



Problems experienced by informal caregivers of individuals with heart failure: An integrative review

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ABSTRACT

Objectives: The purpose of this review was to examine and synthesize recent literature regarding problems experienced by informal caregivers when providing care for individuals with heart failure in the home.

Design: Integrative literature review.

Data sources: A review of current empirical literature was conducted utilizing PubMed, CINAHL, Embase, Sociological Abstracts, Social Sciences Full Text, PsycARTICLES, PsycINFO, Health Source: Nursing/Academic Edition, and Cochrane computerized databases. 19 qualitative, 16 quantitative, and 2 mixed methods studies met the inclusion criteria for review.

Review methods: Computerized databases were searched for a combination of subject terms (i.e., MeSH) and keywords related to informal caregivers, problems, and heart failure. The title and abstract of identified articles and reference lists were reviewed. Studies were included if they were published in English between January 2000 and December 2016 and examined problems experienced by informal caregivers in providing care for individuals with heart failure in the home. Studies were excluded if not written in English or if elements of caregiving in heart failure were not present in the title, abstract, or text. Unpublished and duplicate empirical literature as well as articles related to specific end-stage heart failure populations also were excluded. Methodology described by Cooper and others for integrative reviews of quantitative and qualitative research was used. Quality appraisal of the included studies was evaluated using the Joanna Briggs Institute critical appraisal tools for cross-sectional quantitative and qualitative studies.

Results: Informal caregivers experienced four key problems when providing care for individuals with heart failure in the home, including performing multifaceted activities and roles that evolve around daily heart failure demands; maintaining caregiver physical, emotional, social, spiritual, and financial well-being; having insufficient caregiver support; and performing caregiving with uncertainty and inadequate knowledge.

Conclusions: Informal caregivers of individuals with heart failure experience complex problems in the home when providing care which impact all aspects of their lives. Incorporating advice from informal caregivers of individuals with heart failure will assist in the development of interventions to reduce negative caregiver outcomes. Given the complex roles in caring for individuals with heart failure, multicomponent interventions are potentially promising in assisting informal caregivers in performing these roles.

What is already known about the topic?

- Cardiovascular disease affects more than 17 million individuals worldwide, with many depending upon informal caregivers in the home for assistance with disease management.
- The disease process of heart failure impacts informal caregivers ability to maintain their psychological and physical well-being.

What this paper adds

- Caregivers perform multifaceted activities and roles that evolve around daily demands of heart failure.
- Caregivers have difficulty in maintaining their physical, emotional, social, spiritual, and financial well-being.
- Caregivers have insufficient caregiver support.
- Caregivers perform caregiving with uncertainty and report inadequate knowledge.

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1. Introduction

Over 17 million individuals worldwide are affected by cardiovascular disease, including heart failure (Roth et al., 2015). This figure is expected to increase to almost 24 million by 2030 (World Health Organization, 2010). In 2010, the estimated cost of cardiovascular disease was \$863 billion. Costs are expected to increase by 2030 to \$1044 billion (Bloom et al., 2011). Populations also are spending more time with functional health loss (GBD 2015 Mortality and Causes of Death Collaborators, 2016), including those with heart failure.

Individuals with heart failure often rely on informal caregivers who facilitate their well-being by contributing to heart failure-related tasks (e.g., symptom assessment and management, medication management), activities of daily living (e.g., dressing, bathing, toileting), instrumental activities of daily living (e.g., preparing meals, taking out the garbage), and providing emotional support (i.e., lessening worries of individuals with heart failure). While the availability of caregivers to assist in managing complex medical and self-care treatment regimens has the potential to improve the quality of life of those who experience heart failure (Bidwell et al., 2016; Pressler et al., 2013), caregivers frequently lack formal training to assist with these tasks and report feelings of uncertainty regarding their caregiving role (Kang et al., 2011).

Thus, heart failure often exacts an overwhelming toll on the physical and psychological well-being of informal caregivers, with informal caregivers frequently describing caregiving demands in the home as overwhelming (Gusdal et al., 2016). Informal caregivers of individuals with heart failure often experience burden (Ågren et al., 2010; Gusdal et al., 2016), anxiety, and depression (Bozkurt Zincir et al., 2014; Pressler et al., 2013). In fact, those who experience caregiver strain are more likely to die as compared to informal caregivers with no strain and non-caregiving individuals (Schulz and Beach, 1999). Caregivers deal with clinically unstable family members and complex challenges, such as managing and titrating medications, dealing with emotional and behavior problems, and frequent hospital admissions (Bakas et al., 2006; Burke et al., 2014; Luttik et al., 2007a).

