            | 15 Pt (6/9)                     | 59.7                        |
| Riegel <i>et al.</i> (2007) (USA)              | Structured interviews      | Theoretical            | 29 Pt (18/11)                   | NR                          |
| Riegel <i>et al.</i> (2010) (Australia)        | SSI                        | Purposive              | 27 Pt (19/8)                    | 68.7<br>35-94               |
| Rodriguez <i>et al.</i> (2008) (USA)           | SSI                        | Convenience            | 25 Pt (24/1)                    | 70.4<br>53-87               |
| Rogers <i>et al.</i> (2002) (UK)               | UI                         | Purposive              | 27 Pt (20/7)                    | 69<br>38-94                 |
| Schnell <i>et al.</i> (2006) (Canada)          | SSI                        | Convenience            | 11 Pt (7/4)                     | 64<br>43-79                 |
| Scotto (2003) (USA)                            | SSI                        | Convenience            | 14 Pt (9/5)                     | 63<br>42-84                 |
| Scotto (2005) (USA)                            | SSI                        | Convenience            | 14 Pt (9/5)                     | 63<br>42-84                 |
| Seto <i>et al.</i> (2011) (Canada)             | Survey; SSI                | Convenience            | 94 Pt (74/20)                   | 54.6                        |
| van der Wal <i>et al.</i> (2010) (Netherlands) | SSI                        | Purposive              | 15 Pt (9/6)                     | 70<br>42-87                 |
| Winters (1999) (USA)                           | SSI                        | Purposive              | 22 Pt (15/7)                    | 70<br>38-88                 |
| Wu (2007) (USA)                                | SSI; structured interviews | Convenience; purposive | 16 Pt (9/7)                     | 60.4<br>41-84               |
| Wu <i>et al.</i> (2008) (USA)                  | SSI                        | Convenience            | 16 Pt (9/7)                     | 60.4<br>41-84               |

Cg, caregivers; FG, focus groups; HP, health professionals; NR, not reported; Pt, patients; SSI, semi-structured interview; UI, unstructured interview.

about the purposes of their medications (Clark *et al.* 2005, Gary 2006). Illustrative quote:

Well I'm not too sure what they're for but I know they're either for diabetes or for me heart, or cholesterol, or high blood pressure. (Gary 2006, p. 5)

#### *Diet*

The importance and integration of dietary changes into everyday life was seldom cited (Boren 2001). Even when patients expressed their intent to follow dietary recommendations (Lough 1996, Gary 2006, van der Wal *et al.* 2010), misconceptions about sodium (Gary 2006, van der Wal *et al.* 2010) or serving size (Gary 2006) hampered ability to adhere to dietary restrictions. Issues could be as basic as relating to terminology: patients did not understand that sodium is salt and accordingly failed to restrict sodium (Gary 2006, Riegel *et al.* 2006). Consequently, health

professionals could view patients as 'non-adherent' even when patients appeared motivated to engage in self-care and reported practices they believed wrongly to align with clinical advice and recommendations (Riegel *et al.* 2006). Illustrative quote:

They told me not to have any canned foods, no canned soups and no lunch meats. . . I didn't have any canned foods and lunch meats. I had pizza and hot wings and Pepsi Cola. (Riegel *et al.* 2007, p. 239)

#### *Fluid management*

Patients had particularly poor knowledge of the importance of fluid restriction (van der Wal *et al.* 2010) and of daily weighing (Scotto 2003, van der Wal *et al.* 2010, Dickson *et al.* 2011). The few patients who did report daily weighing misunderstood the purpose of doing so (Scotto 2003) and no studies reported patients engaging in objective daily



weighing for monitoring fluid retention. This absence of actions could be seen as evidence of low knowledge or low capacity. Non-adherence to daily weighing was influenced by other factors, such as forgetfulness (van der Wal *et al.* 2010, Dickson *et al.* 2011) or a belief that fluid retention could be reliably detected in other ways (van der Wal *et al.* 2010). Illustrative quote:

When I drink more [than the fluid restriction allows], I don't have to pee so much, where does it stay? I don't have an explanation for that. (Boren 2001, p. 127)

#### *Timely help-seeking*

Although patients often recognized they had been dyspnoeic (Hoyt 1999, Macabasco-Oconnell *et al.* 2008, Rodriguez *et al.* 2008, Jurgens *et al.* 2009, Rerkluenrit *et al.* 2009) and fatigued (Jurgens *et al.* 2009, Rerkluenrit *et al.* 2009), they did not ascribe meaning to or link such symptoms to HF. Dyspnoea and fatigue were typically not seen as inter-related (Jurgens *et al.* 2009), cues to seek medical help (Hoyt 1999), or appraised as valid signs of HF decompensation (Jurgens *et al.* 2009). Distinguishing worsening HF symptoms from medication side effects or symptoms of other illnesses was problematic for patients (Hoyt 1999, Rogers *et al.* 2002, Rodriguez *et al.* 2008). Only in rare cases were patients attuned to subtle differences in symptoms and able to identify, for example, the underlying cause of shortness of breath as HF or asthma (Hoyt 1999). However, it was not evident in the studies if patients were aware that they lacked in-depth knowledge of HF and/or self-care. Only in two studies did patients identify low knowledge of their 'heart problem' as a major concern (Hoyt 1999, Macabasco-Oconnell *et al.* 2008) and state a desire for more education (Hoyt 1999). Illustrative quote:

