Addressing Heart Failure Challenges through Illness-Informed Social Work

Faith Pratt Hopp, Jessica K. Camp, and Tam E. Perry

This article describes the role of social workers in addressing the needs of people with heart failure. Although previous studies have explored the role of social workers in health care settings, few studies have addressed the challenges of specific chronic diseases such as heart failure. To address this gap in the literature, this study used qualitative interviews with health care social workers ($n = 8$) to obtain in-depth information about activities and challenges related to heart failure care. Findings suggest that health care social workers perceive heart failure as characterized by an uncertain illness trajectory, frequent hospitalizations, and difficulties accessing formal and informal care. These findings suggest the importance of what we term *illness-informed social work*, a practice that combines heart failure knowledge with social work competencies to address the complex psychosocial issues in heart failure care.

KEY WORDS: *access to care; biomedical conditions; chronic conditions; chronic illness; end-of-life care*

I ncreasing numbers of older adults are experiencing heart failure, a type of heart disease in which the heart becomes unable to pump enough blood to meet the needs of the body (National Heart, Lung, and Blood Institute, 2012). In the past decade, the incidence and associated health care costs of heart disease have continued to increase, with nearly 83.6 million American adults experiencing cardiovascular disease or stroke, accounting for \$315.4 billion in direct and indirect health care costs. During this same period, the mortality rate associated with heart disease has decreased, although heart failure still accounts for one out of every three deaths in the United States (American Heart Association, 2013). A study by Hobbs, Roalfe, Davis, Davies, and Hare (2007) estimated the five-year mortality rate for heart failure as between 53 percent (for those with left ventricular systolic dysfunction [LVSD]) and 62 percent (for those without LVSD). High mortality rates, concerns about the underutilization of hospice care by people with heart failure (Pastor & Moore, 2013), and increasing recognition of the need for explicit guidelines for the care of people with heart failure at the end of life (Irving et al., 2013) suggest the need for more attention to heart failure challenges.

Heart failure is a challenging condition because of its often uncertain illness trajectory and high levels of physical, psychological, social, spiritual, and existential pain (Light-McGroary & Goodlin, 2013). Physical

pain, which often involves joint pain, is frequently reported by people with heart failure, particularly in advanced stages (Light-McGroary & Goodlin, 2013). However, social, psychological, and existential pain is also frequently present and can contribute to reduced quality of life (Leeming, Murray, & Kendall, 2014; Light-McGroary & Goodlin, 2013). Research exploring the lived experience of heart failure has found that factors such as unpredictable illness trajectory, deteriorating health status, increased dependence on caregivers, and physical symptoms like breathlessness and fatigue contribute greatly to the experience of social isolation among both people with heart failure and their caregivers (Aldred, Gott, & Gariballa, 2005; Fitzsimons et al., 2007; Leeming et al., 2014).

The social work profession has the potential to play an important role in providing services and supports to people with heart failure and their caregivers. Social workers can help other health care providers recognize the need for more explanation and education about heart failure (Aldred et al., 2005) and facilitate access to community resources (Fitzsimons et al., 2007). Social workers can address psychosocial challenges, help those with heart failure deal with illness uncertainty, assist with end-of-life issues (Kramer, Christ, Bern-Klug, & Francoeur, 2005), and focus on treating depression related to health decline and reduced ability to engage in daily activities (Leeming et al., 2014).

Social workers can support those with heart failure in addressing the challenges of serious illness by helping them to draw on previously acquired strategies such as resiliency, spirituality, and self-care (Hopp, Thornton, Martin, & Zalski, 2012). Social workers can also support caregivers, helping them to deal with the socioemotional stressors that many of them experience and facilitating communication and connection among people with heart failure, their caregivers, and health care providers (Thornton & Hopp, 2011).

