Systematic Review Protocol

Title: Community dwelling patient and caregivers’ self-care needs in relation to heart failure: A qualitative systematic review

Centre conducting review:
Scottish Centre for Evidence Based Care of Older People, Glasgow, Scotland: a Collaborating Centre of the Joanna Briggs Institute.

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Commencement date: November 2010
Expected Completion date: November 2011
Review Questions/Objectives
The objective of this qualitative systematic review is to synthesise the best available evidence related to ‘self-care needs’ from the perspective of patients who have heart failure and that of their lay caregivers. To this end, our research questions are:

1) What is the evidence on self-care needs in heart failure from the perspective of patients who experience this condition?
2) What is the evidence on self-care needs in heart failure from the perspective of lay carers who support patients who experience this condition?
3) What is the evidence on the way in which older age is perceived by patients and lay carers to affect self-care needs in heart failure?

Background
Globally, heart failure is one of the most burdensome and costly health conditions. Heart failure is defined as a complex clinical syndrome resulting from a variety of underlying pathologies, most commonly myocardial infarction or hypertension. Contemporary definitions highlight the need for the presence of symptoms of heart failure, such as shortness of breath at rest or exertion, fatigue; signs of fluid retention such as ankle swelling or pulmonary congestion; and objective evidence of an abnormality of the structure or function of the heart at rest for a diagnosis of heart failure to be made. It is found mostly in older adults, that is, people aged 65 years of age and over and due to the ageing population and increased survival rates from myocardial infarction, heart failure is now at epidemic levels in high-income countries.

Heart failure is known to curtail the length and quality of life. Around 50% of people with heart failure will live for at least 4 years after diagnosis, but life quality after diagnosis is poor because the main symptoms (breathlessness, fatigue, and oedema in the limbs) markedly worsen as the syndrome progresses. Indeed, heart failure severely affects almost all domains of daily life including adverse changes to: functional capacity, sleep, sexual function, and mental well-being. The impact of heart failure on families and other caregivers is also large and wide-ranging, including adverse social, psychological, and occupational changes.

In recent years, there has been a growing recognition that in order to reduce the heart failure burden, it is vital to address the pharmacological and behavioural self-care of people with heart failure and the support provided for this self-care by significant others or lay caregivers. In this context, self-care of heart failure is defined as “the decisions and strategies undertaken by the individual in order to maintain life, healthy functioning and well being.” The term ‘lay caregiver’ refers most often to partners, other family members and, less frequently, friends and neighbours who provide support and care to the patient around daily living, including heart failure self-care. Conceptualization of heart failure self-care has developed markedly over recent years. Although heart failure self-care is an outcome that can be measured, it is also viewed in this synthesis project as being a complex naturalistic process. This is well substantiated by the recent AHA Scientific Statement which views heart failure self-care in terms of ‘naturalistic decision-making’ to emphasize that self-care is a process, undertaken in the real-world setting, that is influenced by individual, contextual, and situational factors. After being comparatively neglected for many years, self-care is now championed as a ‘cornerstone’
of effective heart failure management with recognition of its importance in clinical guidelines internationally. It is also now more widely recognized that the vast majority of ongoing heart failure care is undertaken by the person with heart failure and their lay caregiver(s) in the home - outside of the direct presence, supervision or support of the health professional.

Research has increased into heart failure self-care and its determinants. There is emerging evidence that heart failure self-care is influenced by a number of patient factors such as age, knowledge of heart failure and its symptoms, previous experience, skills, coping strategies, confidence, cognitive status and the effectiveness of family caregivers’ support. However, many studies indicate deficiencies in self-care, which is due to partial, fragmented and low patient knowledge of what heart failure is and what can be done to self-care effectively. These knowledge deficits are important because they can affect outcomes.

