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IDENTIFYING DIFFERENCES IN EXPERIENCES RELATED TO CAREGIVER BURDEN  
AND HEALTH STATUS AMONG CAREGIVERS OF PERSONS WITH HEART FAILURE

HOLLY WEINSCHENK  
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Reviewed and approved\* by the following:

Lisa Kitko, Ph.D., RN, FAHA  
Assistant Professor of Nursing, Josiah S. Macy Jr. Faculty Scholar  
Honors Adviser and Thesis Supervisor

Judith E. Hupcey, Ed.D., CRNP, FAAN  
Professor of Nursing and Medicine, Associate Dean for Graduate Education and Research  
Second Reader

\* Signatures are on file in the Schreyer Honors College.

## ABSTRACT

**Background:** Heart failure (HF) is the leading cause of disability among older adults. Informal caregivers are vital to the health of patients with HF. Existing literature has identified negative outcomes for caregivers such as caregiver burden and decreased health-related quality of life. However, much of the research on caregiver outcomes has used quantitative methods. Qualitative research is needed to describe the individualized experiences which contribute to caregiver outcomes.

**Purpose:** The purpose of this study was to identify experiences related to caregiver burden and health status among caregivers of patients with advanced HF.

**Methods:** Participants, who were part of a larger longitudinal parent study, included caregivers of persons with advanced HF who had less than a 2-year predicated survival. Ten female spousal caregivers were included in this secondary analysis. A qualitative thematic analysis was completed to determine these caregivers' experiences caring for a person with HF.

**Results:** Themes included: *Role adjustment*; *Caregiving is stressful, but not a burden*; and *Minimization of health needs*. Caregivers reported adjusting their lifestyle and experiencing stress, but said caregiving was not a burden. Caregivers prioritized the health of the person with HF over their own and waited until after the person's death to seek medical help for their concerns.

**Conclusions and Implications:** Caregivers of persons with HF describe negative experiences, but are hesitant to describe these experiences as burdensome. They insist that caregiving is their job as a spouse and they do it out of love. Many caregivers do not discuss their own concerns because they feel their health is of lower priority. Providers should assess the caregiver's health during patient visits in order to improve health outcomes for both.

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## **Chapter 1**

### **Introduction**

The global economic burden of heart failure is estimated at \$108 billion each year (Cook, Cole, Asaria, Jabbour, & Francis, 2014). According to the World Health Organization, “cardiovascular disease was the leading cause of noncommunicable disease deaths in 2012” and is a “major healthcare challenge for the twenty-first century” (Mendis et al., 2014). In the United States, an estimated 5.7 million people have been diagnosed with heart failure (Mozaffarian et al., 2016). Heart failure is the leading cause of disability among the older adult population in the United States, and the lifetime risk of developing this chronic condition is 20 percent (Yancy et al., 2013).

By definition, heart failure is a syndrome in which blood flow does not adequately perfuse the body’s tissues due a structural or functional impairment of the heart (Yancy et al., 2013). Because of cardiac decompensation, persons with heart failure experience symptoms including fatigue and dyspnea at rest or during exertion (Dickstein et al., 2008). Blood and fluid can back up into the pulmonary and peripheral vasculature, resulting in complications of fluid overload such as peripheral edema and pulmonary crackles (Dickstein et al., 2008). The chronic nature of heart failure leads to recurring hospitalizations, possible surgeries, and restrictions in activities of daily living as the condition increases in severity (Dickstein et al., 2008; Yancy et al., 2013). In addition, symptom burden related to fatigue and dyspnea can result in functional limitations which inhibit the ability of individuals to care for their heart failure (Dickson, McCauley, & Riegel, 2008).

The assistance of an informal caregiver is vital to the health of persons with heart failure, as caregivers provide the support they need to continue living at home (Pattendan, Roberts, &

Lewin, 2007). In the United States, an estimated 90 percent of care for individuals with chronic illness is delivered by informal family caregivers (Farran, 2001). An informal caregiver is defined as any caregiver who is not monetarily compensated for the services they provide (Adelman, Tmanova, Delgado, Dion, & Lachs, 2014). During 2015, approximately 34.2 million individuals performed the tasks of informal caregiving for older adults, and these caregivers spent an average of 24.4 hours per week providing care (National Alliance for Caregiving et al., 2015). Overall, informal caregivers provide an estimated \$470 billion of unpaid care each year in the United States (Reinhard, Feinberg, Chouler, & Houser, 2015).

Informal caregivers who provide care to persons with heart failure are comprised of adult children, spouses, and other family members or friends (Saunders, 2009). The tasks of heart failure caregiving vary; duties include monitoring the person's adherence to treatment, providing transportation to appointments, preparing low-sodium meals, and detecting changes in the health status of the person with heart failure (Pattendan et al., 2007). Specific tasks of caregiving are dependent on the severity of the person's condition, which can vary over the course of the illness (Luttik, Jaarsma, Veeger, Tijssen, & Van Veldhuisen, 2007). Caregivers of persons with heart failure are generally not needed for activities of daily living such as bathing, using the bathroom, and brushing teeth in the beginning stages of the illness (Luttik et al., 2007). However, caregivers of persons with advanced heart failure provide more assistance with routine care, ambulation around the house, shopping, cleaning, and other activities that require stamina (Luttik et al., 2007). Pressler et al. (2009) found that caregivers perceive the tasks of caregiving as challenging, and caregivers report marked difficulty with some specific tasks such as handling the person with heart failure's moodiness and behavior problems, communicating with the healthcare providers, and managing finances.



Because the tasks of caregiving can be taxing, caregivers report experiencing burden due to their added responsibilities (Adelman et al., 2014). Providing care for a person with heart failure affects all aspects of the caregiver's life, including physical, psychosocial, and financial domains (Adelman et al., 2014). Physically, caregivers can experience fatigue and health problems as a result of chronic stress (Saunders, 2008). Twenty-two percent of caregivers for individuals with long-term illnesses report that their health has worsened as a result of caregiving (National Alliance for Caregiving et al., 2015). The stress of caregiving also takes a toll on mental health; caregivers frequently report episodes of major depression as a result of lower health-related quality of life (Saunders, 2008). In addition, caregivers report feelings of social isolation due to sacrificing time with their friends or family in order to provide care to the person living with an advanced illness (Saunders, 2008). Financially, caring for a person with heart failure is accompanied by expenses; travel to and from appointments can be costly, the person with heart failure can be unemployed due to disease progression, and caregivers may need to take time off from work in order to adequately meet the needs of the person living with heart failure (Pattendan et al., 2007).

