COMPASSION FATIGUE AMONG FAMILY CAREGIVERS OF INDIVIDUALS WITH END-STAGE HEART FAILURE

A Dissertation presented
by
Lisa A. Cross

Submitted to the Zuckerburg College of Health Sciences
University of Massachusetts Lowell,
in partial fulfillment of the requirements for
the degree of

Doctor of Philosophy Nursing
May 2022

Susan and Alan Solomont School of Nursing Program

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COMPASSION FATIGUE AMONG FAMILY CAREGIVERS OF
INDIVIDUALS WITH END-STAGE HEART FAILURE

BY

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DISSERTATION SUBMITTED TO THE FACULTY OF THE SOLOMONT SCHOOL OF NURSING IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF DOCTOR OF PHILOSOPHY NURSING UNIVERSITY OF MASSACHUSETTS LOWELL
May 2022

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Joseph E. Gonzales, PhD
COMPASSION FATIGUE AMONG FAMILY CAREGIVERS OF INDIVIDUALS WITH END-STAGE HEART FAILURE

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Lisa A. Cross

Abstract of a Dissertation Submitted to the Faculty of the Department of the Solomont School of Nursing in Partial Fulfillment of the Requirements for the Degree of Doctor of Philosophy Nursing University of Massachusetts Lowell May 2022

Dissertation Chair: Ainat Koren, PhD, DNP, PMHNP PhD Program Director & Associate Professor, Solomont School of Nursing
Abstract

**Background:** Compassion fatigue is a phenomenon identified in family caregivers. Heart failure is a public health crisis, affecting over six million people in the United States. The need for family caregivers, and the need for them to be supported by health care professionals, is expected to rise. Social distancing during COVID-19 may have added further challenges to caregiving routines.

**Aim:** The purpose of this study was to examine the relation between family caregiver demographic characteristics and compassion fatigue for caregivers who were caring for family members with end-stage heart failure. Specifically, the study examined the relation of compassion satisfaction, social desirability, and the relationship between the family caregiver and nursing provider on compassion fatigue. The research was conducted during the COVID-19 pandemic and examined the family caregiver perception of the effect of COVID-19 on caregiving routines.

**Method:** The Interaction Model of Client Health Behavior was adapted to guide the cross-sectional study. Braun and Clark’s method guided open-ended response thematic analysis. The survey was comprised of four instruments: the Professional Quality of Life Scale, the Caregiver-Provider Relationship Assessment, the Marlowe Crowne Social Desirability Scale Short Form (Form C), and the Bakas Caregiving Outcomes Scale. To determine caregiver perception of COVID-19’s impact, one Likert question and one open-ended response were asked.

**Findings:** One hundred twenty-seven participants completed the entire survey. Increased compassion satisfaction, positive caregiving effects, and a satisfactory family caregiver-provider relationship were associated with decreased compassion fatigue ($p < .001$),
while increased social desirability was associated with increased compassion fatigue \((p < .001)\). An increase in the family caregiver-nursing provider relationship resulted in decreased compassion fatigue, increased social desirability, greater positive effects of being a caregiver, and increased compassion satisfaction \((p < .001)\). Reported less spiritual support yielded an increase in compassion fatigue \((p < .001)\). The COVID-19 open-response question replies (113) yielded themes such as social isolation, added fear, anxiety, or worry, changed appointments, wearing masks, and living status change. Social isolation (46.1\%) was the most common theme; the most significant theme was living status change \((p = .003)\) and family caregivers reported the pandemic affected their routines either negatively or somewhat negatively (62.1\%).

**Conclusion:** Although this study focused on family caregivers of individuals with end-stage heart failure, there are applications to family caregivers of other chronic diseases. FCGs may not recognize needing help; fostering relationship with FCGs will help identify assistance needs. Future research can continue to explore how some family caregivers experience compassion fatigue while others do not. Further, research is needed for the development of standard assessment and uniform services and to guide policies that support care transitions for family caregivers in the heart failure population. Nursing provider assessment of family caregivers is indicated at all points of care for needs in physical, psychological, social, and particularly, spiritual domains to prevent the negative consequences of compassion fatigue and residual effects of COVID-19 on caregiving practices.
Acknowledgements

It is with tremendous gratitude that I thank all who have helped me during my PhD process. First, I would like to acknowledge and thank the Sigma Eta Omega Chapter for awarding a grant for my research study.

This research would not have been possible without support of the faculty members at the Solomont School of Nursing. I especially thank my Dissertation Committee members for the unique and invaluable guidance they each provided: Dr. Jacqueline Dowling (Ret.) who joined a committee for a student she initially did not know and provided insightful suggestions and mentoring; Dr. Joseph Gonzales who spent many hours offering statistical support, encouragement, and feedback; and Dr. Ainat Koren who starting with the interview guided me through the program and throughout the dissertation as my PhD advisor and Dissertation Chair. This research is much stronger because of their contributions.

I would like to acknowledge friends who understood last minute cancellations, as well as my amazing PhD program peer network. Alumni Pam D., Jeff D., Laurie S., and Sandra M. offered helpful guidance and insight. My peers Bill, Christine, Inyene, Janna, Nadia, Pam F., Yifat, and particularly Patty and Amy, offered encouragement, support, and friendship that extended deeper than I can put into words. A special thank you goes to my mentors Dr. Cheryl Williams and Dr. Mary Ann McGovern (Ret.).

Finally, thank you to my parents Mario and Cris for instilling the value of education, and my husband Mike and my children Abigail, Daniella, and Thomas, who supported this endeavor from the beginning. I could not have reached this point without their patience, understanding, and encouragement.
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Chapter I: INTRODUCTION

Compassion fatigue is a phenomenon that has been recognized in family caregivers (FCGs) of individuals with chronic illnesses (Lynch, 2018). The term was first used in the nursing literature to explain burnout, or the “overpowering, invasive stress” that can “dominate” and “interfere with our ability to function” as nurses (Joinson, 1992, p. 116). The term and related constructs have been used since to explain formal caregiver and nursing caregiver stress (Cross, 2019; Jenkins & Warren, 2012; Showalter, 2010; Sorenson et al., 2017; Yoder, 2010). Lynch and Lobo (2012) expanded the construct of compassion fatigue, describing their application for informal caregivers and FCGs. This explanation for FCGs was founded because of the regular caregiving exposure by family in combination with the emotional pain of the caregiver-care recipient relationship; the daily care of seriously ill family members leads to the emotional exhaustion commonly associated with compassion fatigue (Lynch, 2018; Lynch & Lobo, 2012). Stamm (2002) added to the compassion fatigue literature by identifying compassion satisfaction, a related construct, and suggested that it was the positive, protective feeling derived from caring.

In 2019, approximately 53 million adults over age 18 reported they had provided direct care to family members and close friends in the last year (National Alliance for Caregiving [NAC] & American Association of Retired Persons [AARP], 2020). FCGs of individuals with chronic diseases such as heart failure (HF) are often untrained, yet communicate with providers, perform high-acuity care, and offer emotional support as
their family members’ illnesses progress to end-stage (Kitko et al., 2020; Reinhard, Feinberg, et al., 2019). Currently, over six million people in the United States and 26 million people worldwide are affected by HF (Dionne-Odom et al., 2017). As the population ages, HF prevalence is expected to increase, adding to the growing need for FCGs (Dionne-Odom et al., 2017; Kitko et al., 2020).

HF is a chronic syndrome, typically classified in four stages most commonly by the New York Heart Association (NYHA) (American Heart Association [AHA], 2020; Fasolino, 2020). These stages include Stage I, where there are few functional limitations, Stage II where there are mild functional limitations, Stage III where there are more functional limitations due to increasing symptoms, and Stage IV where the limitations are severe and symptomology is advanced (AHA, 2020). As HF progresses to advanced or end-stage, FCGs are involved in planning for high-acuity procedures and surgical options, making advance care planning and end-of-life decisions, and finding further supportive services, adding to their own emotional burden (Kitko et al., 2020). The known caregiving costs in HF associated with FCGs were estimated at $6.5 billion per year in the United States in 2015. By 2030, it is expected that one out of every 33 individuals in the United States will have HF (Dunbar et al., 2018) and that by 2035 the expected financial costs by FCGs for individuals with HF will increase to $13.5 billion per year (Dunbar et al., 2018; Kitko et al., 2020).

Although the financial and emotional contributions by FCGs of individuals with HF are significant, there have been few studies regarding this population (Grant & Graven, 2018; Kitko et al., 2020). Further, negative effects of caregiving for FCGs of individuals with HF have been examined (Petruzzo et al., 2017; Stromberg et al., 2017)
but none were found identifying the negative consequences of compassion fatigue or the helping factor of compassion satisfaction for FCGs. Kitko et al. (2020) indicated further research was warranted to produce evidence-based interventions that recognized FCGs’ supportive needs and skills in HF management including treatment delivery and device monitoring, treating them as care partners as well as care recipients when making decisions. Nurses have multiple roles that are critical to HF management, including providing in-hospital acute care, discharge planning and education, outpatient HF clinic management, in-home case management, and palliative care (Browne et al., 2014; Pattenden et al., 2007). To assist FCG involvement in care, more understanding is needed on FCG characteristics and needs, as well as the significance of their relationship with providers, particularly for the HF population.

This dissertation examined the impact of caregiving on compassion fatigue among FCGs of individuals with end-stage HF. The Interaction Model of Client Health Behavior (IMCHB) (Cox, 1982) was adapted to guide examination of the relationship of demographic characteristics, social influences, previous health care experience, and environmental resources on the resulting effect of compassion fatigue among FCGs who care for individuals with end-stage HF. The IMCHB has previously been used to explain the association between the individual-nursing provider relationship and health outcomes (Ahn & Ham, 2020; Mattisson et al., 2019; Ramelet et al., 2014), and was adapted for this study to examine the impact of the family caregiver-nursing provider relationship (FNR) on compassion fatigue.

This study was administered during the COVID-19 pandemic at a time that vaccines were not fully available to the public and imposed social distancing was
stringent (Italia et al., 2021). Social distancing presented challenges to accessing treatment and supportive services and affected healthcare appointments and delayed treatments for non-COVID-19 illnesses (Haynes et al., 2020). One Likert question and an open-response question regarding FCGs’ perceptions of COVID-19’s effect on caregiving were added to the survey to advance the growing literature surrounding the physical health, socioeconomic, and psychological effects of COVID-19. The method of Braun and Clarke (2012) guided thematic analysis on this open response question. This method has been used in social science research to analyze data and produce themes (Braun & Clarke, 2012).

This dissertation is divided into two monographs. The first monograph, Chapter II, describes the factors associated with compassion fatigue among FCGs of individuals with end-stage HF. Specifically, it will examine the background factors that predict compassion fatigue among FCGs of individuals with end-stage HF and the effects of changeable dynamic factors on compassion fatigue among FCGs of individuals with end-stage HF. These dynamic factors were compassion satisfaction, social desirability, the effects of being a caregiver, and the FNR, and were examined at one time point. The results add to the literature of compassion fatigue and compassion satisfaction in FCGs of individuals with end-stage HF and to the body of knowledge regarding the important relationship between FCGs and providers. The second monograph, Chapter III, examines the impact of COVID-19 on FCGs of individuals with end-stage HF. These results add to the ongoing research on the effects of the COVID-19 pandemic on FCGs. The final chapter, Chapter IV, provides an overall conclusion and future nursing implications.
Literature Cited


Chapter II: FACTORS ASSOCIATED WITH COMPASSION FATIGUE AMONG FAMILY CAREGIVERS OF INDIVIDUALS WITH END-STAGE HEART FAILURE

Heart disease is the leading cause of death in the United States (Centers for Disease Control and Prevention, 2021), with heart failure (HF) affecting six million people and expected to increase to over eight million people by 2030 (Dionne-Odom et al., 2017). HF is chronic; longer disease duration suggests poorer outcomes, frequent hospitalizations, and greater concerns for individuals and family caregivers (FCGs) (Fasolino, 2020). HF is staged according to the New York Heart Association (NYHA): Stage I has little or no activity interference; Stage II has slight activity interference; Stage III, has moderate interference to activity; and Stage IV, end-stage disease, has advanced interference to activity (American Heart Association, 2020). Individuals with end-stage HF often experience multiple comorbidities, requiring higher acuity care and emotional support extending to FCGs’ emotional needs (Pattenden et al., 2007; Wingham et al., 2015).

FCGs comprise 89% (47.2 million) of informal caregivers and 4% of FCGs care for individuals with primary heart diagnosis (188,680 FCGs) (National Alliance for Caregiving [NAC] & American Association of Retired Persons [AARP], 2020). Caregivers care for 50% parent or parent-in-law and three in five (61%) are female, non-Hispanic White (61%) with age for both genders ranging from 18-75 and over one-third aged 50-64 (35%) (NAC & AARP, 2020). FCGs often provide unfamiliar caregiving while performing their normal duties, working out of necessity while balancing
caringgiving with professional responsibilities (Given & Reinhard, 2017). Compassion fatigue is a consequence of caregiving experienced by FCGs, resulting in stress and exhaustion (Lynch & Lobo, 2012), with increased risk to FCGs providing care to chronically ill family members, such as with HF. As reliance for FCGs rises, the FCG relationship with providers needs to be fostered to mitigate effects of compassion fatigue (Kitko et al., 2020; Reinhard, Young, et al., 2019).