The high level of heart failure–related hospitalization, particularly among older adults (Desai & Stevenson, 2012), means that health care social workers are likely to have interactions with people with heart failure. Social workers can help those with heart failure learn about their illness, understand the importance of treatment adherence, manage social factors of illness, and address potential psychological issues (Claiborne & Vandenberg, 2001, 2003). Most important, social workers can help their clients actively participate in decisions about their own care, including advanced care planning (Black, 2006; Claiborne & Vandenberg, 2003; Peterson, 2012). A variety of interdisciplinary models have also been developed to address heart failure care for this population (for example, Lowery et al., 2012), suggesting a particularly important role for social workers in hospital discharge planning and the provision of supportive home care and community support (Proctor, Morrow-Howell, Li, & Dore, 2000; Werner, Carmel, & Zidenberg, 2004).

GAP IN THE LITERATURE

Throughout the history of the profession, social workers have been essential in providing supportive care for people coping with serious illness. Social workers have been shown to play an important role in supporting people with diabetes, helping them to address issues related to time management, stress, fears, and anxieties related to diabetes self-care and symptoms such as hypoglycemia (DeCoster, 2001). A study conducted among people with cancer (Miller et al., 2007) found that better quality of life was associated with a multidisciplinary intervention designed to enhance emotional, spiritual, social, and financial support. A study conducted among a population of African American and Latino patients with renal failure found that social workers were important in addressing mental health symptoms related to anxiety and depression (Dobrof, Dolinko, Lichtiger, Uribarri, & Epstein, 2002). However, little research has addressed the social

worker's role in heart failure care. Obtaining this information is critical to the development of professional and educational opportunities aimed at enhancing the skills, competencies, professionalism, and visibility of the social worker role in health care. To address these issues, the present qualitative study explores the professional role of social workers who provide services for people with heart failure and their caregivers.

METHOD

Participants

We used purposive sampling to identify social workers with experiences in health care on the basis of work locations or job titles that suggested social work focused in medical care, palliative care, or hospice settings. Prospective participants were identified through a list of current social work field supervisors maintained by the Wayne State University School of Social Work.

Recruitment

Prospective participants ($n = 52$) were sent letters informing them about the study and inviting them to participate. A research assistant telephoned social workers who had not responded within two weeks of the initial mailing and asked if they would be interested in participating. For those who had still not responded, a final letter was sent a few months following the initial mailing informing them about the study. If the participant had not been successfully recruited at this point in the study, no further outreach was pursued.

Among the 52 social workers who were mailed an invitation, 26 could not be reached by telephone. Among those who were reached ($n = 26$), nine had experience working with patients diagnosed with heart failure and therefore met study inclusion criteria, and one additional eligible prospective participant was identified by a colleague. Of these 10 eligible participants, two were unable to participate because of illness or scheduling issues.

Data Collection Approach

All participants completed a brief survey focused on demographics and experience in health care social work. An interview guide was used and focused on five areas: (1) the participants' role in the health care setting, (2) the social work referral process, (3) social work activities related to heart failure support, (4) the participants' role in providing caregiver support, and (5) their perceptions of the challenges and barriers in providing heart failure care.

The first two interviews were conducted by the primary investigator with a doctoral-level student research assistant present. The remaining six interviews were conducted by the student research assistant. Interviewers encouraged participants to talk freely but directed discussion toward heart failure–related issues pertaining to social work.

Qualitative Analysis Approach

Two of the three authors conducted open coding and reviewed each transcript in its entirety, using an inductive approach to identify preliminary codes. These codes were applied to textual material that varied in length and could include phrases, sentences, and groups of sentences. The sets of codes developed by the two team members were then compared, and a refined list of codes was developed. This iterative process of coding ensured a holistic and inductive approach (Engel & Schutt, 2014). We developed definitions for each code, along with inclusion and exclusion criteria and examples. The second author coded the interview transcripts again, identifying textual material that corresponded to each code definition, and the two authors met regularly to discuss these codes and develop agreement on common definitions. We created and refined these themes, returning to the transcripts frequently to confirm that these themes were evident in the data. We used a qualitative analysis software program (ATLAS.ti version 7) to organize codes and themes. As a final step in our analysis, a research assistant who was not involved in the interviews or initial data analysis was given all of the code definitions that corresponded to each identified theme. The research assistant coded all of the interview transcripts using the definitions that had been developed. The two authors reviewed discrepancies that were evident between the second author and the research assistant and reached consensus on the passages that corresponded to each code. The third author offered qualitative expertise in data analysis, interpretation, and manuscript preparation.