### **Problem, Purpose and Research Questions**

As the prevalence of heart failure in the United States continues to increase (Bui et al., 2011), research on caregiver outcomes is a critically important topic. Previous research on caregivers of persons with heart failure has identified negative caregiver outcomes such as caregiver burden and decreased health-related quality of life (Adelman et al., 2014; Saunders, 2008). Unpaid caregivers are financially valuable to the United States (Reinhard, et al., 2015); therefore, it is imperative for new research to focus on understanding the role of the caregiver in order to ensure their continued contributions.

The individual experiences which contribute to poor caregiver outcomes are currently not fully understood. Bridging this gap of knowledge could mean better interventions for caregivers and potentially improved caregiver wellness. More research is needed in order to understand the experiences of caregivers of persons with heart failure, and the ways in which these experiences change over time. The purpose of this research was to identify individual differences in the experiences related to caregiver role burden and health status among caregivers of persons with heart failure through a qualitative secondary analysis of data from a recent, longitudinal clinical trial. The specific research questions included:

1. How do caregivers of persons with advanced heart failure describe their role?
2. How do caregivers perceive their level of burden?
3. How do caregivers perceive their health status over time since becoming the primary caregiver for a person with advanced heart failure?

In the next chapter, a review of the literature related to outcomes for caregivers of persons with heart failure will be presented, and gaps that currently exist in the literature will be identified.

## Chapter 2

### Review of the Literature

In this chapter, the review of literature related to caregiver outcomes will be presented. The literature search process and synthesis of the literature will be described in order to establish the state of the science related to caregiver burden and health-related quality of life in the context of heart failure.

#### Purpose of the Review

The purpose of this literature review is to identify the current state of the science regarding outcomes for caregivers of persons with heart failure. In this literature review, two specific caregiver outcomes will be explored: caregiver burden and health-related quality of life. Caregiver burden is defined as difficulties or strain faced by caregivers as a result of their role in providing care (Bozkurt Zincir et al., 2014). Health-related quality of life is a self-reported determination of one's physical and mental health status (Agren, Evangelista, Davidson, & Stromberg, 2011). Due to the rising number of persons with heart failure resulting in a commensurate rise in the number of informal caregivers, many researchers have begun to study caregiver outcomes and the factors which influence these outcomes (Bui et al., 2011). By conducting a systematic search of databases and analyzing the results of this search, the aim is to synthesize the current findings in the literature related to this topic of interest.

#### The Search Process

Three databases were used to conduct this literature search: *PubMed*, *CINAHL*, and *PsycINFO*. Key terms used to identify relevant papers included "heart failure," "caregiver" or "carer," and "burden," "strain," "health-related quality of life," "quality of life," or "health status." Searches were limited to peer-reviewed articles written in the English language and

published between the years of 2010 and 2016. A total of 99 scholarly articles were identified within the three databases when these search terms and limitations were used. Of these articles, 64 were from *PubMed*, 17 were from *CINAHL*, and 18 were from *PsycINFO*.

Certain inclusion and exclusion criteria were developed and applied in order to narrow the search to relevant articles. The goal of the inclusion and exclusion criteria was to identify current literature with a primary focus on informal caregiver outcomes in the context of heart failure. Inclusion criteria were: empiric data, qualitative and quantitative studies, a focus on health-related quality of life or caregiver burden, and study participants who care for a person with chronic or advanced heart failure. Primary research studies, secondary analyses, and systematic reviews were included. Exclusion criteria were: a focus on the outcomes of professional or paid caregivers, caregivers with cognitive limitations, duplicate papers, and individual papers which were analyzed as part of the systematic reviews identified by this literature search. If the review included articles in which caregivers were paid or were not of sound mind, results of the review could be skewed. The exclusion criteria were chosen in order to limit the amount of confounding variables which could have an effect on the level of burden and health-related quality of life in caregivers of persons with heart failure.

After screening the articles by title and abstract for relevance to the topic, 54 articles were retrieved for full text evaluation. The inclusion and exclusion criteria were applied to narrow the search and select the articles for this literature review. Eleven total articles were selected for the review. Eight of the articles were from *PubMed* (Agren, Evangelista, & Stromberg, 2010; Agren et al., 2011; Bozkurt Zincir et al., 2014; Chung, Pressler, Dunbar, Lennie, & Moser, 2010; Imes, Dougherty, Pyper, & Sullivan, 2011; Kang, Li, & Nolan, 2011; Liljeroos, Agren, Jaarsma, & Stromberg, 2014; Marcuccilli, Casida, Bakas, & Pagani, 2014), two were from *CINAHL*

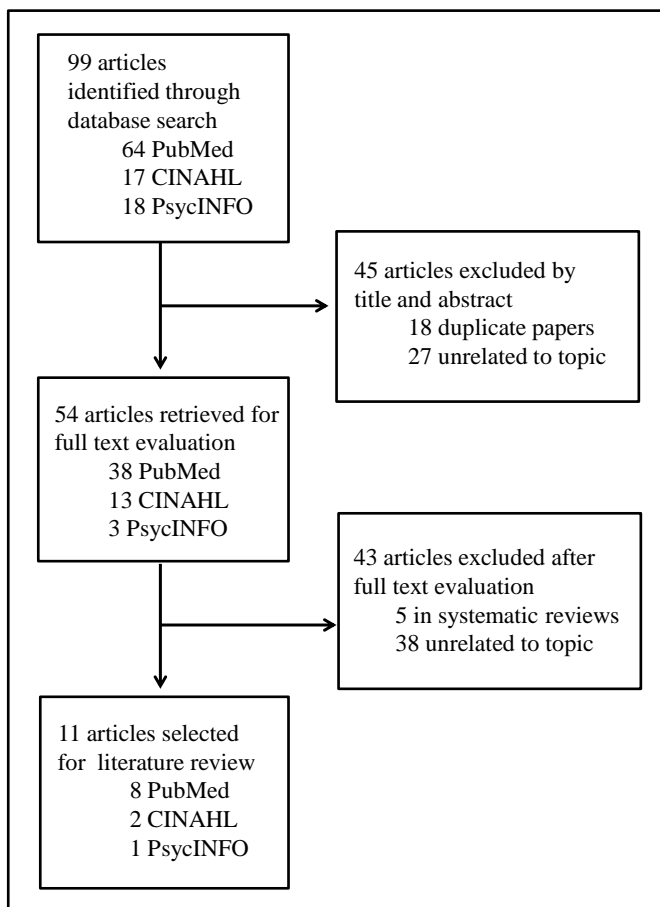
(Hooker, Grigsby, Riegel, & Belkman, 2015; Stromberg & Luttik, 2015), and one from *PsycINFO* (Harkness, Arthur, & McKelvie, 2013). A detailed description of this evaluation process is outlined in Figure 1.