It had gone on for a few months where I just couldn't do some of the physical things I used to do. Like, um, walk a mile. When I got these shortness of breath attacks, I would attribute it more to anxiety than to the heart. I was slower than my usual self. My feet were swollen, too, but that's been going on for years. This time my abdomen was swollen too. On Friday, I couldn't get out of my car so I called a friend [to take her to the hospital]. (Glassman 2007, p. 279)

#### *Self-efficacy: learning and experience*

While some patients could recall HF self-care recommendations, they also noted that self-care requirements were difficult to do in the context of a day-to-day life characterized by unstable and fluctuating symptoms (Granger *et al.* 2009). Despite this, patients' self-efficacy did increase over time as a result of formative learning from attempts to

manage the condition and reactions from these attempts (Riegel *et al.* 2007, Dickson *et al.* 2008). Self-efficacy was evident in the links patients made between shifts in symptoms, knowledge of disease and self-care behaviours (Glassman 2007, Riegel *et al.* 2007, 2010, Dickson *et al.* 2008, Meyerson & Kline 2009). This was associated with a sense of control and coherence that was in contrast to the uncertainty (Lough 1996, Winters 1999, Schnell *et al.* 2006) and ambiguity (Rodriguez *et al.* 2008) that characterized HF for many patients (Dickson *et al.* 2008, Rodriguez *et al.* 2008, Rerkluenrit *et al.* 2009).

Experiential learning (Meyerson & Kline 2009, Rerkluenrit *et al.* 2009) accrued over situations and could help inform patient efforts around self-care (Riegel & Carlson 2002, Scotto 2003, 2005, Crowder 2006, Rerkluenrit *et al.* 2009), provided that management itself was recognized as learnable (Scotto 2003, Reid *et al.* 2006). However, experiential learning did not always improve management, such as when negative hospital care experiences contributed to delays in help-seeking (Hoyt 1999). Bodily experiences came to be viewed as being symptoms (and took on greater significance retrospectively), as patients recognized the consequences of their choices or decisions (Scotto 2003, Seto *et al.* 2011). In this way, both 'adherent' and 'non-adherent' behaviours contributed to experiential learning (Hoyt 1999, Scotto 2003, Jowsey *et al.* 2009). Illustrative quote:

I got some diet stuff from the doctor. I went to the library, I got some books. I read up on the heart failure. I ask a lot of questions when I go to my clinic appointment. (Crowder 2006, p. 240-241)

#### *HF as body experiences, not just clinical symptoms*

Patients' experiences of their bodies played a major role in helping them to assess the perceived severity of their health and HF, not professional medical advice or information (Buetow *et al.* 2001). For example, information from health professionals, such as a state of worsening HF, was questioned by patients when they did not perceive their bodies as being 'different' (Buetow *et al.* 2001). Further, as patients could see HF as an acute, rather than long-term illness (Hoyt 1999, Horowitz *et al.* 2004, Hopp *et al.* 2012), HF was described as episodic and intermittent (Hoyt 1999) rather than a constant and lifelong condition. When symptoms abate, patients do not feel any threat to their day-to-day life from HF, compared with the heightened risk experienced when symptoms worsen. Perceptions of personal risk, in this sense, arose from the symptoms of HF not from the diagnosis of HF.

While physicians tended to evaluate patient health based on clinical indicators, patients' sense of health and HF man-

agement strategies (e.g. dose of medication) were principally informed by how they 'felt' in their bodies (Glassman 2007, Mead *et al.* 2010, Dickson *et al.* 2012). Yet, body sensations were only seen as symptoms when they were attributed to exacerbation of HF. Patients did not report sharing such awareness with their physicians (Glassman 2007) and as such, physicians may be unaware of patients' personal management strategies that seem to extend beyond clinical advice and indicators. Illustrative quote, in reference to the patient's care provider:

I'm trying to tell him what my body is doing, but they are telling me what's happening on the machines. That's annoying and a little scary. (Hopp *et al.* 2012 p. 72)

## Discussion

HF self-care remains affected adversely by potentially avoidable limitations related to knowledge, self-efficacy and symptom interpretation. The findings from this large review convey that the experience of HF symptoms is often ambiguous and occurs mostly in a context of limited knowledge about the nature of HF and its self-care. That said, situated learning about HF and its self-care from formative personal episodes and experiences, combined with a sense of mastery or control when doing so, remained important drivers of effective self-care. While gaps and misconceptions need to be addressed in patient-provider discussions or interventions, merely providing patients with more sophisticated knowledge of HF is unlikely to improve HF self-care (Clark *et al.* 2009, 2014). Such conceptual knowledge must be linked to personal experiences and the broader contexts of patients' daily lives. While patients and caregivers often purported to 'know' self-care recommendations, they also reported an inability in 'how' to apply this knowledge in their day-to-day lives.