Credibility and Trustworthiness of the Data

We took several steps to ensure the credibility and trustworthiness of the analysis (Padgett, 2008). First, we engaged in reflexivity, reflecting on our role as researchers and the way our varied backgrounds influenced our interpretations of qualitative data (Barry, Britten, Barber, Bradley, & Stevenson, 1999). Second, we were not involved in the development,

administration, or clinical operations at any of the employment sites where the respondents worked, which reduced bias. Third, to ensure credibility of the data, all interviews were recorded and transcribed verbatim, and the transcriptionist reviewed the recordings as many times as necessary to ensure accuracy. Fourth, we invited participants to a research presentation on the preliminary findings, and they were asked to provide feedback.

RESULTS

Eight interviews were successfully scheduled and completed. Of these, six interviewees were female, and two were male. Seven of the participants were white, and one participant was African American. The mean age was 48.57 years (range = 29–64 years). All of the participants had an MSW, and one of the respondents also had a DSW. Their mean years of experience working with heart failure was 12.14 years, with a range from three to 32 years. The work settings for each of the social workers are as follows:

Interview 1: home hospice social worker

Interview 2: case manager at large HMO

Interview 3: social work bereavement supervisor, inpatient/outpatient hospice, nonprofit religious affiliation

Interview 4: hospice social worker in hospital-affiliated program

Interview 5: medical social worker who coordinates seniors' transportation to physician appointments

Interview 6: hospital discharge planner

Interview 7: social worker for hospice and palliative care organization

Interview 8: hospital case manager.

In the following sections, we summarize the results according to three themes: (1) trajectory of illness, (2) “frequent flyers,” and (3) challenges of access to care.

Trajectory of Illness

The trajectory of illness refers to statements about heart failure and the progression of the illness over time. For example, a social work bereavement supervisor for an inpatient/outpatient hospice said that heart failure is often a “difficult” diagnosis because “people tend to present differently at different times.” The trajectory can also be unpredictable. For example, a social worker for a hospice and palliative care

organization said, “More of our palliative care patients than hospice patients are [diagnosed with] congestive heart failure because it’s so unpredictable. It’s hard to tell when you’re in the final stages, ’cause today you’re not and tomorrow you might be.” This unpredictability has implications for how people live. For example, the same hospice and palliative care social worker commented on the difficulty of uncertain prognosis in heart failure, noting, “Not everybody dies on schedule . . . [we] think they’re not going to make it through the night, and the next day they’re going out to lunch.”

As the patient’s illness progresses, social workers may need to promote continued involvement and decision making. For example, a home hospice social worker said, “The patient can often be involved in these discussions. Even patients on ventilators are sometimes able to talk or indicate what their wishes are—that they’ve had enough. Sometimes it’s done with hand signals or their eyes.”

These comments about the trajectory of illness suggest that social workers confront the unpredictability of heart failure in daily life and in the course of illness as treatment continues.

Frequent Flyers

The uncertain illness trajectory has implications for hospitalization, as many with heart failure are frequently hospitalized to address their symptoms. Following a commonly used term in health care settings (Mills, 2009), we use “frequent flyers” to describe a theme encompassing specific statements about people with heart failure going back and forth to the hospital. A home hospice social worker described the cycle of rehospitalization in this way: “People are just tired of going back to the hospital and in IVs, and going back and forth on ventilators and all this type of support and intervention can be exhausting.” This same social worker described the relationship between uncertain illness trajectory and frequent hospitalizations, noting that hospitalization is often perceived as a way of improving heart failure symptoms during an illness in which people can get better and then get worse:

It’s a vicious circle, and people are going back and forth to the hospital to treat this condition they can’t fix. They don’t get better; temporarily they get better, but then they take medication like Lasix, and that arrests their kidneys, and they end up in renal failure and die from that.