Figure 1. Decision Tree for the Literature Search Process

### Systematic Reviews Related to

### Caregiver Outcomes

Of the eleven articles included in the review, three were systematic or integrative reviews of literature related to heart failure caregiver outcomes (Hooker et al., 2015; Kang et al., 2011; Stromberg & Luttik, 2015). The three systematic reviews included a sample of over 500 total caregivers across 47 studies conducted from 1967 to 2009. Kang et al. (2011)



reviewed ten qualitative studies published between 2007 and 2008. The aim of this systematic review was to describe the experiences of informal caregivers of persons suffering from chronic heart failure (Kang et al., 2011). This review resulted in recurring themes expressed by caregivers during interviews such as “suffering from anxiety” and “being isolated,” which were closely related to caregiver burden and quality of life. Kang et al. (2011) found that caregivers suffered from anxiety, which decreased their overall quality of life. In addition, the majority of

the caregivers reported burdensome effects of caregiving such as reduced social life, decreased leisure time, and feelings of isolation (Kang et al., 2011).

The other two systematic reviews included in this literature synthesized the results of more recent studies about heart failure caregiver outcomes. Stromberg & Luttik (2015) reviewed 24 articles published in 2013 and 2014. This systematic review primarily focused on individual factors which affect a caregiver's level of burden and health-related quality of life. The findings of this review suggested that health-related quality of life is negatively correlated with patient symptoms and caregiver depression. The more highly symptomatic a person with heart failure was, the lower the caregiver rated their health-related quality of life. Similarly, a caregiver's experience of depressive symptoms was also found to influence their reported health-related quality of life and level of burden. Lower quality of life and higher levels of burden were found in those with depressive symptoms (Stromberg & Luttik, 2015). Other individual caregiver factors were found to influence burden; female gender, young, and poor health were associated with higher levels of burden. Characteristics of the person with heart failure such as instability, worsening condition, and frequent hospitalizations were also associated with an increased risk for high levels of caregiver burden (Stromberg & Luttik, 2015).

Similar to Stromberg & Luttik (2015), Hooker et al. (2015) also focused on factors which affect the level of burden and health of caregivers of persons with heart failure. Specifically, this integrative review aimed to describe the influence of patient-caregiver relationship quality on these caregiver outcomes. Thirteen papers published over the course of a decade, from 2005 until 2015, were included in the review (Hooker et al., 2015). Results suggested that there was a negative association between caregiver-reported relationship quality and level of burden.

Communication difficulties between the person with heart failure and caregiver also put caregivers at risk for greater burden (Hooker et al., 2015).

### **Individual Studies Related to Caregiver Outcomes**

In addition to the three review papers, eight individual studies were identified in the literature search. Of these individual studies, three were qualitative (Imes et al., 2010; Liljeroos et al., 2014; Marcuccilli et al., 2014). The qualitative studies collectively aimed to describe the experience of caring for a person with chronic heart failure. Similar methods were used to conduct the research; caregivers were interviewed either face-to-face or over the telephone, and their responses were coded based on qualitative analysis guidelines appropriated to the methods used in the study. Recurring themes were identified based on the caregiver responses, and conclusions were made about caregiver outcomes. Imes et al. (2010) and Liljeroos et al. (2014) found that caregivers experienced increased demands and burden due to the persons' decreased functional status. Caregivers reported feeling overwhelmed at times and found it difficult to maintain hope. Adaptations made by caregivers included attending less social activities and increasing their schedule flexibility to deal with daily ups and downs (Imes et al., 2010). During an interview, one person with heart failure discussed how the disease did not just happen to them individually, but it happened to both of them (Imes et al., 2010). One unique finding in Imes et al. (2010) was that caregivers reported the need to discuss their burden and rely on family and friends for support. The findings of Marcuccilli et al. (2014) differed greatly from the other two qualitative studies. Although caregivers described taking on more work, experiencing role changes, and added stress, the caregivers unanimously reported that they did not experience caregiver burden. Rather, the caregivers agreed that their additional responsibilities were not a burden, but simply a part of life (Marcuccilli et al., 2014).

Five quantitative studies were included in this review, all of which measured caregiver burden or health-related quality of life using previously validated scales. The studies which describe caregiver burden or health-related quality of life will be reviewed first, followed by a discussion of studies which report factors impacting caregiver burden or health-related quality of life. Both Bozkurt Zincir et al. (2014) and Chung et al. (2010) found that a significant number of caregivers scored in the severe category on the Zarit Burden Interview, a questionnaire used to measure caregiver burden. However, Agren et al. (2010), measured caregiver burden using the Caregiver Burden Scale, and found that only two percent of caregivers reported high levels of burden. A possible confounding variable that could explain this variation is that Agren et al. (2010) measured caregiver burden shortly after patient discharge from the hospital, when the caregiver had just begun their role. Only one of the studies included a specific measure of health-related quality of life (Agren et al., 2011). Agren et al. (2011), in a secondary analysis of the data collected in Agren et al. (2010), measured health-related quality of life using the Short Form-36. This is a questionnaire that measures different dimensions of physical and mental health. In this study, caregivers scored similarly as the age and sex-matched reference group which they were compared. Therefore, no significant changes were found in health-related quality of life among caregivers of persons with heart failure compared to persons of the same age and sex who were not caregivers (Agren et al., 2011).

In addition to measuring caregiver burden and health-related quality of life, the articles included in this review described individual factors which affected these caregiver outcomes. Three of the studies measured depressive symptoms in caregivers using the Beck Depression Inventory (Agren et al., 2010; Chung et al., 2010; Bozkurt Zincir et al., 2014). Unanimously, the three studies found that depressive symptoms and poor mental health are positively correlated



with increased levels of burden (Agren et al., 2010; Chung et al., 2010; Bozkurt Zincir et al., 2014). Similar to the evaluation in the systematic review conducted by Stromberg & Luttik (2015), four of the individual quantitative studies measured the relationship between gender and caregiver outcomes. Agren et al. (2011) found that gender was not associated with health-related quality of life, and both Agren et al. (2010) and Chung et al. (2010) found that gender was not associated with caregiver burden. However, the results from Bozkurt Zincir et al. (2014) showed that female caregivers reported significantly higher levels of burden than their male counterparts.

