# Review Article

# Context Matters in Heart Failure Self-Care: A Qualitative Systematic Review

PATRICIA H. STRACHAN, PhD,<sup>1</sup> KAY CURRIE, PhD,<sup>2</sup> KAREN HARKNESS, PhD,<sup>3</sup> MELISA SPALING, MEd,<sup>4</sup> AND ALEXANDER M. CLARK, PhD<sup>4</sup>

Hamilton, Ontario, Canada; Glasgow, Scotland, United Kingdom; and Edmonton, Alberta, Canada

#### ABSTRACT

**Background:** The aim of this work was to identify the main contextual factors and processes that influence patients' self-care of heart failure (HF).

Methods and Results: A systematic review was conducted with the use of qualitative meta-synthesis. Ten databases were searched up to March 19, 2012. Of the 1,421 papers identified by the systematic search, 45 studies were included in this meta-synthesis. To be included, studies had to contain a qualitative research component, data pertaining to self-care of HF from adults (≥18 y) and be published as full papers or theses since 1995. These studies involved: 1,398 patients (mean age 65.9 y), 180 caregivers, and 63 health professionals. Six main types of contextual factors were found to influence HF self-care in the studies: caregivers; social networks and social support; place; finances and financial capacity; work and occupation; and HF support groups and programs.

**Conclusion:** HF self-care is influenced by contextual elements that fall outside of traditional elements of a HF self-care program. Inclusion of these elements may help to address the current concerns about poor adherence to self-management programs. (*J Cardiac Fail 2014;20:448–455*)

Key Words: Heart failure, self-care, meta-synthesis, context.

Heart failure (HF) self-care is vital<sup>1–6</sup> but still remarkably poorly understood. HF self-care is defined as "the decisions and strategies undertaken by the individual to maintain life, healthy functioning, and well being." It involves behaviors associated with the consumption of medications, <sup>8,9</sup> behavioral/lifestyle management, <sup>1,5,6</sup> timely

help-seeking,<sup>6</sup> regular physical activity, and maintaining social relationships.<sup>1,6</sup> Effective HF self-care in these areas helps to improve the performance of the heart, reduce the demands of the body on the heart, and promote general well-being.

HF self-care is recognized as forming the "cornerstone" of effective HF management, <sup>10,11</sup> and a growing volume of clinical guidelines state that promoting effective HF self-care is necessary to reducing the large and growing burden of HF. <sup>1-6,12,13</sup> A number of recent clinical trials to improve HF-self care have yielded inconsistent results. <sup>14-20</sup> Although various methodologic explanations have been made for these variations, <sup>21,22</sup> very few interventions incorporated an assessment of patient behaviors, needs, or preferences regarding HF-care.

A better understanding of the individual factors that influence HF self-care is necessary for interventions to be more responsive to the needs and preferences of patients.<sup>23</sup> Individual factors known to affect HF self-care include the individual's ability to manage comorbid conditions, depression or anxiety, sleep disturbances, age/developmental issues, levels of cognitive function, and health literacy.<sup>1</sup>

From the <sup>1</sup>McMaster University, Hamilton, Ontario, Canada; <sup>2</sup>Institute for Applied Health Research, School of Health & Life Sciences, Glasgow Caledonian University, Glasgow, Scotland, United Kingdom; <sup>3</sup>McMaster University, Heart Function Clinic, Hamilton Health Sciences, Hamilton, Ontario, Canada and <sup>4</sup>University of Alberta, Faculty of Nursing, Edmonton, Alberta, Canada.

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Reprint requests: Alexander M. Clark, PhD, Level 5, Edmonton Clinic Health Academy, University of Alberta, Edmonton, Alberta. Tel.: 001 780 492 8347; fax: 001 780 492 2551. E-mail: alex.clark@ualberta.ca

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Yet there is little knowledge of the contextual elements external to the individual that affect if and how patients will successfully engage in HF self-care. Knowledge of the nature and influences of these contextual factors is important because the vast majority of ongoing HF care is undertaken by the patient and their caregiver(s) in the home—outside of the direct presence, supervision, or support of the health professional. 10,11 To improve future interventions, deeper understanding is urgently needed of how dimensions of context affect HF self-care. As a first step in developing this understanding, we aimed to identify the contextual factors perceived to influence HF self-care from the large but as yet untapped body of qualitative evidence that exists regarding HF self-care.