Some people with advanced heart failure elect to have hospice care. For these people, enrollment in hospice often changes the pattern of rehospitalization because hospice services provide an alternative form of care focused on comfort and symptom control. For example, the social work bereavement supervisor for the inpatient/outpatient hospice noted,

When people sign on to hospice . . . rather than calling 9-1-1 they call us. We have medications in the home . . . our nurse is always on call; our nurse is talking with them, saying, “Try this, try this.” If they’re not successful in getting them . . . comfortable or calm, then we send a nurse out there to work with the families, so I think that’s a huge benefit, I think, to a lot of patients in general, but especially in patients who . . . don’t want to go back to the hospital.

In contrast, for those who are still seeking treatment, the revolving door continues. For example, a social worker in a hospital-affiliated hospice program noted, “They’re . . . still wanting continued aggressive treatments, even though there’re not really a lot out there, so—but they’ll continue to go back and forth to the hospital.”

This social worker further noted that the frequent flyer phenomenon has administrative implications because people can be rehospitalized before being officially discharged from home care services:

It actually ends up turning into kind of a continuous, you know, they’re at home, they go to the hospital, so we don’t even have the opportunity to discharge the patient, and they come on service again, so some of the patients are never actually officially discharged because of the situations like that.

This suggests that social workers are likely challenged by the administrative burdens of having clients who are simultaneously in two systems (home care and hospital care) when these systems are designed and intended to be used separately and at different times.

In summary, the frequent flyer phenomenon was perceived as a major challenge to heart failure care, given the administrative challenges of handling rapid transitions between hospital and home care services.

Challenges Accessing Care

Challenges accessing care include the complex interrelationships among issues related to social isolation, informal support, and financial difficulties. The social workers in this study described a variety of such challenges. Personal finances were a major concern for people with heart failure, and this concern affected the ability to access services. For example, a social worker based at an HMO said,

A lot of it is financial concerns. A lot of our members, because of their illness they are unable to work . . . their income is very limited, so a lot of their concerns are financial issues . . . and . . . getting their medications and prescriptions.

This same social worker described the process by which a lack of financial resources can lead to health challenges:

Instead of getting . . . more visits to the doctor, because their insurance is limited they cannot see their doctor as often as they should. Their medications, their copays, deductibles are very high . . . sometimes they don't buy medications because they cannot afford the copays and deductibles. So, if you don't take . . . your medication, you're gonna get sicker.

Social isolation can be particularly challenging for people who were already socially isolated before their illness. For example, a social work bereavement supervisor said,

If you have someone who is estranged from family members, who doesn't have . . . a lot of connections with their religious community, then there are times when we [hospice] are the only people they have contact with and [see on multiple occasions].

Social isolation can affect access when health and symptoms deteriorate. This same social worker said,

When people are feeling well and are able to . . . get up and go to the bathroom, get themselves something to eat, there's not an issue. But [when] they're not feeling well, and they're at a huge fall risk, there's lots of safety issues where they have to call the . . . emergency or nonemergency fire department to help them get off the

floor. . . . There's two things: One is a safety piece, but the other is just the pure socialization piece . . . when you have people around to support you from an emotional standpoint, to be there with you versus when you have someone who's all alone.

Within this context, one of the things that social workers do is try to facilitate informal support and care. For example, a home care social worker noted,

A lot of what I'm doing as a social worker is trying to help families figure out who among themselves can help provide care because most people are working. Or they're from out of town or not able to provide the care. . . . It's a real desperate situation, from my point of view.

Addressing psychosocial symptoms is also an important way of helping people deal with social isolation. The same home care social worker noted that social workers used their awareness of the psychosocial issues involved with heart failure in their practice. A home hospice social worker described a typical context:

There's a lot of anxiety in the family. And the patient with heart failure is awake. Many times, that person is very uncomfortable. I was thinking about Henry David Thoreau's quotation, "Most men"—generalized to women—"have lives of quiet desperation." There's this panicky, overwhelmed feeling of not getting enough oxygen. They're starving; they're drowning in congestion and a very panicked picture.