HF impacts FCGs physically, psychologically, spiritually, and socially, and these collective effects constitute an overarching experience of compassion fatigue. With HF caregiving costs estimated at $6.5 billion per year in the United States in 2015 and expected to reach $13.5 billion per year by 2035 (Dunbar et al., 2018), FCGs experience financial expenditures and associated stresses. FCGs have insomnia from worry over diagnosis, loss of control, and fear of the unknown and concerns about medication costs, adherence, and managing family members’ depression and their own (Ågren et al., 2012; Kang et al., 2011; Piamjariyakul et al., 2015). As care duration lengthens or is complicated by cardiac devices, there are frustrations with social isolation, worry about family member sudden death or device failure, and end-of-life management (Wingham et al., 2015). FCGs seek spiritual and emotional solace to allay fears of family members’ dying and for respite from caregiving (Bakas, Pressler, et al., 2006; Doherty et al., 2016; Sullivan et al., 2016). One FCG described caregiving breaks as, “You need a place to be selfish” (Sullivan et al., 2016, p. 5).

Challenges FCGs might face are poor or absent provider communication. This fails to offer FCGs connections with specialists and palliative teams, and might lead to uncertainty surrounding diagnosis and prognosis, unclear knowledge of treatments, and
little understanding of when to ask questions (Browne et al., 2014). Many FCGs want to be involved in their family member’s care and become stressed when not included in decisions (Wingham et al., 2015). FCG perceptions about providers, personal values, culture, or location impact care; FCGs who perceive providers as busy might avoid seeking assistance until family members’ HF symptoms become “intolerable” (Clark et al., 2009). Having a strong provider relationship, providing support, assistance adjusting to family members’ limitations, and earlier information is essential (Sullivan et al., 2016). Provider support and discussion engages FCGs, helping them cope with caregiving and reducing fear, worry, and social isolation (Petruzzo et al., 2017; Wingham et al., 2015). Nurses and nurse practitioners provide caregiver support, information, and communication through their multiple roles including discharge planning, outpatient HF clinic care, case management, and palliative care (Browne et al., 2014; Fasolino, 2020). Therefore, they are positioned to recognize patient and FCG HF caregiving needs that should be addressed (Fasolino, 2020). “I would be lost without our heart failure nurse” stated one FCG (Wingham et al., 2015, p. 313).

The Caregiver Advise, Record, Enable (CARE) Act, adopted by 43 states, assists FCGs when family members return home from hospitalization (AARP, 2019a). State CARE Acts require hospital identification of FCGs for inpatients to ease transition home (Reinhard, Feinberg, et al., 2019). A national policy passed in 2018, Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act supports FCGs through care coordination and program identification and implementation (AARP, 2019b). Despite these policies and others that provide paid family leave and caregiver health assessments in some states, FCGs struggle with care coordination; fewer than three in 10
caregivers reported that a provider asked what they needed for self-care in caregiving which was a 16% decrease from previous data (NAC & AARP, 2020).

There are supportive programs such as respite or palliative care that help FCGs, however, FCGs who realize they need assistance may be deterred and not benefit from services (Reinhard, Feinberg, et al., 2019). Respite offers temporary relief from HF caregiving; however, funding varies by state, creating difficulty in understanding coverage and availability (Reinhard, Feinberg, et al., 2019). Palliative services provide supportive assistance in HF caregiving; however, FCGs may have difficulty accessing programs (Davidson et al., 2013; Reinhard, Feinberg, et al., 2019). One study found that only 38% of 373 HF FCGs were likely to access palliative services despite indications of unmet needs (Davidson et al., 2013). Dunbar et al. (2018) identified that often FCGs in HF require assistance obtaining services including respite, financial aid, and time from work. A consequence of less support is increased HF hospitalizations (Dionne-Odom et al., 2017).

Past FCG HF research has been mostly qualitative, has not offered a theoretical basis for interventions, and overrepresented FCGs who were female and middle-aged; more research is needed describing diverse FCG characteristics to determine access and availability to supportive services (Kitko et al., 2020). There has been little research regarding the FCG-nursing provider relationship (FNR) in HF and little research with compassion fatigue in this group (Kitko et al., 2020). This research intends to add to the knowledge for FCGs in HF by providing information regarding these FCGs’ compassion fatigue related to caregiving. Further, this study examined the role of the FNR on compassion fatigue among these FCGs. Specifically, this study attempted to answer the
following research questions: 1. What are the predictors of compassion fatigue among FCGs of individuals with end-stage HF? 2. What is the role of dynamic factors (compassion satisfaction, social desirability, the effects of being a caregiver, and the FNR) in predicting compassion fatigue among FCGs with end-stage HF?

**Theoretical Model**

This study adapted the Interactive Model of Client Health Behavior (IMCHB) to guide in exploration of variables associated with compassion fatigue. Previous FCG nursing research used the Pearlin Stress Process Model (Lynch et al., 2018; Perry & Edwards, 2015), Bandura’s Self-efficacy Theory (Leow et al., 2015), and the Transactional Model of Stress and Coping (Khalaila, 2020) which were not specific to compassion fatigue; no nursing theories were identified in connection with compassion fatigue and FCGs. The model guided the identification of associations between background variables, dynamic variables, and compassion fatigue (Ahn & Ham, 2020; Carter, 2003; Cox, 2003). The adapted IMCHB model contains four types of background variables: demographic characteristics, social influence, previous healthcare experience, and environmental resources (Figure 1).
Background variables influence dynamic variables, and dynamic variables affect and are affected by other dynamic variables impacting the outcome variable. Dynamic variables were compassion satisfaction, social desirability, effects of being a caregiver, and the FNR which included caregiver affect, caregiver information, and caregiver communication. For study purposes, the provider was the nursing provider, and the individual was the FCG. The nursing paradigm assisted in describing the FNR for the adapted model; the individual was the FCG because person is an individual, family, or community receiving care (Fawcett & Desanto-Madeya, 2013). The health outcome, the dependent variable, was compassion fatigue (Cox, 1982).

Compassion fatigue depicted the health outcome component from the original IMCHB (Cox, 1982). Compassion fatigue is experienced by FCGs who provide daily care to seriously ill or dying family members with simultaneous exposure to the care
recipient’s pain, dually experiencing their own pain, occurring as a result of empathy in response to the caregiving stress, progressing to exhaustion in physical, psychological, spiritual, and social domains (Lynch & Lobo, 2012). Compassion satisfaction depicted the intrinsic motivation component from the original IMCHB, or the extent an individual has control around meeting needs (Cox, 1982); it is the sense of motivation, fulfillment, or joy experienced from the caregiving experience, and is the opposite of compassion fatigue (Lynch et al., 2018; Sacco & Copel, 2018).

Social desirability depicted the cognitive appraisal element from the original IMCHB; cognitive appraisal is the perception of reality and relationships influencing the health concern after accounting for values, emotions, self-concept, and functioning (Cox, 1982). Social desirability was explicated here as the cognitive representation of one’s traits and attitudes applied to their selves in caregiving roles. Because compassion fatigue is a multi-domain health state that is cognitively represented through knowledge, attitudes, beliefs, and possible stigma associated with the caregiving role, social desirability was chosen to represent cognitive appraisal. The effects of being a caregiver was chosen to represent the affective response component from the original IMCHB, or reactions to a health concern, and is the response to caregiving (Cox, 2003).

In the original IMCHB, affective support is the process where a provider tends to the individual’s emotional needs and establishes a therapeutic bond (Cox, 2003), and was represented by caregiver affect, or the FCG’s perception of the provider’s attention (Moore, 2012). Health information on the original IMCHB is the provider’s process of offering useful knowledge to the individual (Cox, 2003), and was represented by caregiver information, or the FCG’s perception of information quality by the provider
(Moore, 2012). Decisional control was represented by caregiver communication, the FCG’s perception of ability to initiate provider communication (Moore, 2012), and on the initial IMCHB is the process of having autonomy to participate in health-related behaviors (Cox, 2003). Provider professional/technical competencies were assumed met through licensure, and that component of the IMCHB was not operationalized in the adapted model (Cox, 1982, 2003). The continued relationship between FCGs and providers allowed for these competencies to be furthered.

The aims for this study were 1) to determine which background factors predict FCG compassion fatigue; 2) to examine the relation of IMCHB dynamic factors on compassion fatigue among FCGs; and 3) to examine the relation of the FNR on compassion fatigue and IMCHB dynamic factors among FCGs.

**Methodology**

The study design was a quantitative cross-sectional correlational online survey to examine the relationship of caregiving and compassion fatigue among FCGs of individuals with end-stage HF (Appendix A).

**Participants**

Inclusion criteria were participants who were FCGs aged 18 or older identifying as FCGs of family members with end-stage HF at the time of the survey. The participants age range was 23 to 78 (M = 50.6). FCGs were predominantly female (88.8%), White (85.1%), and non-Hispanic/Latino (94%). Similarly, many of the respondents were married (69.4%) and were caring for spouses (41.5%). Over one-third had no available help (36.3%), while about half received help from another unpaid adult caregiver (51.1%). Almost one-third (30.5%) of the respondents were from the Northeast region of
the United States, where the researchers were located. FCGs were asked to identify the HF stage of the family members being cared for; despite self-identification as FCGs for relatives with end-stage HF to meet survey criteria, 59.4% indicated Stage IV, an additional 20.3% indicated they were caring for a family member with other stages, while 20.3% reported that they did not know, can’t recall, or had not been told the stage. Additionally, 16.8% had not been provided information to care for their family member by a nurse/ nurse practitioner. With the HF stage expected to be end-stage, 44.8% of the participants reported care lasting 1–4 years, yet 11.9% reported care lasting more than 9 years. Most of the participants indicated working full-time (44%), however 67% specified having to change their work schedule and 43.3% indicated insufficient financial status to care for their family member. One third (35.8%) of these participants did not have prior experience with caregiving nor in healthcare, and many indicated not receiving spiritual support during caregiving (51.5%) (Table 1).
Table 1

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<td></td>
<td></td>
<td></td>
<td>Previous as both healthcare</td>
</tr>
<tr>
<td>Northeast</td>
<td>40</td>
<td>30.5</td>
<td></td>
<td>Less than 6 months</td>
</tr>
<tr>
<td>Midwest</td>
<td>31</td>
<td>23.7</td>
<td></td>
<td>6 months – 1 year</td>
</tr>
<tr>
<td>South</td>
<td>41</td>
<td>31.3</td>
<td></td>
<td>1 year – 4 years</td>
</tr>
<tr>
<td>West</td>
<td>19</td>
<td>14.5</td>
<td></td>
<td>5 years – 9 years</td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
<td></td>
<td>More than 9 years</td>
</tr>
<tr>
<td>Married</td>
<td>93</td>
<td>69.4</td>
<td></td>
<td>Care duration</td>
</tr>
<tr>
<td>Single</td>
<td>32</td>
<td>17</td>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td>Divorced</td>
<td>6</td>
<td>4.5</td>
<td></td>
<td>No</td>
</tr>
<tr>
<td>Widowed</td>
<td>3</td>
<td>2.2</td>
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<td>Work status</td>
</tr>
<tr>
<td>Relationship to recipient</td>
<td></td>
<td></td>
<td></td>
<td>Retired</td>
</tr>
<tr>
<td>Spouse</td>
<td>56</td>
<td>41.5</td>
<td></td>
<td>Disabled / on leave</td>
</tr>
<tr>
<td>Child</td>
<td>34</td>
<td>25.2</td>
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<td>Change in work status</td>
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<tr>
<td>Parent</td>
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<td>17</td>
<td></td>
<td>Care for family member</td>
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<tr>
<td>Grandparent</td>
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<td>11.1</td>
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<td>Yes</td>
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<tr>
<td>In-law</td>
<td>5</td>
<td>3.7</td>
<td></td>
<td>No</td>
</tr>
<tr>
<td>Available help</td>
<td></td>
<td></td>
<td></td>
<td>Spiritual support</td>
</tr>
<tr>
<td>None</td>
<td>49</td>
<td>36.3</td>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td>Unpaid adult over 18</td>
<td>69</td>
<td>51.5</td>
<td></td>
<td>No</td>
</tr>
<tr>
<td>Child under 18</td>
<td>6</td>
<td>4.4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Paid help</td>
<td>11</td>
<td>8.2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Care information provided by nurse /</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>practitioner</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>114</td>
<td>83.2</td>
<td></td>
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</tr>
<tr>
<td>No</td>
<td>23</td>
<td>16.8</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note. Participants not required to respond; n = 131-138.

a n = 131, b n = 133, c n = 134, d n =135, e n =137, f n =138.

Procedures

Potential participants were invited via a flyer to complete an online survey delivered by an anonymized Qualtrics link during February 2021 through May 2021.