Future complex interventions to support effective HF self-care need to move beyond seeing HF self-care as purely a knowledge-based issue. In particular, components of these interventions need to render content more relevant and adaptive to the personal context of each patient (Currie *et al.* 2014), encourage learning from all situations and outcomes and foster a sense of mastery or self-efficacy over the condition. That said, the studies in this review showed that basic elements of HF knowledge and self-care are still problematic. The sophisticated and evidence-based approaches to HF self-care evident in professional recommendations and scientific statements remain starkly absent from patients' reported approaches and accounts. Very few studies reported patients understanding the importance of objec-

tive weight monitoring, HF medications and their benefits and a clear link between HF and its symptoms.

The relationship between patients' formal knowledge of HF and its self-care and outcomes remains complex and, despite the high volume of research reviewed here, remarkably unclear: better knowledge does not always lead to better self-care or better outcomes. Several key factors appear to moderate this relationship between knowledge and self-care behaviours, including learning from one's experience, self-efficacy and views of the body. These gaps and the apparent complexity of the relationship between knowledge and self-care behaviours suggest important lessons for future interventions to promote effective HF self-care (Table 2). These provide new and persuasive empirical evidence for approaches that have been contained in scientific statements around HF non-pharmacological management without research evidence. They emphasize that HF self-care is learnable and can be optimized over time with practice using experience, feedback and coaching (Cranton 2006) and allow health professionals to harness patient experiences as a platform of learning, irrespective of the success or failure of past self-care efforts (Harkness *et al.* 2014). Arguably, more can be learnt from situations where HF self-care was not successfully undertaken (Roger *et al.* 2012).

Future health services interventions to promote HF self-care should incorporate these key steps (Table 2) and could also use algorithms or similar decision aids with patients and caregivers when available (Strachan *et al.* 2014), to help them navigate key stages in decision-making processes around self-care of HF. Although not personalized for each patient, Scotland Chest Heart and Stroke (2013) uses a symptom monitoring and help-seeking decision aid for HF patients known as the 'Traffic Lights for Heart Failure'. Similar decision aids could be co-developed with patients to prioritize their experiences and strategies for addressing challenges to effective HF management. As such, discussions around self-care and management of HF are more likely to elicit and be congruent with patients' personal values and go beyond reiterating conceptual self-care. Future research could explore when implementing such tools would be most beneficial for patients with respect to the progression of HF and at various disease states – for example, immediately after diagnosis, after an acute exacerbation/posthospitalization and/or ongoing throughout a patient's life.

## Limitations

As with all reviews, the findings of this meta-synthesis are constrained by the scope and quality of the included



**Table 2** Lessons for future HF self-care interventions: promoting knowledge and skills via content and processes.

## Key content:

- Address basic educational aspects across all domains of HF self-care
- Emphasize the role and importance of fluid management and weight monitoring
- Address the purposes and benefits of medications with patients and their family members
- Promote integration and cohesion in HF web of aetiology, symptoms and self-care actions
- Adapt content to the personal context of each patient
- Encourage learning from both successes and failures of particular self-care situations and episodes and use these to encourage mastery and self-efficacy around HF self-care

## Key processes:

- Use plain language or link to 'lay' terminology where possible
- Ask open-ended questions to ensure patients and family members understand basic aspects of HF
- Use coaching and feedback to enhance patients' understanding of the links among self-care behaviours and symptom management
- Encourage and support patients to assimilate the diagnosis of HF while fostering sense of control/self-efficacy via self-care
- Co-construct 'decision aids' with patients to help them navigate key stages in decision-making processes around HF self-care
- Help patients to bridge experiences of their bodies and the biological basis of HF
- Harness and prioritize patients' experiences and/or strategies for managing HF and its symptoms

studies. A common critique of the included studies related to superficial themes, which might impact the depth of our analysis. However, the meta-synthesis processes accommodated this by taking into account the quality of each included study and presenting the weaknesses/strengths of all studies (Supplemental File S1). Further, relatively few studies identified additional sources of support, such as HF management clinics, which are more common in some high income countries. Older patients were also under-represented in the studies and there was a lack of age-based analysis and low use of theory to understand the influence of age or other social determinants of health on HF self-care. Similarly, there was a lack of studies addressing the links between self-care and patients or family members' knowledge of HF and/or self-care.

## Conclusion

HF self-care is a value-laden, embodied yet learnable process which emerges from the complex interplay of numer-

ous factors. While the included studies point to consistent misconceptions in patients' knowledge of HF, sophisticated knowledge of HF does not necessarily lead to better self-care. There is strong empirical support for bridging conceptual and actual HF self-care activities, including harnessing patients' self-management experiences and devising decision aids with patients and their caregivers where applicable. Evidence suggests that future complex interventions supporting effective HF self-care need to render content more relevant to patients' contexts and move away from seeing HF self-care as purely a knowledge-based issue.

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None declared.

## Author contributions

All authors have agreed on the final version and meet at least one of the following criteria [recommended by the ICMJE (<http://www.icmje.org/recommendations/>)]:

- substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data;
- drafting the article or revising it critically for important intellectual content.

## Supporting Information

Additional Supporting Information may be found in the online version of this article at the publisher's web-site.

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