Heart failure patients’ experiences of mobile phone-based telemonitoring in self-care: a qualitative systematic review protocol

Asta Heikkilä • Virpi Maijala

Finnish Center for Evidence-Based Health Care: an Affiliate Center of the Joanna Briggs Institute, School of Health Care and Social Work, Seinäjoki University of Applied Sciences, Seinäjoki, Finland

Review question/objective: The objective of this systematic review is to explore heart failure patients’ experiences of mobile-phone based telemonitoring in self-care.

Keywords Heart failure patients; mobile-phone; qualitative; self-care; telemonitoring

Background

Heart failure is rapidly increasing in prevalence and it is one of the most common reasons for morbidity, hospital admissions and high readmission rates.1,2 Total 30% of individuals aged 55 years and over will develop heart failure during their remaining life and only 35% will survive 5 years after the first diagnosis.3 Heart failure is a complex chronic syndrome that is usually the result of any cardiovascular disease, cardiac structural defect or birth defect. Typical symptoms of heart failure include fatigue, shortness of breath at rest or on exertion, signs of fluid retention in the body, swelling of the ankles and rapid weight gain.4 Although there is little evidence about the benefits of long-term lifestyle interventions, multi-professional and tailored patient education have been shown to enhance patient self-care in their daily living.5-7 Self-care is defined as the process whereby individuals perform the daily activities that maintain or restore health and wellbeing, prevent illness and manage symptoms of chronic illness.8 Self-care activities are important throughout the life span, but the need for complex self-care increases with age, particularly with chronic conditions such as heart failure.8

Self-care of patients with heart failure consists of self-care maintenance and self-management.9,10 Self-care maintenance includes activities such as daily weighing and medication intake that are required to maintain physiological and treatment adherence.9 A focus of self-management is autonomous health and illness-related activities.11 Self-care management refers to the decision-making response when symptoms are getting worse, symptom evaluation, treatment implementation and evaluation of self-care activities.9,10

In addition, self-management of chronic conditions often requires self-monitoring, which is defined as awareness of body symptoms, sensations, daily activities and cognitive processes. It also includes measurements, recordings and observations that inform cognition or provide information for independent action or consultation with healthcare providers.11 Heart failure patients’ attempts at self-care fail for a number of reasons.8,12,13 Difficulty engaging in effective self-care and therapy is common and it is manifested in patients with heart failure as non-adherence to the recommended treatment plan and failure to seek treatment for escalating symptoms in a timely manner.8 Heart failure patients demonstrate remarkably high rates of non-adherence with medication taking (from 40% to 60%), and dietary non-adherence (from 43% to 92%), and 20%–64% of heart failure readmissions are due to a lack of adherence.8,10 Positive effects of self-care interventions, though not all statistically significant, have been reported in patients with heart failure; these effects include a reduction in the number of hospital readmitted patients, a decrease in mortality and an increase in quality of life.14 Comprehensive knowledge of signs and symptoms of
heart failure, medical treatment, nutrition and exercise, as well as its effects on mental health, support heart failure patients’ commitment to self-care. Patient education and counseling is a combination of learning experiences influencing behavior change, producing change in knowledge, attitudes and skills that is needed to maintain and improve health status and self-care. In general, patients are physically and psychologically unprepared for learning during hospitalization. Furthermore, patients’ anxiety, level of illness and cognitive function can influence their ability to engage in self-care activities. Therefore, the main goals of patient education for heart failure patients include increased participation in decision-making and self-care, maximization of patient coping skills and promotion of a healthy lifestyle.

Nowadays treatments and self-care for heart failure are increasingly technology driven and patients are expected to take responsibility for self-care of heart failure and modify their behavior to maintain and improve their health. According to a literature review, technology-based disease management and telehealth, such as self-management programs delivered via the internet, web-based health interventions and mobile phone-based telemonitoring, have been shown to significantly improve heart failure patients’ self-care behaviors of daily weighing, medication management, exercise adherence, fluid and alcohol restriction, salt restriction and stress reduction. Technology-based disease management interventions appear to be effective in several ways and improving patients’ participation in self-care. Recent studies indicate that remote monitoring may be an effective strategy for improving heart failure health outcomes and reducing costs by providing real-time physiological information to health care providers and increasing self-care. A description of a mobile phone-based remote monitoring system was provided to all study participants (n = 94) prior to eliciting any feedback. Patients were also walked through a prototype system, demonstrating the steps that they would have to take for the proposed remote monitoring. Mobile phone-based remote monitoring systems are being proposed because mobile phones have considerable computational power while being relatively inexpensive as compared with dedicated remote monitoring hardware. Furthermore, these systems also have the added benefit of being portable, enabling patients to be monitored anywhere that has mobile phone reception. A few studies have investigated the perceptions of different patient populations regarding mobile phone-based remote monitoring, such as for asthmatic and hypertensive patients. However, heart failure remote monitoring has additional challenges and its management requires several different parameters, for example, dizziness, fatigue and weakness to be monitored, resulting in greater complexity and a delayed response to a worsening heart failure condition which could have critical consequences. Furthermore, the average heart failure patient is often older than patients with other chronic illnesses, which could result in them being less willing and able to use certain technologies. Research on heart failure patients’ experiences indicates that patients suffer from significant losses in many areas of life and are required to make significant adjustments in many areas of their daily living. Literature that has explored the experiences of patients with heart failure indicates that patients appear to undergo a process of taking on a new identity or new self and, therefore, their self-care behavior is limited.