Another factor which was measured in relation to caregiver outcomes was time spent in the caregiving role. Chung et al. (2010) found that greater burden was associated with an increased number of hours spent on caregiving tasks. Similarly, Bozkurt Zincir et al. (2014) found that the length of time that a person had spent as an informal caregiver since the person's diagnosis was positively correlated with increased burden. Schedule changes and lack of free time also effected reported levels of caregiver burden. Both Agren et al. (2010) and Harkness et al. (2013) found that caregivers experienced stress and burden from changing their personal schedules in order to provide care and complete the tasks of caregiving. Other factors that were found to increase caregiver burden were the financial strain of caregiving and the impact on the caregiver's health (Harkness et al., 2013).

### **Quality of the Evidence**

Each of the eleven scholarly articles included in this review exhibited certain strengths. With the exception of Stromberg & Luttik (2015), which only included articles from *PubMed*, the systematic reviews were conducted through an extensive search of multiple databases (Kang et al., 2011; Hooker et al., 2015). *PubMed*, *CINAHL*, *EMBASE*, *Cochrane Library*, *Web of Science*, and *PsychInfo* were used to identify articles for the systematic reviews (Kang et al.,

2011; Hooker et al., 2015). Also, each of the systematic reviews included a detailed methods section highlighting the search terms used and the inclusion and exclusion criteria (Kang et al., 2011; Hooker et al., 2015; Stromberg & Luttik, 2015). Overall, these reviews presented a diversified sample of papers and produced strong evidence related to the current state of the science.

Strengths were also evident in the individual research studies in this literature review. The research studies were conducted in multiple different countries including Sweden (Agren et al., 2010; Agren et al., 2011; Liljeroos et al., 2014), Turkey (Bozkurt Zincir et al., 2014), Canada (Harkness et al., 2013) and the United States (Chung et al., 2010; Imes et al., 2010; Marcuccilli et al., 2014). This diverse sample of studies shows that heart failure does not discriminate by race, culture, or location. Also, this sample allows for multicultural comparisons to be made between caregiver outcomes in different locations around the world. Another common strength among the quantitative studies included in this review is that well-known, valid measures were used in order to assess caregiver outcomes. Examples of tools used were the Caregiver Burden Scale, Short Form-36, Beck Depression Inventory, Control Attitude Scale, Zarit Burden Interview, and the Caregiver Reaction Assessment. All of these tools have undergone previous research to ensure their validity and reliability.

### **Chapter Summary**

Overall, the results of this literature review contain evidence that increased level of burden is a problem for caregivers of persons with heart failure. However, there are discrepancies in the findings for health-related quality of life in caregivers of persons with heart failure, and a gap of knowledge still remains in this area. The eleven scholarly articles included in this literature review identify many individual factors which could be associated with varying

caregiver outcomes. Some of these factors include length of time spent in the caregiving role, caregiver age, health status of the person with heart failure, and depressive symptoms experienced by caregivers. Mixed results were found for the relationship between caregiver gender and level of burden, warranting future research on the topic. In addition, little existing research describes the changes in caregiver health and burden over time. In the next chapter, a description of the methods used to conduct a novel qualitative analysis of caregiver outcomes will be described.

## **Chapter 3**

### **Research Design and Methodology**

The purpose of this thesis was to identify experiences related to burden and caregiver health among caregivers of persons with heart failure through a longitudinal qualitative analysis of caregiver interviews. Through an analysis of the interview responses from caregivers of persons with advanced heart failure, reported experiences were compared, and similarities which exist between caregivers were identified. It is hoped that identifying the experiences of caregivers of persons with heart failure will be a catalyst for further research on interventions which aim to improve the caregiver role. This study aimed to answer the following research questions: How do caregivers of persons with advanced heart failure describe their role? How do caregivers perceive their level of burden? How do caregivers perceive changes in their health status over time since becoming the primary caregiver for a person with advanced heart failure?

#### **Study Design**

This study utilized a qualitative secondary thematic analysis in order to explore the individual experiences of caregivers of persons with advanced heart failure. This study design provided a comprehensive, in-depth understanding of the caregiver experience from the perspective of the caregivers. Qualitative methodology was used because of its ability to examine and describe complex phenomena, such as life stories and narratives (Vaismoradi et al., 2013). The current study was designed as a secondary analysis because it utilized a preexisting data set from a prior research study conducted by Hupcey and Kitko (NIH/NINR1RO1NR13419). Data analysis was completed using caregiver interviews which were recorded during the data collection period of the original study. The principles of thematic analysis were used to analyze the data for the current study, as outlined later in the chapter. The Institutional Review Board of

the Penn State Hershey Medical Center (IRB of record for the original study) determined that the use of de-identified data did not require IRB approval. I was added to the original IRB in a modification submitted to the IRB on 4/27/16.

### **The Original Study**

The data used in this study was derived from a prior longitudinal qualitative study which aimed to describe perceptions of illness severity and terminality among persons with Stage D heart failure. In the original study, 100 persons with heart failure were recruited from two Pennsylvania hospitals. These hospitals were large heart failure centers, with one being in an urban setting and the other in a rural setting. Participants were recruited for the study either while in the hospital for an acute heart failure exacerbation or immediately after discharge. The predicted survival of the participants recruited for this study was less than two years, as determined by the Seattle Heart Failure Model upon enrollment (Levy et al., 2006).

The major strategy for data collection in this qualitative study was in-depth interviews. A series of semi-structured interviews were conducted with the participants enrolled in this study over the course of two years. Both the participant living with stage D heart failure and their family caregiver participated in individual interviews occurring approximately monthly over the course of a 2-year period or until the person with heart failure died. Post-death interviews were also conducted with caregivers of participants who died during the data collection period. The goal of these interviews was to delve deeply into patient and caregiver experiences and perceptions about advanced heart failure. An interview guide was developed in order to achieve this goal; the guide consisted of open-ended questions which targeted responses related to experiences with heart failure. Examples of probes included in the interview guide included:

- Tell me about that experience.

- Can you explain how you felt during that time?
- What impact has this had on you?

Each of the interviews was recorded using an audio device and transcribed for future analysis. All transcribed interviews were verified to the original recording for accuracy. The transcriptions were de-identified to protect participant confidentiality. Consent was obtained from heart failure patients and caregivers who participated in this study, and the study was approved by the Institutional Review Board at The Pennsylvania State University and each of the participating hospitals.

### **The Current Study**

In the current study, the interviews from a sample of 10 female spousal caregivers who participated in the original study were analyzed. Ten caregivers were chosen because of the expectation that this sample size would reach saturation, the point at which no new data or themes would be found by analyzing additional data. A requirement of the caregivers chosen for this sample was that the person with advanced heart failure that they cared for must have died during the data collection period. Caregivers included in this sample participated in a maximum of 24 interviews over the course of two years, including an interview after the death of the participant with heart failure. The number of interviews per caregiver varied due to the timing of the death of the participant with heart failure during the data collection period. The post-death interview with the spousal caregiver was included for analysis along with the multiple interviews conducted before death. By analyzing multiple interviews from each caregiver in this longitudinal study, conclusions can be drawn about the changes in the caregiving experience over time. In addition, the inclusion of the post-death interview allowed a glimpse into the retrospective perception of the caregiving experience.