When family support is limited, social workers may seek out formal support organizations or informal support from neighbors or others. For example, a home care social worker noted,

I don't think there's a lot of help available. Sometimes . . . if they're involved in a church, maybe through their parish there may be parish nurses. Sometimes people say, "There's a neighbor across the street that was a nurse and is out of work or retired and can help out."

Helping clients access formal care services is also a social work challenge. One respondent emphasized that qualifying for federal insurance programs such

as Medicaid is difficult for heart failure patients because some conditions, such as advanced stages of cancer, are more quickly administratively processed. Another respondent employed at an HMO noted that heart failure receives less charitable financial support than other diseases. Prescription coverage was also mentioned as a challenge.

In summary, social workers in this study found that they are often in the position of helping people with heart failure obtain greater access to care support. They reported that people with heart failure sometimes experience a lack of informal support and have difficulties accessing both formal and informal help when their condition deteriorates.

DISCUSSION

This study reveals a varied and rich picture of social work roles with heart failure clients. The trajectory of illness, which was perceived as unpredictable and sometimes not fully understood by clients, has implications for patterns of service use. Specifically, frequent rehospitalizations, a phenomenon often described with the term “frequent flyer” (Mills, 2009), pose challenges for social workers. Social workers need to understand the heart failure trajectory and support clients with heart failure in their uncertainty as they make important health care decisions. Social workers can be essential in promoting self-determination in decision making and in educating people with heart failure about hospital care alternatives such as hospice. The social workers interviewed mentioned people with inadequate social ties or insufficient formal support due to structural health care system barriers. They noted that illness-specific initiatives were particularly helpful in addressing the challenges of heart failure care.

Although these results are helpful in highlighting the important role played by social workers for people with heart failure, there is much to be done to enhance and recognize social work contributions in health care. A major emphasis in recent years has been on care coordination, or interdisciplinary strategies targeting people at risk for rehospitalization and improving patient outcomes through enhanced and coordinated health and social support (Brown, 2009). Social workers need to be more involved in care coordination and other multidisciplinary team initiatives, with full inclusion and engagement in the presentation, discussion, and reconciliation of opinions concerning advanced illness issues (Keefe, Geron, & Enguidanos, 2009; Werner et al., 2004).

To enhance the role of social workers in supporting people with chronic illness as well as health and psychosocial outcomes, we suggest that social workers use “illness-informed social work” in their roles in multidisciplinary teams. *Illness-informed social work* refers to social worker knowledge of the challenges of specific illnesses and strategies for helping people cope with these challenges. Illness-informed social work is applicable for heart failure as well as other chronic and serious illnesses. For example, recent scholarship on dementia has highlighted the need to educate social workers about specific illnesses as a preparation for practice (Kaplan & Andersen, 2012). Illness-informed social work was not explicitly evident in the interviews that we conducted. However, one hospice social worker working in a hospital-affiliated program explained the agency’s adoption of a disease management approach in home care targeting heart failure specifically. The participant noted that this approach

is going to allow us a little bit more specialization among our nurses seeing those patients . . . I’m really excited about this, that they’ve switched over to it—it will also give us more of an opportunity to help them understand the different triggers that are making patients more appropriate for hospice, so when we break it down based on diseases, it’s going to be a lot easier to teach . . . the different symptoms and challenges and . . . help link up the patients with the most appropriate programs.

This quote illustrates how illness-informed social work can integrate traditional social work case management approaches with newer care models. More education and training is needed to integrate this approach as a means of better positioning social workers for health care practice.

Study Limitations

Two major limitations of this study should be noted. First and most important, the participants in this study represent a small and select group of health care social workers who were willing to be interviewed about their experiences with heart failure clients. Those who chose not to participate are likely to have quite different knowledge, perceptions, and experiences of heart failure care. Relatedly, the researchers did not specifically address how social workers manage different illness severity levels and care settings.

Second, although the study was conducted in an urban area with a large African American population, the majority of the social workers interviewed were white. The experiences of diverse groups of social work professionals should be obtained in future studies.