#### Methods

Because HF self-care is a complex behavioral process, qualitative research methods are the most appropriate means of identifying the range and depth of contextual factors and processes influencing HF self-care. Moreover, this qualitative research is especially useful because rather than examining contextual factors identified a priori as being influential, this type of research examines the contextual factors that patients, caregivers and health professionals perceived as being important to HF self-care. The synthesis was guided by critical realism which holds that unobservable individual and contextual factors (related to culture, society, and circumstance) come together in complex ways to influence human behavior and outcomes, such as those involved with HF self-care. 24-26 Thus, the interrelationships of individual and contextual factors are seen to be important to understanding patient self-care behaviors.

Systematic review of qualitative research with the use of metasynthesis is credible, having been used widely to understand health outcomes around disease management, 27-29 and, importantly, it does not depend on using studies that self-identify (eg, in titles and abstracts) as being related only to "self-care." This is vital when reviewing qualitative research of HF because studies are often framed in general terms (eg, "patient experiences") but may contain themes and data relating to self-care and/or context.

### **Study Selection**

To be included in the present review, studies had to report primary qualitative data wholly or as part of mixed-methods designs, contain HF population-specific data or themes from adults (≥18 years old) reasonably seen to pertain to HF self-care, and be published as full papers or theses since 1995. The search strategy was designed by an information specialist and combined > 100 general and specific terms relating to HF self-care. These included chronic and/or congestive HF, self-care, self-management, self-medication, disease management, counseling, and self-care components such as medication, diuretic, antihypertensive agents, fluid restriction, diet, smoking cessation, and exercise. These were combined with terms related to qualitative design methodologic terms, such as lived experienced, focus group, and thematic analysis. The following databases were searched up to March 19, 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, and Scopus. We also searched the Proquest Dissertations and Theses database, scanned reference lists of recent

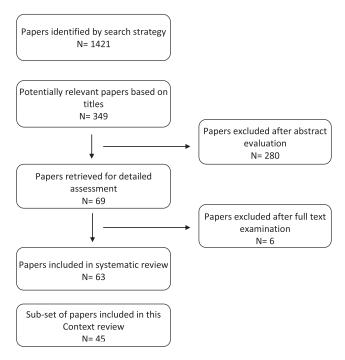
papers, and consulted with colleagues. No language restrictions were used.

The systematic search yielded 1,421 papers after removal of duplicates (Fig. 1). The titles and abstracts of all identified papers were initially screened against the inclusion criteria by K.C. and A.M.C. Results of this screening were discussed and consensus achieved. At this stage, papers were excluded primarily for lacking a qualitative component. The remaining pool of potentially relevant studies (n = 69) were full-text reviewed against the inclusion criteria by K.C. and A.M.C. to determine the cohort of studies included in the meta-synthesis. Six studies were excluded at this stage because they lacked data relating to HF self-care.

A 4-stage process was then used to synthesize the qualitative studies based on Noblit and Hare.<sup>30</sup> Verbatim findings pertaining to HF self-care were extracted from each of the included studies and imported into an analytic matrix. These findings were then read and reread in light of each other, reorganized, and compared to generate lower-order themes which were discussed and agreed on by K.C., A.M.C., and M.S. These themes were then reanalyzed in light of the included studies, and study quality and context were taken into consideration to generate the final analysis. The present paper presents a subset of these themes that focus specifically on patients' and families' HF self-care needs.

During this process, the quality of each included study was independently assessed by K.C., A.M.C., and M.S. according to the criteria from the validated Critical Appraisal Skills Programme (CASP) qualitative appraisal tool. 31 The CASP tool consists of 10 questions to appraise qualitative studies. Based on the CASP questions, studies were ranked as low, moderate, or high quality, though they were not to be excluded on the basis of quality (Table 1). Disagreements in overall quality scores were discussed and resolved by consensus.

Before we began the review, we defined self-care as the decisions and strategies undertaken by the individual to maintain life, healthy functioning, and well-being. To support consistent interpretation among the team, data or themes were interpreted



**Fig. 1.** Study selection process.

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