Recruitment was via convenience and snowball sampling from an online national
caregiver research registry, an online site for statewide councils of aging, social media sites, faith communities and community health centers in New England, and a large home hospice organization north of Boston. There were 290 participants who accessed the survey and 127 participants who completed the entire survey (Appendix B).

**Sample Size**

Power analysis was estimated at 150 with 18 predictors, a medium (0.15) effect size, a margin of error of 5%, and a power of .80; caregiving literature and Cohen’s (1992) guidelines for multiple correlation determined effect size (Hegney et al., 2014; Leow et al., 2015; Lynch et al., 2018). Data collection stopped after three months due to slowed response rate; the resulting power was .70 with 127 participants.

**Ethical Considerations**

Institutional review board approval was obtained from the University of Massachusetts Lowell (#21-016-KOR-EXM) and collaborative agreements were followed for participating institutions. Prospective participants were provided informed consent and indicated their consent for survey participation. The survey was anonymized. Participants who wished to complete the survey via paper and pencil had this option. Participants could withdraw from the survey at any time and refuse to respond to specific items. Participants were informed that group membership benefits were not affected by participation or lack of participation. Compensation for survey time was an optional drawing for a computer tablet.

**Measures**

Five measures were chosen in consideration of the study aims, previous use in the literature, and previously reported reliability and validity: a demographic questionnaire
(Appendix A2), the Professional Quality of Life Scale (ProQOL) (Appendix A1), the Marlowe-Crowne Social Desirability Scale (SDS) Short Form (Form C) (Appendix A5), the Bakas Caregiving Outcomes Scale (BCOS) (Appendix A3), and the Caregiver-Provider Relationship Assessment (CPRA) (Appendix A4).

**Demographic Questionnaire**

The demographic questionnaire included questions about demographic characteristics: gender, race, ethnicity, age, and region. Social influence items were the FCG relationship to family member, number of people available to help, and marital status. Previous healthcare experience items were HF stage knowledge, indication whether a nursing provider had provided care information, and previous experience in caregiving. Environmental resources items were duration of caregiving, work status, work schedule change, financial status, and spiritual status. Due to the breadth of influencing circumstances, all factors (such as religion, culture, and living status) for compassion fatigue were not accounted for in this study.

**Compassion Fatigue**

Compassion fatigue, the dependent variable, was operationalized by the burnout subscale and secondary traumatic stress subscale of the ProQOL version 5, a 30-item instrument, chosen for past use with compassion fatigue and FCGs (Lynch et al., 2018; Thorson-Olesen et al., 2019). The combined burnout and secondary traumatic stress scores for the ProQOL described total compassion fatigue. As there was only one “Very Often” response for item 1 (I am happy) on the ProQOL burnout subscale, this response was combined with the “Often” responses.
**Compassion Satisfaction**

The compassion satisfaction subscale of the ProQOL was chosen to represent compassion satisfaction for past use in FCG literature (Lynch et al., 2018; Thorson-Olesen et al., 2019). The score for compassion satisfaction measured compassion satisfaction.

Each ProQOL subscale consisted of 10 5-point Likert items, with an alpha (α) subscale reliability α = .88 for compassion satisfaction, α = .75 for burnout, and α = .81 for secondary traumatic stress; interscale correlations between the compassion satisfaction and secondary traumatic stress subscales were r = -.23, between the compassion satisfaction and burnout subscales were r = -.14, and between the burnout and secondary traumatic stress subscales were r = .58 (Stamm, 2010). Construct validity was reported with over 200 papers using the scale (Stamm, 2010), and several of these studies operationalized compassion fatigue and compassion satisfaction for FCGs (Hemsworth et al., 2018). For this study, confirmatory factor analysis (CFA) revealed that Item 2 (I am preoccupied with more than one person I care for) from the secondary traumatic stress subscale was not a good fit, and this item was not retained for statistical analysis. There was good internal consistency reliability for the total scale (α = .94), and for scale constructs, compassion fatigue (α = .92) and compassion satisfaction (α = .91). Results replicating the inverse relationship between compassion fatigue and compassion satisfaction (R² = .368, p < .001) demonstrated construct validity.

**Social Desirability**

This SDS has been used to determine individuals’ truthfulness in survey completion; however, this study operationalized it as a separate variable. The SDS was
chosen to represent social desirability consistent with its previous use to assess this construct (Kellogg et al., 2018). Previous evaluation of the SDS has shown this scale to be reliable (KR20 = .76), and to have high convergent validity with the original scale, \( r = .93, p < .001 \) (Crowne & Marlowe, 1960; Reynolds, 1982). Responses were true/false; all items were totaled, with a high score indicating that participants’ responses represented themselves in a manner presumed to be correct, rather than presenting truthful qualities or traits. For this study, there was fair internal consistency (\( \alpha = .65 \)) and content validity for six items with factor scores above .40 (.40-.51) (Devellis, 2017).

**Effects of Being a Caregiver**

The BCOS is a 15-item instrument representing the effects of being a caregiver for past use in the HF caregiver literature (Bakas, Pressler, et al., 2006; Pressler et al., 2009). The BCOS has demonstrated internal consistency (\( \alpha = .90 \), ICC = .66) and criterion validity (\( r = .67, p < .001 \)) (Bakas, Champion, et al., 2006). The scale is on a 7-point response scale with Changed for the Worst = -3 and Changed for the Best = +3; FCGs rated how their lives had changed since they became FCGs. Item scores were transformed from -3 to +3 to 1 to 7 and totaled; item scores greater than 4 indicated positive caregiving outcomes and item scores lower than 4 indicated negative caregiving outcomes. (Bakas & Champion, 1999; Bakas, Champion, et al., 2006; Bakas, Pressler, et al., 2006). In this study, internal consistency reliability was \( \alpha = .94 \) and content validity was supported by factor loadings above .40 (.56 - .86) for all items (Devellis, 2017).

**Family Caregiver-Nursing Provider Relationship**

The CPRA was chosen to represent the FNR based on ability to measure FCG affective support, health information, and decisional control. The CPRA, an adapted
instrument from the 15-item Patient Reactions Assessment (PRA) (Galassi et al., 1992), was created to measure FCGs’ perceptions of their relationship with health care providers (Moore, 2012). Subscales each consist of five items; $\alpha = .93$ for the total scale, $\alpha = .91$ for caregiver affect, $\alpha = .91$ for caregiver information, and $\alpha=.85$ for caregiver communication and the subscales were moderately related to one another ($r = .54$ to .64, $p < .01$) (Moore, 2012). Items are on a 7-point Likert scale, ranging from 1 = Very strongly disagree to 7 = Very strongly agree; the higher the score, the more positive the relationship with providers. For this study, there was content validity with factor loadings above .40 (.46-.88) on all items, and good internal consistency for the total scale ($\alpha = .92$) and within the scale; caregiver affect ($\alpha = .86$), caregiver information ($\alpha = .86$), and caregiver communication ($\alpha = .88$).

**Data Analysis**

Data were exported into the current version of R ver. 4.0.5 (R Core Team, 2021) for all statistical analyses. Descriptive statistics were performed for FCG background variables; missing data were removed for descriptive statistics and individual n amounts were reported. The means, standard deviations, and ranges were reported for interval variables; frequencies and percentages were reported for nominal and categorical variables (Table 1). A two-step approach was used for regression to preserve data for analysis. Full Information Maximum Likelihood (FIML) estimation was used to estimate CFA models for reliability testing; factor scores were estimated and extracted using the *lavaan* package (Rosseel, 2012) and incorporated into conventional regression models. FIML preserved cases with partial missing data in the analyses under the assumption of data missing at random and multivariate normality (Brown, 2015).
Ordinary Least Squares (OLS) regression was performed; bivariate regression was used to assess the relationship between variables, and multiple regression analysis was performed with all the predictor variables for examination (Fox, 2016). Models that generated nonsensical standard errors were log transformed to remove skewness. Due to the number of variables with potential to be related, changing associations in predictors, variance inflation factor was assessed for multicollinearity, with < 2 as acceptable (Fox, 2016). The significance level for this study was .05; levels below .1 were discussed to identify trends for future research.

Results

FCG IMCHB Background Factors that Predict Compassion Fatigue (Aim 1)

Bivariate models were run for all background variables. Four multiple regression models were estimated where compassion fatigue was regressed on demographic characteristics, on the social influence variables, on previous healthcare experience, and then on environmental resources. Demographic characteristics did not explain compassion fatigue in a multiple regression model ($R^2 = .005$, $p = .306$) although race was inversely related to compassion fatigue in a bivariate association ($R^2 = .019$, $p = .060$). Ethnicity was not included in the regression analysis because of low responses to the Hispanic / Latino option (Table 1).

Spiritual status was related to compassion fatigue in a bivariate model ($R^2 = .098$, $p < .001$) and in a model with other environmental resources ($R^2 = .102$, $p = .002$). Specifically, less spiritual support ($\beta = -0.31$, $p < .001$) significantly predicted compassion fatigue. Care relationship was related to compassion fatigue when compassion fatigue was regressed on care relationship ($R^2 = .022$, $p = .048$) and when
compassion fatigue was regressed on social influence variables ($R^2 = .021, p = .122$) including care relationship ($\beta = 0.07, p = .050$). Being a spouse decreased FCG compassion fatigue risk. Having care information ($R^2 = .028, p = .028$) and having no previous healthcare experience ($R^2 = .016, p = .079$) were each bivariately associated with compassion fatigue. Associations also were observed when compassion fatigue was regressed on healthcare experience variables ($R^2 = .037, p = .047$). Having care information ($\beta = -0.23, p = .030$) and not having previous experience ($\beta = 0.14, p = .088$) predicted compassion fatigue. The less FCGs were told about caregiving and the less experience they had with caregiving, the less compassion fatigue risk. A single multiple regression model was estimated where compassion fatigue was regressed on all background variables, explaining 11% of the variance ($R^2 = .107, p = .015$). Spiritual status was the one significant variable. (Table 2). Variance inflation factor was examined for background variables to determine multicollinearity; all values were less than 2 suggesting no multicollinearity (Fox, 2016).
Table 2
Multiple Regression Analysis between Family Caregiver Background Characteristics and Compassion Fatigue

<table>
<thead>
<tr>
<th>Independent Variable</th>
<th>β</th>
<th>SE</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female Gender</td>
<td>-0.12</td>
<td>0.13</td>
<td>-0.88</td>
<td>.380</td>
</tr>
<tr>
<td>White Race</td>
<td>0.05</td>
<td>0.05</td>
<td>0.95</td>
<td>.346</td>
</tr>
<tr>
<td>Numerical age in years</td>
<td>0.00</td>
<td>0.00</td>
<td>0.11</td>
<td>.911</td>
</tr>
<tr>
<td>Care duration one year or less</td>
<td>0.06</td>
<td>0.11</td>
<td>0.58</td>
<td>.566</td>
</tr>
<tr>
<td>Financial status acceptable</td>
<td>-0.09</td>
<td>0.08</td>
<td>-1.06</td>
<td>.291</td>
</tr>
<tr>
<td>Currently working</td>
<td>0.07</td>
<td>0.09</td>
<td>0.72</td>
<td>.473</td>
</tr>
<tr>
<td>Work schedule changed</td>
<td>0.13</td>
<td>0.09</td>
<td>1.58</td>
<td>.117</td>
</tr>
<tr>
<td>Spiritual status acceptable*</td>
<td>-0.21</td>
<td>0.09</td>
<td>-2.39</td>
<td>.018</td>
</tr>
<tr>
<td>No help</td>
<td>0.05</td>
<td>0.09</td>
<td>0.63</td>
<td>.531</td>
</tr>
<tr>
<td>Married</td>
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<td>0.06</td>
<td>0.10</td>
<td>.919</td>
</tr>
<tr>
<td>Spousal relationship</td>
<td>0.07</td>
<td>0.05</td>
<td>1.48</td>
<td>.143</td>
</tr>
<tr>
<td>HF stage not known</td>
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<td>0.10</td>
<td>-0.71</td>
<td>.481</td>
</tr>
<tr>
<td>Told how to care for family</td>
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<td>0.11</td>
<td>-1.33</td>
<td>.186</td>
</tr>
<tr>
<td>No previous caregiving</td>
<td>0.13</td>
<td>0.08</td>
<td>1.57</td>
<td>.119</td>
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</table>

<table>
<thead>
<tr>
<th>Dependent Variable</th>
<th>Intercept</th>
<th>SE</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Compassion fatigue</td>
<td>-0.15</td>
<td>0.25</td>
<td>-0.60</td>
<td>.548</td>
</tr>
</tbody>
</table>

*Note. R² = 0.107, F(14, 118) = 2.128, p = .015.
* p < .05.

FCG IMCHB Dynamic Factors that Predict Compassion Fatigue (Aim 2)

Compassion fatigue was regressed on three IMCHB dynamic variables in

bivariate and multiple regression models with the demographic characteristics. When

compassion fatigue was regressed on compassion satisfaction, compassion satisfaction

predicted compassion fatigue (R² = .368, p < .001); as FCG compassion satisfaction

increased, the associated risk for compassion fatigue decreased. Compassion fatigue was

regressed on compassion satisfaction and the background variables, the regression was

log transformed and the log model had significant predictors (R² = .239, p = .010). FCGs

with less help (β = 0.62, p = .051) and with higher compassion satisfaction (β = 1.23, p <

.001) experienced less compassion fatigue.