### **Data Analysis of the Current Study**

The principles of thematic analysis and content analysis were used to analyze the data for the current study. A thematic analysis is a qualitative approach to data analysis which highlights patterns and themes within a set of data (Vaismoradi et al., 2013). Common threads and points which recur across an entire set of interviews are identified in a thematic analysis (Braun & Clarke, 2006). The interpretation of both manifest and latent content in the interviews are integrated in order to form themes which represent the overall content of the interviews. In thematic analysis, an identified theme captures a meaningful pattern in the data which relates to the research question (Braun & Clarke, 2006). Themes are not identified through quantitative measures; there is no required number of instances of a theme across the set of interviews (Braun & Clarke, 2006). Themes tend to recur in a data set, but there is no correlation between the number of instances and the importance of a theme (Braun & Clarke, 2006).

Braun and Clarke (2006) outline the process of conducting a thematic analysis which was used for this analysis. This process was divided into six phases.

Phase 1: Familiarizing with data

Phase 2: Generating initial codes

Phase 3: Searching for themes

Phase 4: Reviewing themes

Phase 5: Defining and naming themes

Phase 6: Producing the report

In phase 1, I read through the data multiple times to discern patterns in the data. In Phase 2, I systematically coded the entire data set and organized the data into meaningful groups. In phase

3, I combined related codes into potential overarching themes. These themes were reviewed in phase 4 and refined in order to ensure that the themes worked for the entire data set and the patterns identified were clear. In phase 5, the themes were explicitly defined and given names. The final phase of thematic analysis included producing the report of the data analysis in relation to the research questions. This protocol for completing a thematic analysis as outlined by Braun and Clarke (2006) was utilized in the current study. The caregiver interview transcripts were first read through in order to become familiar with the data set. Then, the researcher began to generate initial codes, by writing down notes in the margins and highlighting all parts of the transcripts that seemed relevant to the research questions. In order to search for themes, the researcher began to categorize themes by creating headers and grouping similar pieces of the caregiver interviews together. For example, a caregiver's report that she needed a knee replacement or that she passed out from not eating were both grouped under the heading "caregiver health." These headings were then reviewed to create themes, the themes were named, and the results of the analysis were reported in Chapter 4. During each step of the analysis process, meetings with my research advisor (Kitko) were held to discuss my findings. Any disagreements with my analysis were resolved during the meeting and a consensus was reached. Table 1 displays an example of the coding process that the researcher used to develop qualitative themes from the caregiver interviews.

Table 1. Code Chart

<b>Interview Quote</b>	<b>Code</b>	<b>Qualitative Theme</b>
"I go down every day...he calls me and tells me when he's going to have rehab tomorrow and then I go down there."	Change to Daily Routine	Adjustment to role as caregiver
"It's like there's nobody else to make decisions. That's the tough part...it's just like 100	Pressure felt by caregiver	Caregiving is stressful...



percent is on you.”		
“My stepson came and he put his arms around me and he told me how much they appreciated what I did and I said it’s because we loved each other, you know.”	Caregiving is an act of love	...But it is not a burden
“I’ve been putting that off for a couple years now...I hope this is good news that he’s on the mend so I can get a knee replaced.”	Delay of care	Minimization of caregiver health needs

### Chapter Summary

This chapter has presented the reasons for using a qualitative secondary analysis. The population and sample of the original study has been described, as well as the sample that will be used specifically for this secondary analysis. Details about the data collection process have been stated, and the protocol used to complete the data analysis has been outlined. In the following chapter, the findings of the current study will be presented.

## Chapter 4

### Results

The purpose of this thesis was to identify experiences related to burden and caregiver health among caregivers of persons with heart failure through a longitudinal qualitative analysis of caregiver interviews. In this chapter, the analysis and interpretation of results from this study are discussed. Qualitative themes found within the data, with illustrative quotes, are presented in this section. The four qualitative themes identified in this study were: 1) adjustments to role as caregiver, 2) caregiving is stressful, 3) but not a burden, and 4) minimization of caregiver health needs.

### Demographics

On average, spousal caregivers in this study were 70.3 years old (range 54-88 years). The average length of time spent in the caregiver role as determined by self-report was 12.8 years (range 0.8-44 years). All ten caregivers were female and all identified as Caucasian. In addition, all ten caregivers were spouses of persons with heart failure. Six caregivers were retired, three were still working, and one had never worked outside the home.

Table 2. Demographic Characteristics of Caregivers (n=10)

	Mean	Range	Count
Age (years)	70.3 years	54-88 years	
Years spent in caregiver role	12.83 years	0.8-44 years	
Gender			
Female			10
Ethnicity			
Caucasian			10
Relationship to Person with HF			
Spouse			10
Occupational Status			
Retired			6
Working			3

Never Worked			1
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### **Adjustments to Role as Caregiver**

A common theme among the interviews was the need for caregivers to adjust their normal routines over time in order to fulfill their new role. The extent of these adaptations progressed over time as the patient's disease worsened. Early in the caregiving role, many of the spousal caregivers reported that they did not need to provide a lot of assistance, as the person was very independent. One spousal caregiver reported in an initial interview:

*"You know I don't really take care of him. He is very independent. In fact, even when he's sick, he says 'I'll do it, I can do it, I'll get up. I got to move.' So he's very good."*

Similarly, in the initial interviews, other caregivers stated that they had very little added responsibilities. Often, caregivers reported that their only responsibility was to remind the person with heart failure to take their medicine and record their daily weights. Other caregivers began to prepare low sodium meals, but stated that they were already doing the cooking, so this did not add to their responsibilities. At this point in time early on in the experience of caregiving, caregivers mostly reported that they were satisfied with their arrangements. One caregiver described that she and the person with heart failure were still able to work together to complete their household tasks:

*"Well we always did work together and now he washes the dishes and I dry them. I sit on a chair and dry them and he puts them away. He runs the sweeper for me and I dust and that kind of stuff. I might go down and separate the wash and put the wash in the washer and then he'll put it in the dryer and bring it up and then I'll fold it. We always work together."*

As the interviews progressed over time, caregivers reported increasing responsibilities and additional adjustments to their daily routines. Many of the persons with heart failure became more symptomatic and were unable to complete all of their activities of daily living without assistance. For example, one caregiver who initially reported that the person with heart failure was independent indicated in a future interview that he was no longer able to bathe himself due to shortness of breath, so she was helping him.