Directions for Future Research

Social workers, with their extensive knowledge and experiences in psychosocial care and patient advocacy, have a unique and important contribution to make to heart failure care. More research on social workers in health care settings is needed to improve recognition of social worker activities and expand their potential to contribute to effective psychosocial care for the growing number of adults facing heart failure. Moreover, this study did not find extensive discussions of cultural and racial issues despite previous studies finding that racial and cultural factors are important in advanced care planning (Hopp, 2000) and health care decision making at the end of life (Hopp & Duffy, 2000). This suggests that future studies based on diverse samples of social workers should more fully explore racial and cultural issues in heart failure care and the ways in which these factors are addressed by social workers.

A second area for future research concerns integrating illness-informed social work practice that incorporates knowledge of heart failure symptoms and progressions of the disease trajectory in a variety of health care settings. Future research design should incorporate targeted questions about health care settings and symptoms and progression of the disease trajectory in addition to more general questions about social work approaches to people with heart failure. The participants in this study were from a variety of settings, including hospitals, hospices, and community-based agencies, but there were not enough participants from each setting to fully explore differences in roles, activities, and expectations of social workers in these varied settings. Future research can serve as a basis for further development of illness-informed social work practice for heart failure and other advanced illnesses in a variety of health care settings. **HSW**

REFERENCES

- Aldred, H., Gott, M., & Gariballa, S. (2005). Advanced heart failure: Impact on older patients and informal carers. *Journal of Advanced Nursing*, 49, 116–124.
- American Heart Association. (2013). Heart disease and stroke statistics—2014 update: A report from the American Heart Association. *Circulation*, 129, e28–e292.
- Barry, C. A., Britten, N., Barber, N., Bradley, C., & Stevenson, F. (1999). Using reflexivity to optimize teamwork in qualitative research. *Qualitative Health Research*, 9(1), 26–44.
- Black, K. (2006). Advance directive communication: Nurses' and social workers' perceptions of roles. *American Journal of Hospice and Palliative Medicine*, 23, 175–184.
- Brown, R. (2009). *The promise of care coordination: Models that decrease hospitalizations and improve outcomes for Medicare beneficiaries with chronic illness*. Santa Monica, CA: RAND Corporation. Retrieved from <http://www.nyam.org/social-work-leadership-institute/docs/N3C-Promise-of-Care-Coordination.pdf>
- Claiborne, N., & Vandenberg, H. (2001). Social workers' role in disease management. *Health & Social Work*, 26, 217–225.
- Claiborne, N., & Vandenberg, H. (2003). How can social workers improve outcomes and costs in disease management? *Disease Management and Health Outcomes*, 11, 407–413.
- DeCoster, V. A. (2001). Challenges of type 2 diabetes and role of health care social work: A neglected area of practice. *Health & Social Work*, 26, 26–37.
- Desai, A. S., & Stevenson, L. W. (2012). Rehospitalization for heart failure: Predict or prevent? *Circulation*, 126, 501–506.
- Dobrof, J., Dolinko, A., Lichtiger, E., Uribarri, J., & Epstein, I. (2002). Dialysis patient characteristics and outcomes. *Social Work in Health Care*, 33, 105–128.
- Engel, R., & Schutt, R. (2014). *Fundamentals of social work research*. Thousand Oaks, CA: Sage Publications.
- Fitzsimons, D., Mullan, D., Wilson, J. S., Conway, B., Corcoran, B., Dempster, M., et al. (2007). The challenge of patients' unmet palliative care needs in the final stages of chronic illness. *Palliative Medicine*, 21, 313–322.
- Hobbs, F. D., Roalfe, A. K., Davis, R. C., Davies, M. K., & Hare, R. (2007). Prognosis of all-cause heart failure and borderline left ventricular systolic dysfunction: 5 year mortality follow-up of the Echocardiographic Heart of England Screening Study (ECHOES). *European Heart Journal*, 28, 1128–1134.
- Hopp, F. P. (2000). Preferences for surrogate decision makers, informal communication, and advance directives among community-dwelling elderly: Results from a national study. *Gerontologist*, 40, 449–457.
- Hopp, F. P., & Duffy, S. (2000). Racial variations in end-of-life care. *Journal of the American Geriatrics Society*, 48, 658–663.
- Hopp, F. P., Thornton, N., Martin, L., & Zalski, R. (2012). Life disruption, life continuation: Contrasting themes in the lives of African-American elders with advanced heart failure. *Social Work in Health Care*, 51, 149–172.
- Irving, G., Holden, J., Edwards, J., Reeve, J., Dowrick, C., & Lloyd-Williams, M. (2013). Chronic heart failure guidelines: Do they adequately address patient need at the end-of-life? *International Journal of Cardiology*, 168, 2304–2309.
- Kaplan, D. B., & Andersen, T. A. (2012, July). *Common disorders demand expert care: The need for specialized professional education in disorders of dementia*. Paper presented at the Alzheimer's Association International Conference, Vancouver, British Columbia, Canada.
- Keefe, B., Geron, S. M., & Enguidanos, S. (2009). Integrating social workers into primary care: Physician and nurse perceptions of roles, benefits, and challenges. *Social Work in Health Care*, 48, 579–596.
- Kramer, B. J., Christ, G. H., Bern-Klug, M., & Francoeur, R. B. (2005). A national agenda for social work