The experience of heart failure is individual, but the integration of a new identity with the patient’s sense of self has a major impact on the effectiveness of treatments offered. Therefore, nurses’ knowledge and understanding of the experiences of heart failure patients are an essential and ethical component of care. Studies of technology-based disease management interventions provide evidence of a gap between patients receiving and understanding information on self-care in heart failure. Furthermore, research that explores patients’ experiences of living with heart failure is limited therefore a systematic review is warranted.

Inclusion criteria

Types of participants
This review will consider studies describing adult heart failure patients, aged 18 years or older.

Phenomena of interest
This review will only consider studies that describe heart failure patients’ experiences of mobile phone-based telemonitoring in relation to self-care in the home.

Context
The context for this review is self-care.
Types of studies
This review will consider any interpretive studies that draw on heart failure patients’ experiences of mobile phone-based telemonitoring in self-care. The review will consider studies that focus on qualitative data including, but not limited to, designs such as phenomenology, grounded theory and ethnography.

Search strategy
The search strategy aims to find both published and unpublished studies. A three-step search strategy will be utilized in each component of this review. An initial limited search of PubMed and CINAHL 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. Third, the reference lists of all identified reports and articles will be searched. The search will be limited to the years 2000–2015. Since the year 2000, there has been growing research interest toward mobile-phone based telemonitoring self-care management of heart failure patients. Studies published in Finnish, English, Swedish and German will be included in this review.

The databases to be considered include:
- CINAHL
- ERIC
- MedCine
- Scopus
- PubMed
- PsycINFO
- Web of Science
- MedNar (for unpublished studies)
- ProQuest Dissertations and Theses Database (PQDT)

The search for unpublished studies will also include: Grey literature (e.g. conference materials, internet pages and documents of ministries, WHO, health care organizations and associations).

Initial keywords to be used will be: heart failure patient, adult patient, elderly patient, elderly people, heart failure, congestive heart failure, congestive heart disease, self-care, self-monitoring, self-management, mobile-phone telephone, telemonitoring, web-based, home care, self-care.

Assessment of methodological quality
Qualitative articles selected for retrieval will be assessed by two independent reviewers for methodological validity prior to inclusion in the review using standardized critical appraisal instruments from the Joanna Briggs Institute Qualitative Assessment and Review Instrument (JBI-QARI) (Appendix I). Any disagreements that arise between the reviewers will be resolved through discussion, or with a third reviewer.

Data extraction
Qualitative data will be extracted from articles included in the review using the standardized data extraction tool from the Joanna Briggs Institute Qualitative Assessment and Review Instrument JBI-QARI (Appendix II). The data extracted will include specific details about the interventions, populations, study methods and outcomes of significance to the review question and specific objectives.

Data synthesis
Qualitative research findings will, wherever possible, be pooled using the 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 categorizing these findings on the basis of similarity in meaning (Level 2 findings). These categories are then subjected to a meta-synthesis to produce a single comprehensive set of synthesized findings (Level 3 findings) that can be used as a basis for evidence-based practice. Where textual pooling is not possible, the findings will be presented in narrative form.

Acknowledgements
The authors would like to acknowledge the support received from Seinäjoki University of Applied Sciences.

References

4. McMurray JJ, Adamopoulos S, Anker SD, Auricchio A, Böhm M, Dickstein K, et al. ESC Guidelines for the diagnosis and treatment of acute and chronic heart failure 2012: the Task Force for the Diagnosis and Treatment of Acute and Chronic Heart Failure 2012 of the European Society of Cardiology. Developed in collaboration with the Heart Failure Association (HFA) of the ESC. Eur Heart J 2012;33(14):1787–847.


Appendix I: Appraisal instruments

QARI appraisal instrument

**JBI QARI Critical Appraisal Checklist for Interpretive & Critical Research**

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<th>Question</th>
<th>Yes</th>
<th>No</th>
<th>Unclear</th>
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<td>1. Is there congruity between the stated philosophical perspective and the research methodology?</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 reason for exclusion):
Appendix II: Data extraction instruments

QARI data extraction instrument

JBI QARI Data Extraction Form for Interpretive & Critical Research

Reviewer __________________________ Date __________________________

Author __________________________ Year __________________________

Journal __________________________ Record Number __________________________

Study Description
Methodology __________________________

Method __________________________

Phenomena of interest __________________________

Setting __________________________

Geographical __________________________

Cultural __________________________

Participants __________________________

Data analysis __________________________

Authors Conclusions __________________________

Comments __________________________

Complete Yes □ No □
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