Compassion fatigue was regressed on social desirability; increased social

desirability predicted increased compassion fatigue (R² = .166, p < .001). When

compassion fatigue was regressed on social desirability and the background variables,
there were predictors for compassion fatigue ($R^2 = .261, p < .001$). FCGs who had increased social desirability ($\beta = 1.73, p < .001$) and lower spiritual status ($\beta = -0.18, p = .032$) had an additional risk for compassion fatigue. Additionally, in this model FCGs who were told how to care for their family members with HF ($\beta = -0.21, p = .062$) also had an additional risk for compassion fatigue; as care information decreased, compassion fatigue increased.

Compassion fatigue was regressed on the effects of being a caregiver ($R^2 = .517, p < .001$); as caregiving effects were higher, compassion fatigue decreased. The multiple regression model showed predictors of compassion fatigue ($R^2 = .571, p < .001$). A lower risk for compassion fatigue was observed in male FCGs ($\beta = -0.31, p = .001$), an increase in the effects of being a caregiver ($\beta = 0.31, p < .001$), and FCGs who had no help ($\beta = 0.16, p = .009$). Variance inflation factors were assessed for all dynamic models. All models had values less than 2 indicating no obvious multicollinearity (Fox, 2016).

**FNR Impact on Compassion Fatigue and on FCG IMCHB Dynamic Factors (Aim 3)**

A satisfactory FNR was associated with predicting less compassion fatigue ($R^2 = .154, p < .001$). In multiple regression, the FNR also predicted compassion fatigue ($R^2 = .215, p < .001$). FCGs with increased FNR satisfaction ($\beta = 0.24, p < .001$) and decreased compassion fatigue risk reported a work schedule change ($\beta = 0.14, p = .088$), and lower acceptability with spiritual status ($\beta = -0.19, p = .026$). There was also an association for decreased compassion fatigue with the spousal relationship in this regression model ($\beta = 0.08, p = .084$).

A positive FNR was related to increased compassion satisfaction ($R^2 = .177, p < .001$). In a multiple regression model with compassion satisfaction and background
variables there were significant associations ($R^2 = .339, p < .001$). A positive FNR ($\beta = 0.27, p < .001$), decreased age ($\beta = -0.01, p = .035$), low spiritual status ($\beta = -0.34, p = .002$), being married ($\beta = 0.18, p = .011$), and having no previous healthcare experience ($\beta = 0.31, p = .002$) were all related to increased compassion satisfaction.

The bivariate model for social desirability and the FNR was log transformed, and a positive FNR ($R^2 = .052, p = .037$) predicted lower social desirability. In a multiple regression model ($R^2 = .005, p = .421$) with social desirability and background variables, being male ($\beta = -0.07, p = .039$) was the only predictor for less social desirability.

A positive FNR ($R^2 = .045, p = .01$) was associated with more positive effects of being a caregiver. In a multiple regression model with the FNR and background variables, there were predictive associations ($R^2 = .281, p < .001$). Having a positive FNR ($\beta = 0.39, p = .008$), being White ($\beta = 0.23, p = .092$), being female ($\beta = 0.7, p < .031$), having more help ($\beta = -0.45, p = .028$), and not having healthcare experience ($\beta = 0.36, p = .059$) were related to increased effects of caregiving. Having less spiritual support ($\beta = -0.59, p = .006$) was related to positive caregiving effects.

Compassion fatigue was regressed on compassion satisfaction, social desirability, and the effects of being a caregiver and the model ($R^2 = .67, p < .001$) and each dynamic variable was significant; increased compassion satisfaction, increased social desirability, increased effects of being a caregiver, and an increased satisfaction with the FNR were all predictors of lower compassion fatigue (Table 3).
Table 3

Multiple Regression Analysis between the Dynamic Variables and Compassion Fatigue

<table>
<thead>
<tr>
<th>Independent Variable</th>
<th>β</th>
<th>SE</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>FNR**</td>
<td>0.11</td>
<td>0.04</td>
<td>2.92</td>
<td>.004</td>
</tr>
<tr>
<td>Compassion satisfaction***</td>
<td>0.18</td>
<td>0.05</td>
<td>3.63</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Social desirability ***</td>
<td>0.95</td>
<td>0.23</td>
<td>4.24</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Effects of being a caregiver ***</td>
<td>0.2</td>
<td>0.02</td>
<td>8.13</td>
<td>&lt;.001</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Dependent Variable</th>
<th>Intercept</th>
<th>SE</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Compassion fatigue</td>
<td>-0.02</td>
<td>0.02</td>
<td>-0.64</td>
<td>.522</td>
</tr>
</tbody>
</table>

Note. $R^2 = 0.67$, $F(4, 123) = 65.23$, $p < .001$.

*** $p < .001$. ** $p < .01$.

In a multiple regression model where compassion fatigue was regressed on the dynamic variables and the background variables there were predictive associations. The effects of being a caregiver and compassion satisfaction showed an inverse relationship with compassion fatigue. Increased social desirability was significant, satisfaction with the FNR, and numerical age as well as being male lowered the risk for compassion fatigue. The entire model explained 68% of the variability ($R^2 = 0.683$, $p < .001$) (Table 4). Variance inflation factors were assessed for all FNR models, and all models had values less than 2 indicating no obvious multicollinearity (Fox, 2016).
Table 4
Multiple Regression of All Variables on Compassion Fatigue

<table>
<thead>
<tr>
<th>Independent Variable</th>
<th>β</th>
<th>SE</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>FNR</td>
<td>0.09</td>
<td>0.04</td>
<td>2.13</td>
<td>.036</td>
</tr>
<tr>
<td>Compass satisfaction**</td>
<td>0.24</td>
<td>0.06</td>
<td>4.26</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Social desirability**</td>
<td>0.67</td>
<td>0.24</td>
<td>2.74</td>
<td>.007</td>
</tr>
<tr>
<td>Effects of being a caregiver***</td>
<td>0.21</td>
<td>0.28</td>
<td>7.57</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Female gender†</td>
<td>-0.19</td>
<td>0.09</td>
<td>-2.11</td>
<td>.037</td>
</tr>
<tr>
<td>White race</td>
<td>0.04</td>
<td>0.04</td>
<td>1.00</td>
<td>.322</td>
</tr>
<tr>
<td>Numerical age in years†</td>
<td>0.01</td>
<td>0.00</td>
<td>2.25</td>
<td>.026</td>
</tr>
<tr>
<td>Care duration one year or less</td>
<td>0.02</td>
<td>0.07</td>
<td>0.35</td>
<td>.729</td>
</tr>
<tr>
<td>Financial status acceptable</td>
<td>-0.05</td>
<td>0.05</td>
<td>-0.94</td>
<td>.348</td>
</tr>
<tr>
<td>Currently working</td>
<td>-0.01</td>
<td>0.05</td>
<td>-0.10</td>
<td>.922</td>
</tr>
<tr>
<td>Work schedule changed</td>
<td>0.07</td>
<td>0.05</td>
<td>1.23</td>
<td>.221</td>
</tr>
<tr>
<td>Spiritual status acceptable</td>
<td>0.03</td>
<td>0.06</td>
<td>0.44</td>
<td>.663</td>
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<td>No help</td>
<td>0.08</td>
<td>0.05</td>
<td>1.46</td>
<td>.148</td>
</tr>
<tr>
<td>Married</td>
<td>-0.04</td>
<td>0.04</td>
<td>-1.18</td>
<td>.242</td>
</tr>
<tr>
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<td>0.03</td>
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<td>.111</td>
</tr>
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<td>0.06</td>
<td>-0.34</td>
<td>.737</td>
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<tr>
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<td>0.08</td>
<td>0.27</td>
<td>.788</td>
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<tr>
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<td>0.05</td>
<td>-1.20</td>
<td>.234</td>
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Dependent Variable | Intercept | SE  | t    | p    |
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<th></th>
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<td>Compassion fatigue</td>
<td>-0.37</td>
<td>0.16</td>
<td>-2.37</td>
<td>.020</td>
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</table>

*Note. R² = 0.683, F(18, 108) = 16.11, p < .001.
**p < .001. ***p < .01. *p < .05.

Discussion

This study adapted the IMCHB to guide in variable description and assist in testing study aims. This approach was able to explain non-causal associations of background variables and dynamic variables (compassion satisfaction, social desirability, and the effects of being a caregiver, and the FNR) in relation to compassion fatigue. Additionally, the use of the FNR as described in the adapted model uniquely identified non-causal relations between the FNR and the other dynamic variables, and between the FNR and the health outcome, compassion fatigue. There were some variables that significantly predicted compassion fatigue, while others had no relation to compassion fatigue. Gender, age, having no help, being married, knowing HF stage, care duration, currently working, work schedule change, and financial status were not significant predictors of compassion fatigue in any of the background variable statistical models;
however, gender, age in years, having no help, being married, and work schedule change were significant in some regression models containing the dynamic variables. The dynamic variables demonstrated a relation to compassion fatigue, and the FNR had associations with compassion fatigue, compassion satisfaction, effects of being a caregiver. The FNR predicted social desirability in a bivariate model.

Interestingly, care duration or work status did not have a significant relation to compassion fatigue. There were 21.8% FCGs caring for a family member for one year or less, however, 44.8% were caring for a family member for 1-4 years; this represented more than one-third the participants. End-stage management usually occurs at end of life, however better treatments have increased care duration as well as care expectations (Kitko et al., 2020). There were 61.9% FCGs currently working and 67.7% FCGs had to change work schedules to perform care duties; this was consistent with national data that has shown caregivers balancing working and duties (NAC & AARP, Given & Reinhard, 2017; 2020). A medium effect was used to determine the sample size, and although this effect can determine a visible effect, the effect for this sample may not have been detected due to the smaller size (Cohen, 1992). Thus, the significance of some results may not have been identified. Resulting associations are discussed herein.

**Background Variables**

**Spousal Relationship**

FCGs who were spouses (41.5%) reported less compassion fatigue in a model with other social influence variables and in a model with the FNR and all background variables. This finding was not expected as national data reported spousal FCGs to be 12% (NAC & AARP, 2020). However, the chronic and unexpected trajectory of HF
requires unique knowledge of prognosis, opportunities for advocacy, and end-of-life management (Kitko et al., 2020), and spouses may be best suited for these activities. This finding suggests that FCGs caring for their spouses with HF may benefit from the caregiving relationship during end-stage HF management. Additionally, this finding indicates that non-spousal FCGs in end-stage HF may require additional support from nursing providers to safeguard from compassion fatigue. Past literature has emphasized the critical role of nurses in HF management (Fasolino, 2020; Petruzzo et al., 2017; Wingham et al., 2015), however, specific assessment of the FCG care relationship as well as associations of the FNR has been lacking (Kitko et al., 2020). More research is needed on the caregiving outcomes for spousal and non-spousal FCGs in the end-stage HF population.

**Spiritual Support**

Less spiritual support was associated with greater compassion fatigue and interestingly, greater compassion satisfaction. Although previous caregiving literature has found that FCGs of individuals with HF look for spiritual connections and support (Bakas, Pressler, et al., 2006; Doherty et al., 2016), there have been no quantitative studies addressing this relationship. The spiritual domain is one of the areas where compassion fatigue is manifested in FCGs (Lynch, 2018); however, this has not been well studied in FCGs or in FCGs caring for family with HF. Although less spiritual support was seen in relation to positive compassion satisfaction and caregiving effects, the satisfaction with the FNR remained higher. One consideration is that FCGs perceived greater support from the nursing provider instead of spiritual support from other sources. Another possibility is that a positive FNR may encourage FCGs to rely on their nursing
providers for recognition and provision of supportive needs such as spiritual support. Future research can examine the relationship of the FNR and address spiritual status in FCGs who care for individuals with end-stage HF, as well as FCGs who care for individuals with other chronic disease to guide supportive nursing interventions.

**Care Information by the Nursing Provider**

The less FCGs were told about how to care for their family members, the more compassion fatigue there was. These findings were unexpected, however, compared with the literature where FCGs experienced worries and stress over their performance with care duties and fear of making a mistake (Sullivan et al., 2016; Wingham et al., 2015), having less caregiving information may have had a mitigating effect on compassion fatigue due to the lack of knowledge or worries about caregiving performance. Further, FCGs who completed this survey were primarily caring for family members with advanced HF (Stage III and IV = 73.9%). The survey asked for FCGs to identify if they were caring for individuals with end-stage HF (Stage IV) before FCGs could proceed. Some FCGs did not know or didn’t recall the stage of the person they were caring for (6.5%) and 13.8% indicated they had not been told before. They may have forgotten being told or were not present when information was provided, however, not understanding the severity of disease could result in FCGs not recognizing disease progression, lead to confusing goals of care and treatment, contribute to hospital readmissions, and prevent FCGs from advocating for supportive services or palliative care (Fasolino, 2020). Past research has indicated the importance of a provider relationship that offers communication and healthcare information early and often at multiple time points for FCGs (Browne et al., 2014; Clark et al., 2009). To optimize
understanding, nurses will have to rely on their individualized assessment of FCG readiness to learn new information over all care interactions.