In addition to the added responsibilities when taking on the role as caregiver of a person with heart failure, caregivers also described ways in which they sacrificed their personal time to meet the needs of the participant. Caregivers commonly reported that they gave up activities that they once enjoyed, such as being a member on the board at the local senior center. One caregiver described her lack of hobbies and personal time by saying, “There’s never any time for me. That’s why I work.” This caregiver also said that she felt she had lost herself and her life was now defined by her husband’s illness:

*“I’m a caregiver only. I live and breathe for him. So, without him, I don’t know a life without him. My life is taking care of him. I think about it a lot. Who am I? What do I do? I don’t know.”*

Another frequent role adjustment for caregivers was making time to visit the participant when they were admitted to hospitals, rehabilitation facilities, or nursing homes. Once the participant’s health worsened to the point of not being able to live at home, the caregiver needed to set time aside to travel to the facility and visit with the spouse with heart failure. It was not uncommon for the caregivers to visit for hours each day, which was a big change from their normal routine. One caregiver described how she plans her daily visits around her husband’s rehab schedule:

*“I go down every day. He can find out his schedule for the following day like around supper time and then he calls me and tells me when he’s going to have rehab tomorrow and then I go down there.”*

### **Caregiving is Stressful...**

A recurrent theme among the interviews of the ten caregivers was the experience of stress. When describing the stressors in their life, many caregivers reported that they worried a lot about the uncertainty of the future. Participants in this study were advanced in their disease processes, so caregivers commonly stated that they worried about how much time they had left with their spouse and how they would be able to cope with their spouse’s death. Other recurring sources of stress for the caregivers in this study were the pressure to make decisions for the person with heart failure and feeling like they are responsible for the person’s health. Caregivers mentioned that they worried that something would happen to the person with heart failure, and it would be their fault since they were caring for the person. For instance, one caregiver felt stressed because she thought she accidentally gave her spouse too much morphine and hurt him. Another caregiver explained the pressure that she feels:

*“My concern is if something happens to him, who am I? It’s tough. It’s just everything is about him, everything...It’s just sometimes , it’s like there’s nobody else to make decisions. That’s the tough part. You know, you went from two people having a discussion about it and now it’s just like 100 percent is on you.”*

### **...But Not a Burden**

Although caregivers described high levels of stress and changes in their lifestyle due to their role in caring for their spouses, the caregivers were reluctant to describe their experiences as burdensome. When one caregiver was asked if it was a burden to care for her spouse, she

responded, “Definitely not. I do whatever I can for him. This caregiver went on to describe how caring for her husband forced her to do things that she did not like, but why she does not feel that it was a burden:

*“Two things I have trouble with is vomit and diarrhea, but you know I just have to do it and it’s part of my life. I would never change it. So you know right now I just have to do everything because he can’t do anything.”*

The opinion that caregiving was not a burden, but rather was a “part of life” or their “job as wife” was shared by many of the caregivers in this study. Despite the pressure and challenges that these caregivers faced on a daily basis, the caregivers reported that they did not mind this responsibility. Many of the caregivers stated that they were willing to make these sacrifices out of love. One caregiver described:

*“I mean I like helping people, but not medically. So it’s kind of weird when I do it to him, but it’s because it’s him. It’s not because I want to take care of other people. It’s all because it’s him. It’s family.”*

Another finding from the caregiver interviews was that caregivers felt thankful that they were able to care for the person with heart failure. Instead of describing their experiences as burdensome, many of the caregivers were grateful that they could assist their husbands with care. In fact, a lot of caregivers turned down offers for professional help because they wanted to take care of their spouses themselves. Commonly, the caregivers refused offers for home health aides and hospice nurses to assist them with providing care. One caregiver described her feelings about caring for her husband:

*“Everything seems to be going good as far as, you know, that I can take care of him. I’m so thankful for that.”*

During the post-death interviews, caregivers tended to reflect positively on the caregiving experience. Even after the participant died and the caregiver's added responsibilities ceased, caregivers did not reflect back on their time taking care of their husbands as being burdensome. Rather, the caregivers continued to express that they did not mind the extra tasks and stress, and that they cared for their husbands out of love. One caregiver summed up her experience by saying:

*“My stepson came and he put his arms around me and told me how much they appreciated what I did and I said it’s because we loved each other, you know.”*

### **Minimization of Caregiver Health Needs**

Throughout the caregiver interviews, one consistent finding was that the caregivers continuously placed their spouse's health at a greater priority than their own health. Since the sample of this study included all spousal caregivers, the caregivers were around the same age as their spouse and often experienced health problems of their own due to their older age. Some of the health conditions that caregivers in this study reported in the initial interview included hypertension, high cholesterol, obesity, diabetes, arthritis, and previous heart attacks and strokes.

Although the caregivers in this study were older adults with their own comorbidities, they continued to take on the additional commitment of providing care to their spouses. For many caregivers, their constant worry about their spouse's health and needs took away from their own self-care. For instance, multiple caregivers reported forgetting to take their own medications and one caregiver with diabetes reported passing out because she did not have time to eat breakfast and her blood sugar became too low. Also, the tasks of caregiving were taxing for many of the older caregivers, and they no longer had the time or energy to take care of their own needs. Many of the caregivers mentioned that they were exhausted, had no time to rest, or felt like they were

going to collapse. One caregiver described her lack of exercise due to her responsibilities as caregiver:

*“They’re always on my case to lose weight and exercise. But all I’m doing is caregiving and doing what I have to do. I’m too tired to exercise.”*

In addition to the tasks of caregiving being tiresome, they could be dangerous for the caregiver’s health. As time went on and the heart failure progressed, many of the participants became too dyspneic and weak to complete their activities of daily living without assistance. This left the caregivers to provide assistance with showers, dressing, and transferring in and out of bed. These activities involved a lot of heavy lifting, and some of the caregivers reported hurting themselves on the job. For example, one caregiver needed a hip replacement because she popped her hip out while raising the bed up to help her spouse.

While caregivers were vigilant about monitoring changes in the health status of the person with heart failure, they often minimized concerns about their own health. For instance, many of the caregivers put off going to their medical appointments and delayed surgeries because they did not want to compromise their ability to care for their husbands. One caregiver specifically stated that her husband’s health was the top priority at the time. Two of the caregivers in this study had arthritis and needed knee replacements, but chose to delay the surgeries because of their husband’s heart failure. One of the caregivers explained her decision:

*“I’ve been putting that off for a couple years now because I just didn’t feel that he would have been able to take care of himself and me. I hope this is good news that he’s on the mend so I can get a knee replaced.”*

One of the themes that emerged upon analysis of the post-death interviews was that caregivers began to prioritize their health again shortly after their spouse’s death. Within a few



months of the death, many of the caregivers had changed their habits or gone to see their healthcare providers about concerns that they had pushed aside while their spouse was alive. Multiple caregivers reported that they had been more active since their spouse's death and had gotten back into exercise programs. Some of the caregivers scheduled surgeries that they had been delaying within a few months after their spouse's death. One caregiver had the knee replacement surgery that she needed and another caregiver had cataract surgery that she said she was supposed to go for a long time ago, but it wasn't the right time because of her spouse's health.