To provide enhanced support to patients and lay caregivers, a better understanding of and responsiveness to patient heart failure self-care needs and the needs of their lay caregivers is required. In conceptual terms, there are many definitions of what constitutes a ‘health need.’ For the purpose of this synthesis, we drew on a taxonomy of ‘needs’ to define a ‘heart failure self-care need’ as: a lack of something wanted or deemed necessary for effective heart failure self-care by patients, caregivers or by research. Accordingly, heart failure self-care needs can be:

- **Normative** (i.e. needs that are interpreted reasonably in the light of research to constitute needs whether identified or not by the patient or lay caregiver)
- **Felt** (i.e. needs that are perceived wants, wishes, and desires of the patient or lay caregiver)
- **Expressed** (i.e. vocalized needs by the patient or lay caregiver)

Though less is known about lay caregivers’ contributions to self-care, they appear to share many of the same knowledge limitations as patients and seldom receive support themselves to improve abilities to support effective heart failure self-care, for example, through involvement and support in patient consultations with health professionals.

The theoretical approach informing this review is that of critical realism; briefly, critical realism is a theory that points to the importance of understanding how individual and contextual factors come together in complex ways to influence human behaviour and outcomes. Qualitative research methods are those best suited to examining the complexities of self-care processes and behaviours as they occur in natural settings and can capture the ‘insider’ perspectives of those most closely involved around felt or expressed needs while allowing interpretations of normative needs. While quantitative evidence can provide useful findings in relation to outcomes of self-care, it does not do so from the ‘insiders’ perspective’ and is less well suited to exploring the complexity of processes when relatively little is known.

Given the suitability of qualitative methods to provide evidence on the subjective insider perspective of ‘self-care’ for those patients and lay caregivers involved in meeting self-care needs associated with heart failure, it is anticipated this review of the evidence will provide insight into the nature and complexity of heart failure self-care needs. This systematic review and evidence synthesis will be used to inform the development and evaluation of future patient and caregiver focused self-care guidance. We believe this
approach is congruent with the FAME scale (Feasibility, Appropriateness, Meaningfulness and Effectiveness) developed by the Joanna Briggs Institute (JBI) for Evidence-Based Healthcare to complement their inclusive approach to the categorisation, synthesis and implementation of evidence.

Review of the COCHRANE, JBI and DARE databases was undertaken to ensure this topic has not been previously addressed. Whilst a JBI protocol 'The experiences of heart failure patients following their participation in self-management patient education programmes: A systematic review' is registered, the focus on patient education is sufficiently different from the proposed review to make both worthwhile and potentially complementary. No further systematic reviews of qualitative evidence related to self-care needs in heart failure were located on COCHRANE or DARE databases and therefore it is anticipated this review will add to existing knowledge of this topic area.

Inclusion Criteria

Types of Participants
For inclusion, studies should involve adults over the age of 18 years who have heart failure, irrespective of age, gender, context, treatment or severity of heart failure, in order to include the widest possible range of circumstances facing people with heart failure.

Phenomena of Interest
To support consistent interpretation between the research team, we will define data or themes relevant to the phenomena of interest as being: 'findings related to any process, phenomena or construct that pertains to meeting the self-care needs of heart failure in patients or support of self-care needs by lay caregivers.'

Context
It is well recognised that self-care needs are influenced by contextual or cultural factors such as where the patient lives and the availability of social support, as well as the type of patient education and professional support provided; evidence related to the context in which specific self care needs are expressed, and the effectiveness with which they are met, will be sought.

Types of studies
This review will consider research studies that focus on qualitative data, including but not limited to designs such as phenomenology, grounded theory, or ethnography.

Search strategy
An initial scoping exercise, including review of COCHRANE, DARE & JBI systematic review databases, has been undertaken to check that the proposed topic has not been reviewed already recently and also to identify appropriate search terms.