**Having No Previous Experience**

FCGs with no previous caregiving experience had a lower risk for compassion fatigue. Having less experience may have produced a similar association for FCGs as not being told care information. FCGs may have derived more caregiving joy and motivation by having to rely on their own experiences. The absence of worries and stressors related to past care experiences may have protected FCGs during their first caregiving roles. Assessment for past caregiving responsibilities may be necessary to recognize FCG supportive needs, prevent cumulative stress, and ultimately, prevent compassion fatigue.

**Compassion Satisfaction**

This study found that as compassion satisfaction increased for FCGs, the associated risk for compassion fatigue decreased. The ProQOL in combination with other measurement instruments has been used to examine compassion fatigue and compassion satisfaction in FCGs (Lynch et al., 2018) and in informal and formal caregivers (Thorson-Olesen et al., 2019); the findings from the current study contribute to understanding this previously observed inverse relationship. Although there have not been studies identified for compassion fatigue or compassion satisfaction among FCGs of individuals with end-stage HF, this confirmatory finding suggests that results may be applicable to FCGs in chronic disease populations. Additionally, FCGs who had no help realized a decrease in compassion fatigue, indicating perhaps that having no additional helpers could have motivational characteristics in caring, and prevent compassion fatigue. Sullivan et al. (2016) found that some FCGs exhibited care vigilance or compassion maintenance, the
recognized desire to continue care with compassion. Some FCGs feel guilt when accepting help (Petruzzo et al., 2017) and may have difficulty requesting help, thinking they are being a burden (Wingham et al., 2015). These behaviors especially require monitoring and assessment by nursing providers, as FCGs may not recognize when caregiving is becoming difficult.

**Social Desirability**

Increased social desirability was related to increased compassion fatigue. The more FCGs cognitively appraised their attitudes, values, beliefs, and possible concerns and stigma related to the FCG caregiving role, compassion fatigue risk increased. Although a significant finding for this study, there are no FCG studies using the SDS or social desirability as an independent variable for compassion fatigue. Thus, additional research is needed on the impact social desirability has on compassion fatigue.

**Effects of Being a Caregiver**

Positive effects of being a caregiver had an inverse relationship with compassion fatigue. The BCOS measurement instrument has not been used previously in relation to compassion fatigue, however, has been used to examine effects of being a caregiver for FCGs for individuals with end-stage HF (Bakas, Pressler, et al., 2006; Pressler et al., 2009); the results from this current study were expected based on past literature. As in past research, this sample had greater response from White and female FCGs (Table 1); thus, stratified sampling is a recommendation for future FCG studies.

**Family Caregiver-Nursing Provider Relationship**

The FNR was inversely associated with compassion fatigue. It was expected that a favorable FNR would decrease compassion fatigue risk as FCGs have indicated
wanting to be involved with providers in care decisions for HF (Wingham et al., 2015) and look for reassurance that they are doing the best for their family member (Sullivan et al., 2016). Similarly, satisfaction with the FNR was associated with compassion satisfaction. Additionally, when FCGs perceived positive support, information, and communication with the nursing provider they also reported having positive FCG caregiving effects. For optimal outcomes, nursing providers can further communication and supportive efforts, and offer timely information to foster a reciprocal interaction with FCGs to prevent compassion fatigue and foster the caring and motivation associated with compassion satisfaction.

Previous literature has indicated that values and perceptions of providers and caregiving in HF have influenced FCGs’ understanding, coping, and engagement (Browne et al., 2014; Clark et al., 2009; Petruzzo et al., 2017). When the FNR was regressed with the dynamic variables, results showed that a positive FNR, increased social desirability, greater compassion satisfaction, increased effects of being a caregiver decreased compassion fatigue (Table 3). This supports that the dynamic variables in the adapted IMCHB were related to compassion fatigue.

These findings reinforce the theoretical underpinnings of the dynamic variables; FCG perceptions of each dynamic variable are related to FCG perceptions regarding the other dynamic variables, particularly the FNR. The association of a positive FNR on compassion fatigue is observed in addition to the relation of the dynamic variables on compassion fatigue. The relationship between social desirability and the FNR previously has not been examined using the SDS as a variable. Lack of comparison for this finding
as well as a small sample requires further research to determine how FCGs of individuals with end-stage HF appraise caregiving and the resulting impact on compassion fatigue.

**Strengths and Limitations**

This dissertation adapted a theoretical framework to guide study aims and used measures shown to be reliable and valid with this sample, adding to the theoretical HF caregiver literature. The SDS instrument, previously used to detect social desirability in responses, was uniquely operationalized as a variable to determine if FCGs appraised values, beliefs, or attitudes associated with caregiving, finding support for the role of positive appraisal in caregiving to reduce compassion fatigue. Further, a positive FNR was related to decreased compassion fatigue, increased compassion satisfaction, and positive effects of being a caregiver adding to the literature on the role of the caregiver-provider relationship for FCGs in HF.

Consistent with past literature, the majority of FCGs replying to this survey were White and female; however, multiple sociodemographic variables were examined, yielding new associations for the HF FCG literature. Compared to other literature, spouses (41.5%) comprised the largest number of FCGs, suggesting that their relationship is suited to the complex management in HF, and also suggesting the need to assess non-spousal FCGs for compassion fatigue risk. Many responses from participants (73.2%) caring for family individuals with end-stage or Stage III HF identified new variable associations in relation to compassion fatigue and compassion satisfaction, such as the role of spiritual support. Results further supported the poorly understood inverse relationship between compassion fatigue and compassion satisfaction, adding to the HF FCG literature as well as confirming construct validity for the ProQOL. HF has a chronic
progression with end-stage disease expecting poorer outcomes for individuals; the majority of FCGs (78.4%) in this study indicated caregiving for greater than a year, presenting support for multiple assessment of FCGs during the long caregiving trajectory. Further, this study received responses from participants between ages 23 and 78, demonstrating the wide range of FCG ages, and the need to address all FCGs.

Convenience and snowball sampling was used for this cross-sectional study, that reached participants across the United States through multiple locations and recruitment sites during the COVID-19 pandemic. The ongoing social distancing during data collection may have affected recruitment and attrition, however, recruitment via social media methods possibly reached participants otherwise not accessible (Haynes et al., 2020). Many FCGs who were following social distancing restrictions were at home and in a position to respond to the survey. To minimize the potential limitation with online survey administration, paper surveys were offered for participants who indicated this preference. Eleven potential participants opted for paper, and 10 did not provide an address and the one survey that was mailed was not returned. The study was predicated on the understanding that the participants had basic knowledge about their family members’ HF; lack of understanding may have excluded participants. The majority (59.4%) FCG responses identified caring for a family member with stage IV HF, however the method of self-report may have yielded misinformation due to limited recall or response bias. The survey was limited to participants who could read English due to time constraints for this project.

Survey length may have led to survey fatigue; to reduce and minimize time burden, participants were permitted to stop and return to the survey as needed. Five
participants opted to stop and return to the survey for completion, and the average survey completion time (13:33 minutes) by participants was within researcher estimation (15 to 20 minutes). There was engagement and attrition; approximately 44% of the 290 participants who accessed the survey completed it, and 68% of the 186 participants who opted to proceed completed it, indicating interest in relaying FCG experiences in end-stage HF.

**Conclusion**

FCGs for individuals with end-stage HF care for their family members and provide advocacy and decision-making. However, the findings from this study may be applicable to other FCGs of chronic disease. FCGs may not recognize when to ask for help. Health care providers must learn to recognize compassion fatigue in FCGs to foster a positive caregiving community. This study found that although FCGs indicated being offered information to care for their family members, there were still some FCGs who did not know or did not recall the HF stage of their family members. FCGs’ understanding of information may affect care delivered; however, the more FCGs were told by the nursing provider increased compassion fatigue suggesting that information is needed at different time points or in multiple formats, such as verbal, written and online, to prevent FCGs from becoming overwhelmed. More than half of the FCGs in this study (51.5%) reported not having spiritual support, yet this is one of the four domains for compassion fatigue (Lynch, 2018). Some FCGs realized a positive FNR and reported less spiritual support, suggesting FCGs perceived greater support from the nursing provider instead of spiritual support from other sources. Another consideration is that a positive FNR may encourage FCG reliance on nursing providers for supportive needs such as spiritual support.
Targeted efforts can identify FCGs who need supportive services early in the diagnosis progression. This might include identifying FCGs at other care points earlier than appointments or hospitalization. Future research should address spiritual support of FCGs using a comprehensive measurement instrument.

The ProQOL has been used to assess for compassion fatigue, however, additional instruments are often required to assess the construct (Stamm, 2002) as in this study; future survey development is warranted in creating one specific measure for compassion fatigue for FCGs in end-stage HF. Additionally, assessments are required to recognize compassion fatigue symptoms for FCGs already experiencing compassion fatigue symptoms, such as insomnia, fatigue, anxiety, social isolation, and financial difficulties. Spouses accounted for 41.5% FCGs and realized less compassion fatigue; assessment for the FCG relationship may assist FCGs who are unable or have difficulties engaging with, advocating, or communicating with providers due to the relationship to the care recipients. Future studies examining the effects of an intervention to enhance compassion satisfaction and reduce compassion fatigue in FCGs caregiving for individuals with HF are warranted.

**Recommendations**

Providing care for individuals with chronic illnesses has been identified as difficult; however, some FCGs are able to provide care without adverse effects while others suffer negative consequences such as compassion fatigue (Given & Reinhard, 2017). Based on findings, there is indication for assessing FCGs for these effects via compassion fatigue domains: physical, psychological, spiritual, and social. Nurses and nurse practitioners are uniquely positioned to monitor patients who have HF and their
FCGs during multiple points of care and are frequently the provider that the patient and FCG see most often (Fasolino, 2020). Specialty HF nurses and nurse navigators may provide consistent and frequent assessment. Nursing provider education on ways to improve the FNR through communication, support, and information to FCGs can strengthen this relationship found to have a significant association in compassion fatigue reduction. Organizational policies are needed to keep nursing providers updated and accountable for follow-up and to ensure consistent training, including assessment for respite programs and timely palliative evaluations and services.

Additionally, policy work at the state and national level is needed for language consistency in programs (Reinhard, Feinberg, et al., 2019). FCGs have indicated difficulties in care transitions, yet not all states have enacted the CARE Act. There are variations in coverage and interventions among states, as well as states that have not enacted this act (Reinhard, Feinberg, et al., 2019). Policies that support state enactment and implementation of CARE Acts would ensure smooth transitions from the hospital to the community. Funded programs like respite offer needed breaks from physical duties (i.e., ARCH National Respite and Resource Center). In-person and virtual support services are available to assist with psychological, spiritual, and social worries. Updated caregiver policies at the national level will assist with program standardization, offering financial, social, physical, and emotional support to FCGs. Additional policies that support communication methods between the nursing provider and the FCG are needed. Increased telemedicine monitoring and virtual visits can facilitate time point assessments. Research in the areas of nursing provider education, assessment development and
standardization, and improving current intervention methods is needed, and policies that encourage these measures should be supported.
Literature Cited


Chapter III: IMPACT OF COVID-19 ON FAMILY CAREGIVERS OF INDIVIDUALS WITH END-STAGE HEART FAILURE

The COVID-19 pandemic that started in March 2020 in the United States has been well documented. The response to managing this global health crisis affected health systems and management of chronically ill patients (Italia et al., 2021; Reza et al., 2020). Social distancing, delayed appointments, and use of virtual visits were healthcare practices that disrupted many healthcare systems (Reza et al., 2020). Home care visits were consolidated, and many supportive services were halted or switched to virtual (Reza et al., 2020). Patients and family caregivers (FCGs) avoided accessing emergency care due to fears and concerns with social distancing (Haynes et al., 2020; Reza et al., 2020). Individuals who experienced chronic or acute illnesses and were not familiar or did not have access to virtual care were not able to keep appointments (Haynes et al., 2020; Italia et al., 2021). Further, individuals requiring medical attention chose to remain at home rather than being isolated in hospitals (Reza et al., 2020).

Heart disease is the leading cause of death in the United States (Centers for Disease Control and Prevention, 2021). Heart failure (HF) is a part of heart disease and is a syndrome often classified in four functional stages by the New York Heart Association (NYHA) to assist in provider understanding of later disease (American Heart Association [AHA], 2020; Fasolino, 2020). The four stages include Stage I with little physical limitations, Stage II with mild symptoms and limitation to physical activity, Stage III with marked physical limitations due to increased symptoms including dyspnea, and Stage IV with severe physical limitations and symptoms (AHA, 2020). HF affects over
six million people in the United States (Dionne-Odom et al., 2017; Kitko et al., 2020) and is a significant health problem. Individuals who have HF often rely on family members, other caregivers, and supportive services to provide care to manage their illnesses (Kitko et al., 2020). There is a range of services and professionals involved in HF management, including specialized clinics, palliative care, and support groups (Browne et al., 2014; Kitko et al., 2020), and many were suspended during the pandemic (Italia et al., 2021).