Although caregivers were hesitant to discuss their health needs in the interviews while their spouse was alive, they readily admitted that they had been neglecting themselves in the post-death interviews. Many of the caregivers stated that caring for their husbands has interfered with their ability to care for themselves. One caregiver summarized this finding by saying, "I've been trying to take care of myself this week because I've been neglecting myself."

### **Chapter Summary**

The overarching themes found from this secondary thematic analysis were that caregivers made adjustments to their role; the experience of caregiving is stressful, but not a burden; and caregivers minimize their own health needs. Becoming a caregiver for a person with advanced heart failure resulted in daily routine changes, added responsibilities, and stress. However, even with these negative experiences, caregivers did not perceive their role as being burdensome. Instead, caregivers described their experiences as just a part of their life or their job as a spouse.

## **Chapter 5**

### **Discussion**

The purpose of this study was to identify experiences related to burden and caregiver health among caregivers of persons with heart failure through a longitudinal qualitative analysis of caregiver interviews. The study aimed to answer the following questions:

1. How do caregivers of persons with advanced heart failure describe their role?
2. How do caregivers perceive their level of burden?
3. How do caregivers perceive their health status over time since becoming the primary caregiver for a patient with advanced heart failure?

By answering these questions, the experience of being a caregiver for a person with advanced heart failure can be better understood. Areas needing further research can be identified and future interventions to improve caregiver wellbeing can be developed.

### **Connections to Literature**

The findings of this secondary analysis expand upon the themes which existed in the literature review. Both the literature review and this study found that caregivers of persons with heart failure made adjustments to their life. Similarly to Kang et al. (2010), in this study, the caregivers' responsibilities interrupted their social lives and reduced their leisure time. Also, a common theme in both previous research and this study was caregiver stress. Liljeroos et al. (2014) found that caregivers experienced increased demands and stress as the person with heart failure's functional status decreased over time. This study demonstrated the same result; caregiver stress increased over time as the person with heart failure's health declined and death became closer.

In addition to the correlations that existed between this study and the literature review, differences were discovered. The literature review did not find any significant changes in the way that caregivers self-reported their physical and mental health status over time. In contrast, this study found that caregivers experience multiple comorbidities that worsened over time. The reason that caregivers cited for their worsening health status was that their spouses' health needs were a greater priority than their own. This particular finding was not discussed in the literature review. This discrepancy may be due to the longitudinal design of this analysis.

In the literature review, mixed results were found regarding the experience of caregiver burden. Multiple quantitative studies about caregivers of persons with heart failure have found that caregivers scored in the severe category on the Zarit Burden Interview (Bozkurt Zincir et al., 2014; Chung et al., 2010). Literature on the topic suggests that length of time as caregiver (Bozkurt Zincir, 2014) and decreased functional status of the patient are associated with greater burden (Liljeroos et al., 2014). However, Marcuccilli et al. (2014) conducted a qualitative study, and found one of the major themes was that caregiving was not a burden, but a part of life. This same theme was reflected in the current study. Caregivers reported stress and difficulties related to their experiences, but were hesitant to call these experiences burdensome. Rather, caregivers became defensive and insisted that their actions were out of love and that they were grateful they were able to care for their spouses during this time. Therefore, while some of the findings in this study supported what the literature has already discovered about heart failure caregivers, some novel findings arose from the data in this study. Further research will be needed.

### **Future Implications**

This study clearly identified that there is a gap between the findings related to caregiver burden in qualitative studies and the results of quantitative scales that measure caregiver burden.

Currently, the Caregiver Burden Scale and Zarit Burden Interview are popularly used measures for quantifying caregiver burden. The Caregiver Burden Scale measures functional ability, types of care provided, and perceived stress associated with caregiving responsibilities (Macera et al., 1993). The Zarit Burden Interview measures objective and subjective burden through questions about caregiver health, mental well-being, finances, and interpersonal relationships (Yap, 2010). Both of these measures have been validated in multiple cultural populations (Macera et al., 1993; Yap, 2010). Interestingly, although these measures have been consistent and used widely among researchers in the field of caregiving in the context of heart failure, the results still contrast with qualitative findings related to burden. Qualitative methods of measuring burden consist of in-depth interviews and open-ended questions asking caregivers to describe the burden they experience.

One possible reason behind the gap between quantitative and qualitative measures of caregiver burden is that the actual term “burden” has a negative connotation among the caregiver population. In particular, this study was entirely comprised of spousal caregivers. Many of these caregivers may have been uncomfortable describing the stress they were feeling as a burden because the word itself implies negativity. Caregivers may feel as though the word suggests that they want to rid themselves of the burden of caregiving, which in this case would either mean their spouse dying or being placed in a facility to receive care. Many of the caregivers reported that they wouldn’t change the way things were and that they cared for their spouses out of love, so “burden” may not be the best term for describing their experiences. Future research should focus on the terminology used in questions on the quantitative burden measures and how specific word choice can impact results. For instance, studies should be conducted to compare scales

which use the word “burden” in the questions with those that use more neutral phrases such as “greater responsibilities” or “added stress.”

Another area of future research should focus on caregiver health status and the way in which caregivers prioritize the health needs of the person they are caring for above their own. Many studies were identified in the literature on health-related quality of life among caregivers, which is a caregiver’s self-reported physical and mental health status. Although the literature review found no significant changes in health-related quality of life among caregivers of persons with heart failure, this does not mean that the caregivers had no incidence of declining health. Rather, since most spousal caregivers are of advanced ages, this finding may mean that caregivers simply do not experience significantly more health problems when compared to the general population of older adults. However, no information was found in the literature review about the caregivers’ perception about the importance of their own health. As seen in the previous chapter, many caregivers in this study reported experiencing multiple comorbidities, as is common in the older adult population. A common theme among these caregivers was delaying their own health care because they believed their spouse’s health was more important.

More research is needed about caregiver’s perception and prioritization of their own health. In addition, interventions should be developed and researched in order to improve caregiver health. A possible caregiver health intervention could consist of a nurse’s visit for the caregiver at the patient’s appointments. Most caregivers do not have time to see their own primary care providers, but still attend all of the patient’s appointments. A quick caregiver assessment and vital signs check by a nurse at these appointments could meet some of the caregiver’s needs without taking up more time from their busy schedule.