The search strategy aims to find both published and unpublished research studies. A three step search strategy will be utilised in each component of this review. An initial
limited search of the databases listed below will be undertaken followed by analysis of the text words contained in the title and abstract, and of the index terms used to describe the article. A second search using all identified keywords and index terms will then be undertaken across all included databases. Thirdly, the reference list of all identified articles will be searched for additional studies. A detailed search strategy has been developed which uses an extensive qualitative research design filter to identify qualitative studies and combines general and specific terms in relation to heart failure and qualitative design (appendix I)

**Databases to be searched will be:**

Ovid MEDLINE (In Process & Other Non-Indexed Citations) and Ovid Medline, Ovid EMBASE, Ovid,PsycINFO, CSA Sociological Abstracts, Ovid AARP Ageline, EBSCO Academic Search Complete, EBSCO CINAHL, EBSCO SociINDEX, ISI Web of Science: Social Sciences Citation Index and Science Citation Index Expanded and Scopus. Proquest Dissertations and Theses database will be searched for unpublished doctoral or master's theses and conference abstracts. Mednar and TRIP databases will also be searched for further grey literature.

**Timeframe & Language**

Due to changes in heart failure care over recent years, only papers published during or after 1995 until March 2010 will be reviewed. Only papers published in English will be reviewed.

**Assessment of methodological quality**

Initially, identified papers will be assessed by two independent reviewers for relevance based on the title/abstract using broad inclusion criteria i.e. ‘heart failure’ and ‘self care’; this stage will mainly serve to exclude non-qualitative papers or papers on non-heart failure populations.

Thereafter, qualitative papers selected for retrieval will be assessed by two independent reviewers for methodological validity prior to inclusion in the review using standardised critical appraisal instruments from the Joanna Briggs Institute Qualitative Assessment and Review Instrument (JBI-QARI) (Appendix II). However, the appraisal criteria will not be used to generate a cut-off score for inclusion, nor will any specific criteria be given greater weighting than another. Any disagreements that arise will be resolved through discussion or with a third reviewer. The number of papers included and excluded at this stage and the main reasons for exclusion will be recorded.

**Data extraction**

Qualitative data will be extracted from papers included in the review using the standardised data extraction tool from the Joanna Briggs Institute Qualitative Assessment and Review Instrument (JBI-QARI) (Appendix III). The data extracted will include specific details about the phenomenon of interest, populations, study methods
and outcomes of significance to the review question and specific objectives. Specific findings will be identified by 2 independent reviewers and entered into the JBI analytical module QARI, with levels of credibility attributed to the findings as described in the JBI-QARI module.

**Data synthesis**

Qualitative research findings will, where possible be pooled using JBI-QARI. This will involve the aggregation or synthesis of findings to generate a set of statements that represent that aggregation, through assembling the findings (Level 1 findings) rated according to their quality, and categorising these findings in the basis of similarity in their meaning (level 2 findings). These categories are then subjected to a meta-aggregation in order to produce a single comprehensive set of aggregated findings (level 3 findings) that can be used as a basis for evidence based practice. This categorisation will be done independently and then discussed during a series of teleconferences / meetings in consultation with the wider team to ensure consistency of approach and agreement on the assignment of categories and the aggregation of categories into synthesised findings. Where textual pooling is not possible, findings will be presented in narrative form, with emphasis on creating a textual summary of study characteristics and relevant findings. Where this is not appropriate, the findings will be presented in narrative form.

**Acknowledgements:**

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**Potential conflicts of interest:** None
References:


28. Pearson A. Balancing the evidence: incorporating the synthesis of qualitative data into systematic reviews. *JBI Reports* 2004; 2:45-64.
Appendix I Search databases, terms and filters

Ovid Platform Databases
exp Searched for term and its conceptually narrower terms
/ Searched for the term preceding / as a subject heading
.mp. Searches for the term in the title, original title, abstract, name of substance word, subject heading word fields
* Unlimited truncation
adj# Retrieves records that contain search terms within a specified number (#) of words from each other in any order.
.tw. Searched for the term in the title and abstract fields.
.ti. Searched for the term in the title field
.ab. Searched for the term in the abstract field.

