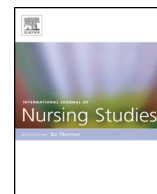




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## Review

## How do patients' values influence heart failure self-care decision-making?: A mixed-methods systematic review



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## ABSTRACT

**Background:** Values are central to ethical and effective nursing and health care. However, in relation to heart failure, an extremely common and burdensome syndrome, the role that patients' values have in influencing self-care is poorly understood.

**Methods:** A mixed methods systematic review was conducted using a critical meta-narrative synthesis approach to synthesizing qualitative and quantized data. Nine databases were searched (14 March 2014). To be included in the review, studies had to contain data on heart failure patients' values and self-care behaviors, include adults aged  $\geq 18$  years with symptomatic heart failure, and be published  $\geq 2000$  as full articles or theses. Study quality was assessed using a mixed-methods appraisal tool.

**Findings:** Of 6467 citations identified, 54 studies were included (30 qualitative, 8 mixed methods, and 16 quantitative; 6045 patients, 38 lay caregivers, and 96 health care professionals). The synthesis identified multiple bi-directional interactions between heart failure, patients' values, and self-care. Patients are motivated by self-related and other-related values. Self-related values are tied directly to intimate personal feelings (self-direction, pleasure, and being healthy) or related to individuals' life circumstances (maintaining a healthy lifestyle and financial balance). Other-related values, which are fundamentally socially-based, are related to benefits received from society (social recognition and socialization) and social obligations (responsibility, observing traditions, and obedience). For each decision, several values are involved; some are incompatible and some are in conflict. Patients make their self-care decision based on the values they prioritize and those that are blocked.

**Conclusion:** Values are integral to how patients approach and undertake HF self-care. These values both affect and respond to this self-care and the severity of HF symptoms. Values extend to those relating to the self and others and incorporate a range of personal, life, and social dimensions. Values cannot be assumed to be fixed, normative or similar to those held by nurses and other health professionals. Future interventions to improve HF self-care must address and respond to the complexity of patients' values and how they influence patient behavior in undertaking heart failure self-care.

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## What is already known about the topic?

- Patient values are important to understand and respond to in nursing care for ethical and practical reasons.
- Heart failure is a very common and burdensome syndrome with high costs in high income countries;

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heart failure self-care involves a wide range of complex behaviors.

- Understanding and incorporating patient values into healthcare is important to promote effective heart failure self-care.

#### What this paper adds

- The process in which patient values influenced HF self-care was fluid and iterative, incorporating values that were prioritized and/or blocked.
- A wide range of values associated with the self and others influenced HF self-care.
- The effects of HF on self-care were cyclical and iterative – self-care and its behaviors influenced which values the patients prioritized while values also influenced HF self-care behaviors.

## 1. Background

Whether and how health professionals incorporate patients' values into care are important ethical and practical issues. Values are defined here as being *abstract core beliefs which start to develop in a person's early years but then guide and are expressed in behaviors over a lifetime* (Rokeach, 2000; Schwartz, 2006). As such, values exist and guide decisions across many domains of life, including social, family, political, sexual, and religious realms (Caprara et al., 2006; Honeycutt and Milliken, 2012; Padilla-Walker et al., 2012). Values are diverse and can also evolve markedly over time, for example, key aspects of human life such as health, love, helpfulness, honesty (Rokeach, 2000; Schwartz, 2006), can be influenced by particular circumstances, such as age or single 'major' events (Schwartz, 2006).

Incorporating patients' values into care is central to nursing because it is ethical to do so (The Canadian Nurses Association, 2008). This recognizes patient autonomy in decision-making when choosing an alternative from a number of care options and avoids paternalism on behalf of the nurse (Noone, 2002). Patients' values should be incorporated into nursing care decisions because these personal values influence patients' behaviors (Feather, 1995; Torelli and Kaikati, 2009). A range of nursing theories and models can help practicing nurses integrate patients' values into their care, for example: via patient-centered theory (Abdellah et al., 1961), the Oberle and Raffin Model (Oberle and Bouchal, 2009), or the brief motivational interviewing approach (Miller, 1983). These approaches involve exploring and responding to patients' values to improve positive patient outcomes, such as adherence, and patient satisfaction (Constand et al., 2014; O'Connor et al., 1999).

Heart failure (HF) is a common condition affecting up to 10% of adults aged over 65 years in high income countries but HF outcomes, avoidable hospitalizations and symptoms, can be improved by effective HF self-care (Clark et al., 2014; Riegel et al., 2009). This self-care involves consuming medications as prescribed, seeking help promptly from health professionals to manage symptoms, restricting salt and alcohol consumption, doing regular physical activity, checking weight and fluid intake, and

monitoring mental health (Mahoney, 2000; Scotto, 2003; Sethares et al., 2014; van der Wal et al., 2010). The effects of this self-care are important because HF is widely prevalent across high income countries (due to rapidly aging populations) and symptoms are burdensome on patients, their families (Clark et al., 2008), society, and healthcare systems (Robertson et al., 2012; Zannad et al., 2009). For example, worsening HF severely reduces quality of life (Goodman et al., 2013), results in frequent rehospitalization, and high health care costs (Robertson et al., 2012; Zannad et al., 2009). With the aging global population and greater survival from myocardial infarction, this burden is increasing and will continue to rise (Ambrosy et al., 2014; Bleumink et al., 2004).

### 1.1. Values and heart failure self-care

Nurses and other health professionals have an important role in promoting effective HF self-care. Patient values are a particularly important facet of HF self-care because they stand to influence HF self-care behaviors – which themselves influence quality and length of life (Moser et al., 2012; Poelzl et al., 2014). While attempts have been made to understand which factors influence and improve HF self-care behaviors (Jaarsma, 2005; Siabani et al., 2013; Wu et al., 2008), poor self-care remains dominant worldwide (Ambrosy et al., 2014). Less than half of HF patients exercise regularly (Nieuwenhuis et al., 2012), less than 40% of patients adhere to prescribed medication regimens (Nieuwenhuis et al., 2012; Riegel et al., 2011) or monitor weight daily, while as few as 10% consume a low-sodium diet (Lainscak et al., 2007; Ni et al., 1999). Interventions to support effective HF self-care have had inconsistent effects (Chaudhry et al., 2010; Clark and Thompson, 2008; Savard et al., 2011) and the relationships amongst knowledge, self-care practices and outcomes remain unclear (Davis et al., 2012).

Given that HF self-care is primarily based on patient decision-making in the home, outside of the direct control and influence of health professionals, and values are practically and ethically central to concepts of health and nursing care, a pivotal but neglected element relates to whether and how patients' values influence HF self-care (Clark et al., 2014; Cortis and Williams, 2007; Hicks and Holm, 2003). This synthesis is the first to bring together research findings regarding the influence of patients' values on HF self-care. This knowledge can be used to help researchers and health-care professionals better understand self-care in patients with HF.

## 2. Methods

Patients' values can be inferred from qualitative or quantitative data. For example, qualitative studies can address what is important to patients from their own perspectives ("Should I remove salt from my diet?") while quantitative studies may study the roles of factors in patients' decision-making processes. Accordingly, this systematic review (SR) synthesizes the full range of qualitative, quantitative, and mixed-methods data. Using different types of data in this way generates more

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