Another further area of research could compare burden and health among caregivers of persons with heart failure to caregivers of persons with other chronic conditions. Caregiving can be stressful regardless of the specific disease process, so it is likely that all caregivers experience some common experiences. Also, in addition to heart failure, most chronic diseases occur in the older adult population. This means that spousal caregivers for persons with conditions such as dementia may be of similar ages as caregivers of persons with heart failure and experience similar problems regarding their own health. However, it is also important to note the qualities that make caregivers of persons with heart failure distinct. Persons with advanced heart failure often experience dyspnea that inhibits them from independently completing activities of daily life such as bathing and transferring. Therefore, caregivers help with these physically laboring tasks, and may have a greater risk of injury compared to caregivers that do not have physically demanding roles. Research is needed to compare the experiences of these different types of caregivers, as future caregiver interventions will need to be developed to help more than just caregivers of persons with heart failure.

### **Strengths/Limitations**

Overall, the design of this study exhibited both strengths and limitations. The demographics of caregivers included in this study were narrow. All caregivers were spouses of the person with heart failure and all caregivers were women. Because of this narrow sample, it is hard to generalize the findings among this sample to all caregivers of persons with heart failure. A more variable sample in terms of caregiver age, relationship to the person with heart failure, and gender would help increase the generalizability of findings. Another limitation of this study was that it was a secondary analysis, rather than a primary study. Therefore, interview questions were not refined to specifically address the aims of this study (Hinds, Vogel, & Clarke-Steffen,

1997). Rather, data were gathered by making inferences from caregiver responses to the primary study's interview questions. In addition, some potential bias may have existed and impacted the findings of this study. Many of the caregiver interviews were conducted with the person with heart failure present in-person or over the phone within earshot of the person. Caregivers may have been less likely to admit burden or negative feelings about the experience of caregiving in an attempt to not hurt their spouse's feelings.

Although these limitations existed, the study exhibited strengths which improved the quality of the evidence. One strength of this study is that saturation was reached. This means that the data set in this study was large enough and the content of the interviews were detailed enough that caregiver experiences were repeated and common themes emerged. Also, the researcher worked closely with a mentor who is both a member of the primary research team and an expert in the field. The mentor confirmed the results of this study, which helped to increase the validity of the findings, and complete interview transcripts were available for each participant. In addition, the qualitative methodology used in this study was appropriate for the research aims. In-depth interviews allowed for caregivers to give detailed explanations, and a deeper understanding of the caregiving experience resulted from this choice of methodology.

### **Conclusion**

This study aimed to identify experiences related to burden and health status among informal caregivers of persons with advanced heart failure. A secondary longitudinal qualitative analysis was used to analyze interviews of ten caregivers. Caregivers in this study were interviewed at multiple points in time while the person with heart failure was still alive, and then again after the participants' deaths. During these interviews, caregivers provided detailed accounts of their experiences caring for their spouse as well as their perceptions of their role.

Overarching themes from the data included adjustments to the role as caregiver; caregiving is stressful; but not a burden; and minimization of caregiver health needs. Caregivers reported role changes, stress, and challenges with their own health, but were reluctant to use the word “burden” to describe their experiences. Future research should examine how caregivers prioritize their own health needs and how caregivers react to the word “burden” versus other terms. Increased knowledge in these areas could lead to the development of interventions designed to reduce stress and improve the health of caregivers. Informal caregivers are valuable to the health of heart failure patients, and future research is imperative in order to improve the overall wellness of these caregivers.



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# ACADEMIC VITA

**Holly Weinschenk**  
hmweinschenk@gmail.com

## EDUCATION

**B.S.N., Nursing; Minor in Rehabilitation and Human Services** **Anticipated May 2017**  
*Pennsylvania State University, University Park, PA*

- Schreyer Honors College, Honors in Nursing
  - Thesis Title: Identifying Differences in Experiences Related to Caregiver Burden and Health Status Among Caregivers of Persons with Heart Failure
  - Presented at the 29th Annual Eastern Nursing Research Society Scientific Sessions
- Sigma Theta Tau International Honor Society of Nursing

## EMPLOYMENT

**University of Maryland Medical Center** **May 2016 - July 2016**  
*Student Nurse Residency Program*

- Cared for patients in the Pediatric Intensive Care Unit within the scope of a Certified Nursing Assistant
- Worked with a preceptor to monitor and meet needs of children with life-threatening medical conditions

**National Institutes of Health** **June 2015 - August 2015**  
*Summer Internship Program*

- Interned with Clinical Center Nursing Department on the Hematology/Oncology Transplant Unit
- Observed role of the research nurse in clinical and laboratory settings
- Presented research poster at NIH Summer Poster Day symposium

## CLINICAL EXPERIENCE

**Mount Nittany Medical Center** **August 2016 - Present**  
*Medical-Surgical Nursing, Community Health Nursing, Senior Capstone*

- Manage care for adult patients with complex needs on telemetry and medical oncology units, and at an outpatient radiation oncology clinic
- Learn time management by completing tasks and documentation on up to six patients in one shift

**Penn State Milton S. Hershey Medical Center** **August 2015 - May 2016**  
*Medical-Surgical Nursing, Pediatric Nursing, Nursing Care of the Childbearing Family*

- Cared for patients of all ages and developmental stages in an acute inpatient environment
- Balanced tasks between multiple patients and utilized time management skills

## ACTIVITIES

**Penn State Dance Marathon (THON)** **October 2016 - Present**  
*College of Nursing THON Committee, Technology Leader*

- 46 hour dance marathon benefitting Four Diamonds at Hershey Children's Hospital
- Collaborate with IT department to develop an electronic medication administration record to use for documentation of all dancer medications during THON
- Ensure the health and safety of all dancers during THON

*Donor and Alumni Relations Committee* **October 2014 - February 2015**

- Distributed donation envelopes for the university, communicated with alumni and major donors

*OPPerations Committee* **October 2013 - February 2014**

- Worked behind the scenes to prepare the Bryce Jordan Center for THON

**Best Buddies at Penn State** **August 2014 - Present**  
*Executive Board Member, THON Chair*

- Work one-on-one with members of the community with physical and developmental disabilities
- Organize and implement all fundraising for the Penn State Dance Marathon through Best Buddies

**College of Health and Human Development Women's Leadership Initiative** **August 2015 - May 2016**

- Developed leadership skills such as public speaking, cultural competency, and business etiquette
- Applied strategies for effective communication with colleagues and peers