Ovid MEDLINE In Process & Other Non-Indexed Citations and Ovid Medline 1950 to present
1 HF/ or dyspnea, paroxysmal/ or oedema, cardiac/ or HF, diastolic/ or HF, systolic/
2 HF*.tw.
3 cardiac failure*.tw.
4 heart decompensation.tw.
5 cardiac oedema *.tw.
6 (CHF or HF).tw.
7 congestive heart.tw.
8 or/1-7
9 self-care/ or self administration/ or self medication/ or risk reduction behavior/
10 (self adj3 (manag* or care or administ* or monitor* or efficac*)).ti,ab.
11 disease manag*.mp.
12 Attitude to Health/ or Health Knowledge, Attitudes, Practice/ or Patient Acceptance of Health Care/ or Health Behavior/ or Patient Compliance/ or Medication Adherence or Patient Participation/ or Patient Satisfaction/ or Refusal to Participate/
13 (patient adj (complian* or comply or complies or adherence or co operat* or cooperat* or concordance or adheren*)).tw.
14 (noncomplian* or non complian* or nonparticipa* or nonadherence).tw.
15 intention/ or decision making/ or choice behavior/
16 treatment refusal/ or patient dropouts/
17 Exercise Therapy/ or Motion Therapy, Continuous Passive or Muscle Stretching Exercises or Resistance Training
18 (physical adj (fitness or activit*)).mp.
19 (exercise training or exercise program*).tw.
20 Diet/ or Diet, Atherogenic/ or diet therapy/ or caloric restriction/ or diabetic diet/ or diet, fat-restricted/ or diet, mediterranean/ or diet, reducing/ or diet, sodium-restricted/
21 (health* adj eat*).tw.
22 (low adj (sodium or salt)).tw.
23 (fluid adj (therapy or restrict* or intake)).mp.
24 alcohol.mp.
25 smok*.tw. or "tobacco use cessation"/ or smoking cessation/
26 exp diuretics/ or exp angiotensin-converting enzyme inhibitors/ or exp antihypertensive agents/ or exp andrengic beta-antagonists/ or exp vasodilator agents/
27 or/9-26
28 education/ or health education/ or consumer health information/ or patient education as topic/
29 health promotion/ or healthy people programs/
30 Learning/
31 counseling/ or directive counseling/
32 community health services/ or community health nursing/
33 (cardiac or heart) adj rehabilitat*.mp.
34 (educat* or rehabilit* or prevent* or manag*) adj3 (program* or clinic$1)).tw.
35 (manag* adj3 (illness or disease)).ti,ab.
36 or/28-35
37 (patient* or adult* or client* or participant* or individual* or consumer*).mp.
38 (train* or educat* or teach* or instruct* or inform* or counsel* or program*).mp.
39 37 and 38
40 36 or 39
41 8 and 27 and 40
42 limit 40 to yr=1995-Current
43 exp qualitative research/
44 exp Nursing Methodology Research/
45 exp anthropology, cultural/
46 exp focus groups/
47 exp tape recording/
48 exp Video Recording/
49 qualitative.mp.
50 (ethnol$ or ethnog$ or ethnonurs$ or emic or etic).mp.
51 (leininger$ or noblit).mp. or hare.ti,ab.
52 (field note$ or field record$ or fieldnote$ or field stud$).mp.
53 (participant$ adj3 observ$).mp.
54 (nonparticipant$ adj3 observ$).mp.
55 (non participant$ adj3 observ$).mp.
56 (hermeneutic$ or phenomenolog$ or lived experience$).mp.
57 (heidegger$ or husserl$ or merleau-pont$).mp.
58 (colaizzi$ or giorgi$).mp.
59 (ricoeur or spiegelberg$).mp.
60 (van kaam$ or van manen).mp.
61 (grounded adj5 theor$).mp.
62 (constant compar$ or theoretical samp$ or triangulat$).ti,ab.
63 (glaser and strauss).mp.
64 (content analys$ or thematic analys$ or narrative analys$).mp.
65 (unstructured categor$ or structured categor$).mp.
66 (unstructured interview$ or semi-structured interview$).mp.
67 (maximum variation or snowball$).mp.
68 (audiorecord$ or taperecord$ or videorecord$ or videotap$).mp.
69 (audio or tape or video$) adj5 record$.mp.
70 ((audio$ or video$ or tape$) adj5 interview$).mp.
71 (metasynthes$ or meta-synthes$ or metasummar$ or meta-summ$ or meta-stud$ or meta-stud$).ti,ab.
72 (meta-ethnog$ or metaethnog$ or meta-narrat$ or metanarrat$ or meta-intepret$ or metainterpret$).mp.
73 (qualitative adj5 meta-analy$).mp.
74 (qualitative adj5 metaanaly$).mp.