Caregivers experience uncertainty and need guidance in understanding the heart failure diagnosis, disease trajectory and treatments, and future (e.g., palliative care services and caring for individuals at end-of-life). Understanding heart failure medications and devices and related side effects are troublesome along with inadequate knowledge about when and how to seek medical care. Difficulty in handling unplanned hospitalizations and other emergencies also are a problem for caregivers. Another problem is fragmented health care services, with insufficient coordination and communication between themselves and health care providers. Caregivers feel health providers either ignore their value or place too much responsibility on them, while they wish to be partners in heart failure self-care (Dionne-Odom et al., 2017; Doherty et al., 2016; Strömberg and Luttik, 2015; Whittingham et al., 2013).

Other challenging issues for spouses of individuals with heart failure include dealing with heart failure troublesome behaviors (e.g., moodiness), receiving and giving emotional and spiritual support, caring for themselves as caregivers, managing dietary needs, monitoring signs and symptoms, and obtaining access to formal and informal support services. Daily household tasks are more difficult to manage for younger caregivers as a result of working part- or full-time, in conjunction with completing caregiving, child care, and household responsibilities. These tasks include cleaning; managing finances, bills, forms concerning the heart failure patient's illness, and transportation. Contacts with friends and social activities diminish as a result of these responsibilities, leading to social isolation and inadequate social support. Less sexual intimacy also is a significant issue for caregivers and individuals with heart failure (Dionne-Odom et al., 2017; Doherty et al., 2016; Strömberg and Luttik, 2015; Whittingham et al., 2013).

Empirical data concerning the difficulty of caregiving problems associated with providing care for individuals with heart failure in

empirical literature are limited. Specifically, information related to problems experienced by informal caregivers when providing home care for individuals with heart failure is fragmented and lacks synthesis. This synthesis is necessary for the development of effective interventions for heart failure caregivers. Previous reviews have focused either on informal caregivers' contributions to heart failure self-care (Buck et al., 2015), the impact of the caregiving role on the caregiver (Molloy et al., 2005), or examined experiences of caring for individuals with heart failure using qualitative data only (Kang et al., 2011). A few reviews examine factors that contribute to caregiver burden, but data are older (i.e., unclear starting date until 2012; Whittingham et al., 2013), the focus is on a broader purpose than caregiver problems (e.g., quality of life and burden; Whittingham et al., 2013), and the review covers limited search years (i.e., 2013–2014; Strömberg and Luttik, 2015) or few databases (e.g., PubMed or PubMed and CINAHL; Dionne-Odom et al., 2017; Strömberg and Luttik, 2015). No known published studies have synthesized data recently from qualitative, quantitative, and mixed design studies regarding informal caregivers' problems in assisting individuals with heart failure in the home.

2. Definitions and concepts

Informal caregivers are individuals who have a personal relationship with and provide unpaid assistance to other individuals who have a chronic or disabling condition, such as heart failure. Typically, informal caregivers are relatives, friends, partners, or neighbors. These individuals may or may not live with the individual receiving care. In contrast, formal caregivers provide formal service, either as a volunteer or as a paid worker (Family Caregiver Alliance[®], 2014).

Problems are current or anticipated life situations which require adaptive functioning, but lack effective reactions by individuals because of barriers or inadequate resources. Problems may either occur within the environment (e.g., task requirements) or within the person (e.g., needs, etc.) (D'Zurilla et al., 2004).

3. Methods

Methodology described by Cooper (1982) and others (Dixon-Woods et al., 2004; Whittemore and Knaf, 2005; Lubbe et al., 2012) for integrative reviews of quantitative and qualitative research was used. This integrative review used thematic synthesis, in which the quantitative studies were analyzed deductively and the qualitative studies inductively. Non-experimental and experimental designs were included to provide a synthesis of current literature which may potentially impact evidence-based nursing practice (Whittemore and Knaf, 2005). Quality appraisal of the included studies was evaluated using the Joanna Briggs Institute (2016) critical appraisal tools for cross-sectional quantitative and qualitative studies.

To identify relevant literature, key nursing, medical and psychosocial databases were searched from January 2000 to December 2016 using PubMed, CINAHL, Embase, Sociological Abstracts, Social Sciences Full Text, PsycARTICLES, PsycINFO, Health Source: Nursing/Academic Edition, and Cochrane computerized databases. As reflective in Table 1, a combination of Subject Terms from Medical Subject Headings (MeSH) and other keywords were used to retrieve appropriate studies that met inclusion criteria. These keywords were used to assure obtaining new articles or articles that have not been yet fully indexed with appropriate terms. MeSH terms were unavailable for problems, so the conceptual definition of problems, caregiving empirical literature, and the dictionary were used to identify search terms (Merriam-Webster, 2017).

Studies were included in this review if they: (1) were published in English and (2) examined aspects of problems experienced by informal caregivers when caring for individuals with heart failure in the home. Studies were excluded if they (1) were written in languages other than English; (2) did not mention elements (by name or description) of caregiving in heart failure in the title, abstract, or text; (3) were

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