HF affects afflicted individuals as well as FCGs in the community and health care systems. It is responsible for over 990,000 live hospital discharges annually (Fasolino, 2020). Many individuals with HF are rehospitalized within six months of discharge with 70% due to HF exacerbations (Bergeethoven et al., 2016; Fasolino, 2020). Frequently, HF is accompanied by other comorbidities, including dementia (Dunbar et al., 2018; Fasolino, 2020). FCGs of individuals with HF manage complex disease-modifying treatments for their relatives. These interventions include diet and nutrition management, appointment scheduling, medication access and administration, and care of surgical devices (Kitko et al., 2020; Reza et al., 2020). In addition to the day-to-day management, FCGs also are involved in providing emotional and social support to family members (Kitko et al., 2020; Petruzzo et al., 2017; Wingham et al., 2019). These caregivers have learned to navigate the medical system and identify services to provide support and coping as disease progresses and prognoses change for their family members (Kitko et al., 2020; Wingham et al., 2019). With the physical, emotional, and social challenges that FCGs face on behalf of their chronically ill family members, they too require support (Bekelman et al., 2011; Gorodeski et al., 2020; Petruzzo et al., 2017; Wingham et al., 2015). And despite the level of care FCGs provide to their family members, frequent
hospital readmissions continue because of HF (Bergethon et al., 2016; Dunbar et al., 2018; Fasolino, 2020).

COVID-19 presented new challenges for HF management. Many institutions had health or disaster preparedness policies in place prior to COVID-19; however, with the onset of this pandemic, health care systems were overwhelmed with caring for patients afflicted with COVID-19 and challenged with identification of high risk individuals with HF, while maintaining communication with lower risk patients and their FCGs (Bansal et al., 2020; Italia et al., 2021). Continuing to provide quality care during this time of enforced isolation was difficult (Bansal et al., 2020). FCGs for individuals with HF already faced difficulty and uncertainty in balancing their caregiving roles (Gorodeski et al., 2020; Haynes et al., 2020; Petruzzo et al., 2017). Hospitalizations related to HF declined 50-60% in the United States during the pandemic (Italia et al., 2021), potentially increasing HF mortality. This is indicative of changes in how patients and FCGs managed illness during the pandemic. Moreover, HF is a leading comorbid risk factor for severe COVID-19 effects and death; this knowledge may have presented additional concerns for HF morbidity and mortality for FCGs and affected individuals (Gorodeski et al., 2020; Italia et al., 2021).

It is unclear how fully FCGs have been impacted by the social distancing guidelines and other changes imposed during the pandemic (Gorodeski et al., 2020; Haynes et al., 2020). FCGs have previously reported isolation in HF caregiving (Petruzzo et al., 2017; Sullivan et al., 2016), however FCGs may have experienced even greater isolation in response to COVID-19 restrictions. Further, it has yet to be determined how social distancing affected those FCGs who provided routine care for family members
with HF living in other residences or in structured facilities (Gorodeski et al., 2020). FCGs may have been separated from their family members during affected individuals’ illness exacerbations and hospitalizations, causing further duress (Gorodeski et al., 2020). Regular postponement of non-COVID-19 treatment, including HF treatment, as well as FCG and patient fear of inpatient settings during the pandemic may have resulted in delays to critical medical care and caregiver support options that may have had unknown impact on the individuals with HF, as well as their FCGs (Reza et al., 2020). This study aims to examine the impact of the COVID-19 pandemic on FCGs of individuals with end-stage HF. Specifically this study will attempt to answer the following research question: How did COVID-19 affect family caregivers providing care for individuals with HF?

**Methodology**

This study was part of a larger cross-sectional online quantitative survey on FCGs of individuals with end-stage HF.

**Participants**

Inclusion criteria were participants who were FCGs aged 18 or older identifying as FCGs of family members with end-stage HF at the time of the survey. One hundred thirty-two respondents completed this portion of the survey. The age range of the participants was age 23 to 78 (M = 50.58). FCGs were predominantly female (88.6%), White (85.6%), and non-Hispanic/Latino (93.9%). Similarly, many of the respondents were married (68.9%). The survey asked for FCGs to identify the HF stage of the family members being cared for; despite identification as FCGs for relatives with end-stage HF, 59.8% indicated the stage was Stage IV, and an additional 13.6% indicated they were
caring for a family member with Stage III HF. Many of the respondents were recruited from Facebook groups (59.8%). Almost one-third (29.5%) of the respondents were from the Northeast region of the United States, where the researchers were located, although all regions of the United States were represented (Table 5).

### Table 5

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<td>Non-Married</td>
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Note. *n = 132.

### Procedures

Participants were recruited via convenience and snowball sampling from an online national caregiver research registry, an online site for statewide councils of aging, social media sites, faith communities and community health centers in New England, and a large home hospice organization north of Boston. Potential participants were invited to complete an online survey on Qualtrics (Qualtrics, 2021) during February 2021 through May 2021.
Ethical Considerations

Study procedures received institutional review board approval from the University of Massachusetts Lowell prior to the onset of the study (#21-016-KOR-EXM) and collaborative agreements were followed for all participating agencies. Prospective participants were provided informed consent, and participation indicated consent. Participants were able to withdraw from the survey at any time, as well as to refuse to respond to specific items. All data were anonymized.

Measures

Demographics

The demographic portion of the larger survey had 19 questions. The variables chosen for this study were age in years, gender identity, HF stage, ethnicity, race, and marital status.

COVID-19 Questions

The larger study included one Likert-style COVID-19 question (C19Q), “How has COVID-19 affected your caregiving routines since March 2020?” Participants could respond with Negatively, Somewhat Negatively, Neither Negatively nor Positively, Somewhat Positively, and Positively. To ensure contextual richness one open-ended COVID-19 question was added, “What are some ways COVID-19 has affected your caregiving routines?”

Data Analysis

Thematic analysis was conducted using the six-step method of Braun and Clarke (2012): familiarize yourself with the data, generate initial codes, search for themes, review potential themes, define and name themes, and produce the report. This flexible
approach has been used to identify relevant themes in qualitative literature. Qualitative data analysis (QDA) was performed by two methods; data were coded by hand and by using computerized data analysis. Initial data review and coding was conducted in a Microsoft Excel ver. 16.53 matrix. Initial themes were determined by highlighting text, reviewing each item separately, and then as a whole dataset. Data were then exported to the current version of R ver. 4.0.5 (2021) for review and confirmation of themes. (Estrada, 2017; R Core Team, 2021). Use of both methods allowed for visualization of data, researcher collaboration, and methodological triangulation (Creswell & Poth, 2020; Estrada, 2017). QDA text mining in R was performed using the tm package to assist with determination of the most frequently responded words, identification of word associations, and generation of codes and subsequent themes (Feinerer et al., 2008). The 12 most common words or associations that determined R codes and themes are reported herein (Figure 2). Text mining themes were compared against the themes in the data matrix for comparison and analysis of common themes, redundant themes, and negative and alternative explanations. Thematic analysis, text mining, and R syntax were conducted by one researcher and reviewed by two researchers for rigor, trustworthiness, and inter-coder agreement (Creswell & Poth, 2020; Estrada, 2017). Initial themes were compared in the matrix and in R, and researcher review and discussion confirmed the themes.
Multiple linear regression was performed in R on the C19Q responses; the predictors were demographic characteristics and the themes that emerged from QDA. The variance inflation factor was assessed to determine if there was multicollinearity with any of the variables, with greater than 2 indicating multicollinearity (Fox, 2016). A Chi-square test was performed on the C19Q to determine if an endorsement of responses had values for caregiving. The responses somewhat negatively and negatively were clustered together (C19Q-neg), and the responses somewhat positively and positively (C19Q-pos) were clustered together for Chi-square probabilities. Descriptive statistics were analyzed in R.

Results

Caregiving Effects

There were 132 responses for the C19Q question. A majority (62.1%) of the respondents indicated that COVID-19 had affected their caregiving routines either negatively or somewhat negatively. Conversely, 3.8% of the respondents reported that
COVID-19 had affected their routines somewhat positively or positively. In comparison to both extremes, approximately one-third (34.1\%) of the respondents shared that the pandemic had not affected their caregiving routines either negatively or positively. A chi-square test was performed between the responses C19Q-neg, neither negatively nor positively (C19Q-neut), and C19Q-pos (Table 6). The odds of having a negative effect on caregiving routines was more than one and a half times greater than having a positive or neutral effect on caregiving routines (Table 6).

Table 6
Family Caregiver Responses to C19Q

<table>
<thead>
<tr>
<th>Question</th>
<th>n</th>
<th>%</th>
<th>Response</th>
<th>( \chi^2 )</th>
<th>p</th>
<th>Odds</th>
</tr>
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<tr>
<td>COVID-19 Caregiving Effect</td>
<td></td>
<td></td>
<td>Cluster</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Negatively</td>
<td>44</td>
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<td>C19Q-neg</td>
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<td>.005</td>
<td>1.64</td>
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<td>0.52</td>
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<tr>
<td>Neither negatively nor positively</td>
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<td>34.1</td>
<td>C19Q-pos</td>
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<td>0.04</td>
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<td>3</td>
<td></td>
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<tr>
<td>Positively</td>
<td>1</td>
<td>0.8</td>
<td></td>
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</table>

Note. n= 132.

Thematic Analysis

There were 113 responses to the open-ended questions. Five themes were identified from thematic analysis on the open-response question. They were themes of:

Social isolation was real, Changes in everyday routines, Keeping or making appointments was challenging, Masks and precautions were necessary, and There was added fear, anxiety, or worry.

Social Isolation was Real

Forty-seven respondents (41.6\%) identified that social isolation, either for themselves or the family members they were caring for, was a concern. The common words that helped to identify this theme were home, isolation, outside, and social. FCGs were concerned about the toll that caregiving had on their own time. One FCG reported,
“[I] can’t get outside and away enough.” A second participant concurred, “No outlet to get away.” There were concerns with missing other family members, “No interaction with my family.” Additionally, FCGs found difficulty in caring for themselves. One FCG indicated, “[I] am unable to get proper care due to the visitor restrictors…” An additional participant stated, “I can’t do my own things…volunteering and the gym, seeing family.” A sixth FCG indicated, “…[I] couldn’t take a couple hours for me.”

FCGs also were concerned about restricting visitors in their homes, as well as the visitor restriction policies for their family members when family members were inpatient or at other living facilities. One respondent indicated the hardship in seeing family members who became ill, “My mom fell ill during this terrible time…very difficult to be with my mom.” Another participant stated, “Hospital visitation policies make it hard to care for my wife.” A third FCG imposed visitor restrictions, “I am more vigorous in limiting visitors.”

Some FCGs found that social distancing restrictions extended to church services. One respondent stated, “…not having any social interactions with others…not being able to attend church…” In comparison, another respondent found that the church was not supportive, “Isolated to stay safe as primary caregivers for his mom, then ostracized by church for staying home.”

FCGs also were concerned about the lack of socialization for their family members. One respondent stated, “…unable to bring loved ones out of the home for socialization.” An additional respondent similarly stated, “Can’t take him out in public…activities are severely limited.” Another FCG indicated, “…Keep loved one home from hair and nail [appointments].” Another FCG found difficulty in bringing
family out, “My mom is medically fragile, so getting her out to move has been very limited.” The FCG experience presented a concern when FCGs became ill, “My dad was in the hospital and rehab 2x. Not able to visit. I had COVID and could not care for him.”

Change in Everyday Routines

Forty-one (36.3%) respondents indicated a change to their overall caregiving routines. These were on subthemes of change in living status, change in work or financial status, change to supplies, and change to availability of help. The common words that helped to identify this theme and subthemes were able, affected, break, care, everything, extra, get, help, supplies, unable, and work. Some FCGs found that their family members’ locations were changed to provide better care for them, “Moved mom out of assisted living and in with us”, and another FCG added, “I moved mother home with me after 8 years in a nursing home because we couldn’t see her.” A third FCG stated that family member relocation was not optional, “While figuring out home care my grandmother was placed in a nursing facility and I could not visit.” FCGs with children reported they now had children at home while performing caregiving routines, “Harder to ask for outside help, kids are home instead of at school …” Having children at home added to FCG parental duties while caregiving; however, children may have also provided help.

In addition to living status changes FCGs reported that there were changes in work schedules and financial situations. One FCG indicated, “I lost my part time job”, and another participant responded, “working from home full time affects me as a caregiver …reduced salary also affected me”, and a third FCG stated, “I am working
from home since last March. Used to get a little break going to work”, and a final FCG agreed, “…financial constraints.”