- research in palliative and end-of-life care. *Journal of Palliative Medicine*, 8, 418–431.
- Leeming, A., Murray, S. A., & Kendall, M. (2014). The impact of advanced heart failure on social, psychological and existential aspects of personhood. *European Journal of Cardiovascular Nursing*, 13(2), 162–167.
- Light-McGroary, K., & Goodlin, S. J. (2013). The challenges of understanding and managing pain in the heart failure patient. *Current Opinions on Supportive and Palliative Care*, 7(1), 14–20.
- Lowery, J., Hopp, F. P., Subramanian, U., Wiitala, W., Welsh, D., Larkin, A., et al. (2012). Evaluation of a nurse practitioner disease management model for chronic heart failure: A multi-site implementation study. *Congestive Heart Failure*, 18, 64–71. Retrieved from <http://onlinelibrary.wiley.com/doi/10.1111/j.1751-7133.2011.00228.x/abstract>
- Miller, J. J., Frost, M. H., Rummans, T. A., Huschka, M., Atherton, P., Brown, P., et al. (2007). Role of a medical social worker in improving quality of life for patients with advanced cancer with a structured multidisciplinary intervention. *Journal of Psychosocial Oncology*, 25, 105–119.
- Mills, R. M. (2009). The heart failure frequent flyer: An urban legend. *Clinical Pathologic Correlations*, 32(2), 67–68.
- National Heart, Lung, and Blood Institute. (2012). *What is heart failure?* Retrieved from <http://www.nhlbi.nih.gov/health/health-topics/topics/hf/>
- Padgett, D. K. (2008). *Qualitative methods in social work research* (2nd ed.). Thousand Oaks, CA: Sage Publications.
- Pastor, D. K., & Moore, G. (2013). Uncertainties of the heart: Palliative care and adult heart failure. *Home Healthcare Nurse*, 31(1), 29–36.
- Peterson, J. K. (2012). Shared decision making in health care settings: A role for social work. *Social Work in Health Care*, 51, 894–908.
- Proctor, E. K., Morrow-Howell, N., Li, H., & Dore, P. (2000). Adequacy of home care and hospital readmission for elderly congestive heart failure patients. *Health & Social Work*, 25(2), 87–96.
- Thornton, N., & Hopp, F. P. (2011). “So I just took over”: African American daughters’ caregiving for parents with heart failure. *Families in Society*, 92, 211–217.
- Werner, P., Carmel, S., & Ziedenberg, H. (2004). Nurses’ and social workers’ attitudes and beliefs about and involvement in life-sustaining treatment decisions. *Health & Social Work*, 29, 27–35.

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ROBERTA R. GREENE AND NANCY P. KROFF

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