75 purposive samp$).mp.
76 action research.mp.
77 focus group$).mp.
78 (exp interview/ or exp interview as topic/) and px.fs.
79 or/43-78
80 42 and 79
81 (mixed method* or multi-method* or multiple research method* or multiple method* or multimethod* or mixed model* or mixed research).tw.
82 ((qualitative or qual) and (quantitative or quan) and (nested or blend* or concurrent or complementary or expansion or initiation or holistic or transformative or embedded or iterative or triangulat*)).tw.
83 ((qualitative or quan) and (phenomenolog* or ethno* or (grounded adj3 theor$) or hermeneutic* or lived experience* or content analys* or thematic or theme* or narrative* or interview* or focus group* or action research)).tw.
84 (triangulat* adj5 (method* or data or concurrent or sequential or simultaneous or design*)).tw.
85 (qualitative adj5 quantitative adj5 (combin* or mixed or mix or integrat* or method* or analys*)).tw.
86 exp qualitative research/ and quantitative.tw.
87 or/77-82
88 (qualitative and quantitative).tw.
89 exp Nursing Research/ or exp Health Services Research/ or exp Rehabilitation/
(px or nu or rh or ed or og or es or eh).fs.
91 (nurs* or educat* or rehabilitat* or psych* or social or socio* or service* or interview* or questionnaire* or survey*).af.
92 or/84-88
93 83 and 88
94 83 or 89
95 (clinical trial* or evaluation studies or randomized controlled trial).pt.
96 (randomized or (clinical adj3 trial*) or (controlled adj3 trial*)).mp.
97 91 or 92
98 qualitative.mp.
99 93 and 94
100 ((qualitative or quantitative) adj5 nested).tw.
101 90 or 95 or 96
102 97 and 42
103 76 or 102
## Appendix II: JBI QARI Critical Appraisal Checklist for Interpretive & Critical Research

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
<th>Unclear</th>
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<tbody>
<tr>
<td>1. Is there congruity between the stated philosophical perspective and the research methodology?</td>
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<td>2. Is there congruity between the research methodology and the research question or objectives?</td>
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<td>3. Is there congruity between the research methodology and the methods used to collect data?</td>
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<td>4. Is there congruity between the research methodology and the representation and analysis of data?</td>
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<td>5. Is there congruity between the research methodology and the interpretation of results?</td>
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<td>6. Is there a statement locating the researcher culturally or theoretically?</td>
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<td>7. Is the influence of the researcher on the research, and vice-versa, addressed?</td>
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<td>8. Are participants, and their voices, adequately represented?</td>
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<td>9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?</td>
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<td>10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?</td>
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Overall appraisal:  
- Include [ ]  
- Exclude [ ]  
- Seek further info. [ ]

Comments (Including reasons for exclusion):

________________________________________________________________________

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Appendix III: JBI QARI Data Extraction Form for Interpretive & Critical Research

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<thead>
<tr>
<th>Study Description</th>
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<tbody>
<tr>
<td>Methodology</td>
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Extraction of findings complete: YES

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