FCGs also indicated there was difficulty in getting supplies. One FCG stated, “…[I] couldn’t get out to see other people or shop”, and another offered, “Everything changed, insurance getting medical supplies or prescriptions”, and a third FCG added, “I couldn’t get out of my house to get groceries & medicine”, and a final FCG concurred that there were, “Less trips to the store.”

Additionally, there was the issue of difficulty with help for FCGs during the pandemic. FCGs reported that other caregivers were absent, unreliable, or unable to make it due to social distance requirements. One FCG indicated, “Our paid caregiver is unreliable…” and, another FCG stated, “…have to rely more on myself…”, and one FCG responded, “Aunt would not come to relieve me due to stay-at-home order” and a fourth FCG offered, “Can’t get help from anyone else because you can’t let them in the house.” One respondent indicated, “…not as much respite as we are limiting visits.”

Keeping or Making Appointments was Challenging

Twenty-six (23%) respondents indicated that medical or other provider appointments for their family members were cancelled or affected. The common words that helped to identify this theme were appointments, attend, doctor, hospital, medical, and visit. The concern of no respite also was observed with limited hospice appointments. “Hospice doesn’t have volunteers available to help offer respite.” Another respondent reported that “hospice didn’t come as often.” And a third respondent indicated that “Adult day care closed for [our] loved one.”
“Cancelled Dr. appointments”, “…doing virtual appointments…”, and “…unable to attend most appointments…”, were worries by three participants. One FCG indicated that “provider care decreased [as they appeared] only concerned with covid and very concerning for those with serious disease not being able to accompany [family] to procedures.” Other family members were concerned about who would care for and advocate for their family members at the appointments in their absence. One FCG offered, “Not allowed in hospital as his advocate”, and another said, “I am unable to attend medical visits with my ill spouse. He forgets to advocate for his needs…”

**Masks and Precautions Were Necessary**

Eighteen respondents (15.9%) stated considerations regarding masks and precautions. The common words that helped to identify this theme were masking, masks, and precautions. One respondent indicated that masks changed the way facial expressions could be interpreted, “…reduce the amount of info you can read in one’s face.” Three participants addressed the amount of time masks and precautions added, “More time disinfecting surfaces, reminding…about mask and hand hygiene…”, and “more thorough cleaning…”, and “often teaching use of precautions.”

One participant indicated not liking the extra precautions, “I dislike wearing the mask constantly…”, while another participant indicated that the mandatory precautions provided ease, “made mask wearing easier and acceptable.” An additional FCG expressed difficulties because imposed precautions and masks were used by everyone during the pandemic, making it difficult to obtain needed masks for at-home treatments, “…difficulty in getting masks in dressing change kits…”
**There was Added Fear, Anxiety, or Worry**

Fifteen (13.3%) respondents indicated fear, anxiety, or worry for themselves or their family member contributing to concerns during the pandemic. The common words that helped to identify this theme were anxiety, covid, fear, and worried. These FCGs were concerned about contracting COVID-19 and possibly passing it on to their family members. Respondents indicated an inability to bring in other caregivers in fear of transmitting the virus. One FCG stated, “…for fear of Covid I’m it 128-168 hrs/wk”, and another said, “…anxiety for giving my loved one the virus, no break or help with caregiving.” One respondent indicated, “I’ve had to go to the emergency room on several occasions unvaccinated and terrified of covid.” Another respondent summed things up as, “…always worried that I could bring it home to him. Just always worried.” And another stated, “Anxiety, stress, precautions, lack of socialization.”

**No Change**

Despite the above themes, 11 respondents (10%) indicated there was no change in their caregiving routines. The common word that helped to identify this response was none. One person replied that there was “the same isolation due to transplant.” Another person stated, “it [Covid] has not affected me.” Other participants did not elaborate in their replies. Two respondents addressed the potential ease that COVID-19 had on their situation. One person indicated that that their family member was post “heart transplant in Feb 2021”, and “covid eased the transition to disability.” Another respondent added that there were “less blood draws,” suggesting that not having to deal with this procedure was a positive effect.
Regression Analysis

Each of the demographic variables and themes was regressed on the C19Q. When individually regressed, the variables age, gender, marital status, race, and ethnicity did not have associations with C19Q. Changes in everyday routines ($R^2 = .057, p = .007$) and Keeping or making appointments was challenging ($R^2 = .027, p = .045$) had bivariate associations with C19Q. All five themes and the variables age, gender, race, ethnicity, marital status, and HF stage were regressed on C19Q. The HF stage variable restricted the model’s variability due to 19.7% participants indicating either they did not know or could not recall their stage, resulting in loss of degrees of freedom. Due to this substantial loss of data, this variable was omitted from the final regression model. With the resulting model ($R^2 = .14, p = .004$), Changes in everyday routines ($p = .003$), Keeping or making appointments was challenging ($p = .007$), and Social isolation ($p = .009$) had a significant association with C19Q (Table 7). Masks and precautions were necessary and Added fear, anxiety, and worry did not have any significant associations with C19Q. Variance inflation factor was estimated for predictors to help assess for multicollinearity; all variance inflation factor values were below 2, indicating no substantial multicollinearity (Fox, 2016).
Table 7
Multiple Regression COVID-19 Effect on Caregiving Routines

<table>
<thead>
<tr>
<th>Dependent Variable</th>
<th>Intercept</th>
<th>SE</th>
<th>t</th>
<th>p</th>
</tr>
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<tbody>
<tr>
<td>C19Q***</td>
<td>2.18</td>
<td>0.21</td>
<td>-2.77</td>
<td>&lt;.001</td>
</tr>
</tbody>
</table>

Note. $R^2 = 0.141$, $F(10, 102) = 2.833$, $p = .004$.

*19 observations removed for missing data. ***p < .001. **p < .01.

Discussion

The aim of this research was to identify the impact of the COVID-19 pandemic on caregiving routines for FCGs who cared for family members with end-stage HF. FCGs reported some negative consequences similar to previous caregiving experiences identified in the caregiving literature for HF: social isolation, affected work experiences, change in living experiences, no respite, difficulty getting help, and fear, anxiety, and worry. Findings from this study that were associated with caregiving during the pandemic were precaution-related and appointment-related.

FCGs found that they were socially isolated, could not perform their own routines, or had no interaction with other family members. Social isolation has been discussed in other HF literature (Doherty et al., 2016; Fasolino, 2020; Kitko et al., 2020; Sullivan et al., 2016). FCGs in a study by Sullivan et al. (2016) were concerned with having the ability to find an “escape” and “to be a good caregiver.” Doherty et al. (2016) indicated that a result of social isolation could be poorer quality of life, or the possibility that FCGs could not continue to care for their family members. Fasolino (2020) stated
that not experiencing a break in caregiving could lead to loss of resilience in FCGs. Often, palliative care, spiritual care, or respite care can offer needed support from caregiving (Doherty et al., 2016; Fasolino, 2020; Kitko et al., 2020), however, the nature of many services changed during the pandemic (Gorodeski et al., 2020; Haynes et al., 2020; Italia et al., 2021). Not having a spiritual respite during the pandemic was a difficulty identified by two respondents; this may have contributed to lack of emotional and spiritual well-being during this time (Doherty et al., 2016). Interestingly, social isolation was the most common, but not the most significant, theme. This may be due to FCGs previously reporting isolation prior to COVID-19 (Doherty et al., 2016).

FCGs also found there were changes to their overall routines. New changes included added difficulties in accessing or purchasing supplies and as well as having the added burden of caring for school-aged children at home. Furthermore, some FCGs reported having to alter their living circumstances to be more convenient due to visiting restrictions imposed by the pandemic (i.e., moving the family member into the FCGs’ home). In a previous qualitative study, Petruzzo et al. (2017) found FCGs who had to change their living situations to be closer to family members due to strenuous HF caregiving routines. Financial difficulties and job loss have been associated with caring for individuals with HF as well (Doherty et al., 2016; Pressler et al., 2009). Findings associated with changes to living status were significantly associated with the response to how COVID-19 impacted caregiving. A more in-depth examination of FCGs’ living situations and changes over the progression of HF caregiving is an area for future research.
FCGs in a study by Petruzzo et al. (2017) also spoke of the importance of being engaged in care and helping family members cope with their illness. FCGs stated concerns over having appointments cancelled, missed, changed from in-person, and not being able to accompany their family members to appointments where they advocate on behalf of their family members. Sullivan et al. (2016) similarly found that FCGs were concerned with caregiving responsibilities, including “being there” for their family members. The FCGs needed to perform these activities and attend appointments to assist family members with management and care decisions (Kitko et al., 2020; Petruzzo et al., 2017). And although appointment challenges and cancellations were a newer finding related to the pandemic, it has previously been found that insufficient time with healthcare providers has been a dissatisfaction for FCGs caring for family members with HF (Doherty et al., 2016). Family members want to be involved in care for their ill family members and should be involved.

Some FCGs reported that enforced pandemic precautions added new burdens such as increased time necessary to perform caregiving activities, difficulty obtaining needed masks, and compliance with COVID-19 precautions by family members. Additionally, there were feelings of fear, anxiety, or worry reported with caregiving routines during the pandemic; however, they were not significantly correlated. These feeling have been similarly associated with caregiving routines in times other than COVID-19, suggesting that just caring for an individual with HF may elicit these feelings. There has been literature supporting that the unknown trajectory of HF can cause anxiety in FCGs (Petruzzo et al., 2017; Sullivan et al., 2016).
Some FCGs (10%) reported that there was no change in their caregiving routines. Several factors may have contributed to this finding: care duration, prior caregiving knowledge, care relationship, and availability of help (Petruzzo et al., 2017; Sullivan et al., 2016). Additionally, coping ability differs from person to person; hence, each FCG’s ability to perceive the pandemic as a stressful situation and its impact on the day-to-day routine may vary. Another factor contributing to unequal impact may have been the area of the country the FCG was from. Each state interpreted and mandated precautions differently, and thus the caregiving experiences may have been perceived differently in one region of the country than another.

**Strengths and Limitations**

This study adds to the expanding literature on the impact of COVID-19, specifically on FCGs who care for family members with end-stage HF. COVID-19 presented an overwhelming response nationally and globally with restrictions and social distancing, and this study revealed how those factors impacted the FCG experience. The cross-sectional design allowed for interpretation of non-causal associations during the same time period, which coincided with the pandemic. The open-ended responses offered opportunity for rich, contextual reports on the additional challenges COVID-19 presented to FCGs. Thematic analysis offered a flexible and credible approach to analysis (Braun & Clarke, 2012) and was conducted by two approaches to QDA: manual thematic analysis for generation of themes and computerized QDA using text mining for confirmation of the themes. QDA manually and in R contributed to methodological triangulation, logistical coding of data, ease of retrieval, documentation, and storage, and inter-coding for rigor, credibility, and trustworthiness (Creswell & Poth, 2020). Researcher
comparison and agreement of themes for thematic analysis was performed; however, a formal assessment rating for inter-coder reliability was not used (O’Connor & Joffe, 2020). Future studies may use a formal assessment for enhanced rigor.

The sample was representative of the four regions of the United States, providing new information on the collective experience of FCGs during a time when social distancing guidelines may not have been uniform across the United States. Much of the recruitment was limited to social media groups due to social distancing, however, this provided opportunity to reach FCGs who may not have been reached otherwise as many FCGs were home during the pandemic. The online survey administration allowed for ease in survey completion.

The data supported the previous literature that is known on FCGs for individuals with end-stage HF, adding findings that FCGs responded to crisis differently. Some FCGs reportedly did not feel a change to caregiving duties, while others relayed negative or positive effects. Consistent with previous HF literature, there was little diversity in FCG race or gender (Petruzzo et al., 2017; Sullivan et al., 2016; Wingham et al., 2019), however new information added the importance of FCGs seeing providers, being engaged in care, and serving as advocates for family members. The findings also identified associations with FCG living status changes, and these effects were accompanied by social isolation and appointment changes (Table 6). It is unknown if the small sample size contributed to the nonsignificant associations for other caregiving themes. Odds for experiencing a negative effect to caregiving during COVID-19 were 1.64 (Table 6), confirming the added burden during the pandemic.
The views from this study were from a sample representing FCGs who care for family members with HF; many responses (73.4%) were from family members who identified as caring for family members with stage III or stage IV HF, adding to the literature gap of FCGs caring for family members with later stage HF (Kitko et al., 2020). Further, 19.7% of the respondents replied that they did not know, can’t recall, or had not been told the HF stage of their family, introducing the possibility that these FCGs were in fact caring for family members with advanced stage illness, however this is not clear. This highlights a previously identified gap in care transitions for this population; family members need to be included in conversations when caring for their family members for understanding and successful outcomes to be realized (Kitko et al., 2020).

**Conclusion**

COVID-19 affected caregiving routines for FCGs of individuals with end-stage HF. Past FCG research for HF has indicated that more interventions are needed to facilitate caregiving services and needs, as well as recognition of FCG skills and coping (Kitko et al., 2020). FCGs have indicated that they want to be included in their family members’ care decisions. However, the social isolation and restrictions imposed during the COVID-19 pandemic halted many in person programs and efforts, making access to caregiving services more difficult. There were restrictions to hospitals and health care resources during the pandemic, and there was needed determination of current program availability and access to services to provide patients with HF and their FCGs continuity of care (Bansal et al., 2020).

This research found that FCGs continued to be isolated and experienced lifestyle changes during the pandemic, negatively impacting their already difficult caregiving
experience. Additionally, there were FCGs who stated their caregiving routines were not affected by the pandemic; it is possible for them that the pandemic’s impact has not been experienced yet, or they have experienced similar caregiving routine experiences reported by other FCGs and have already learned to cope with these changes. How FCGs cope during crisis may prepare them for the uncertain trajectory of caregiving in HF and is a future research indication.

**Recommendations**

With the ongoing restrictions and effects of COVID-19, recognizing how FCG cope during difficult situations or crises that cause significant duress may help health care professionals design and implement long-standing strategies that mitigate the negative consequences of caregiving. Future nursing research efforts identifying how FCGs cope with care transitions, particularly those who reported being unaffected by COVID-19 in their routines, may assist with long-term FCG interventions and policy decisions. Using specialty nurses to follow up on missed visits and track availability and use of supportive services may assist in continued program access and in keeping options attainable (Reinhard, Feinberg, et al., 2019). Ongoing referrals for respite, palliative care, and other services are needed as well as education initiatives for staff and FCGs. As the COVID-19 pandemic continues, assessment for appropriate visit options that include FCGs can assist with advocacy for individuals with HF. Provider virtual visits, implemented during the pandemic, can include patients and their FCGs; assessment and education for availability and access to these options may help FCGs and their family members feel less worry in seeking in-patient care when indicated. Funding that supports policies for new FCG
programs and continued research in FCG assessment, monitoring, and care transitions should be supported.
Literature Cited


Chapter IV: CONCLUSION

This study aimed to address the need for research in the heart failure (HF) population with family caregiver (FCG) characteristics, caregiver and provider communication, a theoretical nursing framework, and measures (Kitko et al., 2020). The study used an adapted Interaction Model of Client Health Behavior (IMCHB) to examine the associations on an unexplored consequence in the HF literature: the outcome of compassion fatigue in FCGs caring for individuals with end-stage disease. Measurement instruments previously validated in the literature were used to explain associations for this sample. Compassion fatigue is a stressor from caregiving seen through physical, psychological, spiritual, and social domains. Due to the occurrence of the COVID-19 pandemic during data collection for the first study on compassion fatigue in HF FCGs, a secondary aim that emerged was the evaluation of the impact of the COVID-19 pandemic on caregiving during this time using thematic analysis.

The adapted IMCHB was helpful in framing some associations that predicted compassion fatigue in this caregiving population. This model uniquely accounted for the family caregiver-nursing provider relationship (FNR), highlighting the critical role of the nursing provider in HF management. Nurses serve in hospitals, clinics, and communities as case managers, educators, navigators, HF specialty clinicians, and palliative team members (Browne et al., 2014; Fasolino, 2020). Nurses are suited to recognize FCG compassion fatigue through these care opportunities.
In this study, statistical analysis demonstrated that higher compassion satisfaction is associated with lower compassion fatigue in FCGs; that higher social desirability is associated with higher compassion fatigue in FCGs; and that higher effects of being a caregiver are associated with lower compassion fatigue in FCGs. Additionally, higher satisfaction with the FNR is associated with lower compassion fatigue; higher satisfaction with the FNR is associated with higher compassion satisfaction; and higher satisfaction with the FNR is associated with higher effects of being a caregiver. There is an association and regressed effect between the FNR and social desirability; as satisfaction with the provider relationship increases and there is higher social desirability, there is lower compassion fatigue.

Decreased FCG spiritual support had a relationship with increased compassion fatigue. There have not been studies on spiritual interventions in FCGs in this population. There were 41.5% spouses in this sample, and the spousal relationship had an association with decreased compassion fatigue. Interestingly, the less FCGs were told how to care for family members was related to decreased compassion fatigue, and having less experience also was related to decreased compassion fatigue. These findings support nursing interventions that assess for readiness for learning and retaining information and offering individualized HF education for FCGs. There was a screening question for the survey asking potential participants if they were FCGs for a family member with end-stage (Stage IV) HF. Participants were unable to proceed if they screened out, however 15.8% responded they were FCGs for other stages and 20.3% replied that they either didn’t know or had not been told. These results further support interventions that improve nursing provider information and communication with FCGs of individuals with end-
stage HF, ensuring FCG understanding and retention of instructions and care details, engagement, and involvement in care. FCGs have indicated that they want to be involved in care for their family members (Wingham et al., 2015), and continued evaluation of nursing provider teaching and communication can support FCG involvement in care.

Braun and Clarke’s (2012) thematic analysis was conducted to determine caregiving themes that impacted FCGs during the pandemic. FCGs were concerned about social isolation (41.6%), change in status (36.3%), having appointments cancelled or affected (23%), that masks and precautions were necessary (15.9%), and added fear, anxiety, and worry (13.3%). Additionally, there were FCGs who stated their caregiving routines were not affected by the pandemic (10%). Regression analysis showed that FCGs were 1.64 times more likely to report negative caregiving outcomes related to COVID-19 relative to reporting positive or neutral caregiving changes. While 62.1% of caregivers reported negative caregiving effects by COVID-19, 3.8% reported positive caregiving effects, and 34.1% reported that caregiving was neither positively nor negatively affected. These findings support previous observations that FCGs respond differently to caregiving stressors (Reinhard, Feinberg, et al., 2019) and the need to address negative responses. As the pandemic continues, with differing social distancing guidelines among states, it is important to recognize and consider FCG coping factors in interventions. Understanding FCG characteristics or strategies that prevent negative occurrences during times of duress will guide future interventions. More provider recognition of FCGs that respond negatively to stressful situations can mitigate negative consequences such as increased patient hospitalizations, avoidance of medical care, and
FCG compassion fatigue, through supportive interventions that include offering palliative care or respite.

Although this study focused on FCGs of individuals with end-stage HF, there are applications to FCGs of other chronic diseases. Future research should continue to explore how some FCGs experience compassion satisfaction, or the joy and motivation in caregiving, while others do not. Compassion satisfaction is not well understood and has demonstrated an inverse relationship to compassion fatigue in past studies, as well as in this study. Development of one comprehensive scale for compassion fatigue for HF and other chronic illnesses might capture other qualities of these constructs as well as have the benefit of a shorter measurement and attracting potential participants. Additionally, future work with social desirability as a factor in caregiving and caregiver provider relationships may provide insight to those vigilant FCGs who may be striving to be the best caregiver, while avoiding seeking provider assistance or other help, increasing their own risk for compassion fatigue.

Nursing providers can assess patients and FCGs at all care points to determine if all services, including respite, palliative, and spiritual options, are being offered and accessed. Funding for policies that assist FCGs should be supported and reviewed on an ongoing basis. This includes funding for national policies that standardize care, state policies that lack cohesive enactment, such as the CARE Act, and organizational policies that support provider and FCG communication methods and technology as well as education for these methods. State CARE Acts have not passed in all states and are not consistently implemented in states that have passed them; future policy work should continue to provide universal language and coverage to minimize confusion and optimize
coverage for this group (Reinhard, Feinberg, et al., 2019). As the population ages, and HF increases and FCGs are increasingly relied on to provide caregiving activities for family members, it is critical to address FCG physical, psychological, spiritual, and social needs and update service accessibility, availability, and education, especially during uncertain pandemic times.
Literature Cited


Appendix A

Survey

INTRO

Consent Thank you for choosing to complete this survey. The estimated completion time is 15 to 20 minutes. You can start and save your progress. This survey is looking for caregivers of family with end stage heart failure.

You can access the consent to continue: Consent form (hyperlink)

- I consent [Skip to screener]
- I do not consent [Skip to end of Survey]

Screener

Q1 Do you care for a family member with end-stage heart failure?

- Yes [Skip to PAPER]
- No [Skip to end of Survey]

PAPER If you prefer a paper survey to be mailed to you, please indicate PAPER. Add your mailing information. All survey responses are confidential. If you prefer to continue, please indicate PROCEED

- PAPER [Skip to ADDRESS]
- PROCEED [End of Block]

ADDRESS Please complete your Name, mailing address, postal code for survey mailing only. Survey responses will remain anonymous.

- Name ________________________________________________________________________
- Address _______________________________________________________________________
- Address 2 ______________________________________________________________________
- City __________________________________________________________________________
- State __________________________________________________________________________
- Postal code ______________________________________________________________________[Survey will end here]

INTRO PROQOL The next questions are about your experiences, both positive and negative, as a caregiver. Consider each of the following questions about you and your current caregiving situation. Select the number that honestly reflects how frequently you experienced these things in the
last 30 days.

Q2 I am happy
   ○ Never
   ○ Rarely
   ○ Sometimes
   ○ Often
   ○ Very Often

Q3 I am preoccupied with more than one person I care for
   ○ Never
   ○ Rarely
   ○ Sometimes
   ○ Often
   ○ Very Often

Q4 I get satisfaction from being able to care for people
   ○ Never
   ○ Rarely
   ○ Sometimes
   ○ Often
   ○ Very Often

Q5 I feel connected to others
   ○ Never
   ○ Rarely
   ○ Sometimes
   ○ Often
   ○ Very Often
Q6 I jump or am startled by unexpected sounds
   ○ Never
   ○ Rarely
   ○ Sometimes
   ○ Often
   ○ Very Often

Q7 I feel invigorated after working with those I care for
   ○ Never
   ○ Rarely
   ○ Sometimes
   ○ Often
   ○ Very Often

Q8 I find it difficult to separate my personal life from my life as a caregiver
   ○ Never
   ○ Rarely
   ○ Sometimes
   ○ Often
   ○ Very Often

Q9 I am not as productive at work because I am losing sleep over traumatic experiences of a person I care for
   ○ Never
   ○ Rarely
   ○ Sometimes
   ○ Often
   ○ Very Often

Q10 I think that I might have been affected by the traumatic stress of those I care for
Q11 I feel trapped by my job as a caregiver
   - Never
   - Rarely
   - Sometimes
   - Often
   - Very Often

Q12 Because of my caregiving role, I have felt "on edge" about various things
   - Never
   - Rarely
   - Sometimes
   - Often
   - Very Often

Q13 I like my work as a caregiver
   - Never
   - Rarely
   - Sometimes
   - Often
   - Very Often

Q14 I feel depressed because of the traumatic experiences of the people I care for
   - Never
Q15 I feel as though I am experiencing the trauma of someone I have cared for

- Never
- Rarely
- Sometimes
- Often
- Very Often

Q16 I have beliefs that sustain me

- Never
- Rarely
- Sometimes
- Often
- Very Often

Q17 I am pleased with how I am able to keep up with caregiving techniques and protocols

- Never
- Rarely
- Sometimes
- Often
- Very Often

Q18 I am the person I always wanted to be

- Never
- Rarely
Q19 My work makes me feel satisfied

- Never
- Rarely
- Sometimes
- Often
- Very Often

Q20 I feel worn out because of my work as a caregiver

- Never
- Rarely
- Sometimes
- Often
- Very Often

Q21 I have happy thoughts and feelings about those I care for and how I could help them

- Never
- Rarely
- Sometimes
- Often
- Very Often

Q22 I feel overwhelmed because my work load seems endless

- Never
- Rarely
Q23 I believe I can make a difference through my work

- Never
- Rarely
- Sometimes
- Often
- Very Often

Q24 I avoid certain activities or situations because they remind me of frightening experiences of the people I care for

- Never
- Rarely
- Sometimes
- Often
- Very Often

Q25 I am proud of what I can do to give care

- Never
- Rarely
- Sometimes
- Often
- Very Often

Q26 As a result of my caregiving, I have intrusive, frightening thoughts

- Never
- Rarely
Q27 I feel "bogged down" by the system
- Never
- Rarely
- Sometimes
- Often
- Very Often

Q28 I have thoughts that I am a "success" as a caregiver
- Never
- Rarely
- Sometimes
- Often
- Very Often

Q29 I can't recall important parts of my work with trauma victims
- Never
- Rarely
- Sometimes
- Often
- Very Often

Q30 I am a very caring person
- Never
- Rarely
Sometimes
Often
Very Often

Q31 I am happy that I chose to do this work

Never
Rarely
Sometimes
Often
Very Often

INTRO DEMO These next few questions are about you and your caregiving experience.

Q32 What is the heart failure stage for the family member you care for?

Stage I
Stage II
Stage III
Stage IV
Don’t know / Can’t recall
Have not been told

Q33 Have you been told by a nurse or nurse practitioner how to care for your family member?

Yes
No

Q34 Have you been a family caregiver or worked in health care?

No past health care or caregiving experience
Past experience working as a health professional only (example: nursing, medical, dental, allied health)
Past experience as a family caregiver only
☐ Past experience working in healthcare and as a family caregiver

**Q35** How are you related to the family member you care for?

☐ Child

☐ Spouse

☐ Parent

☐ Grandparent

☐ Sibling

☐ In-law

☐ Aunt/Uncle, Niece/Nephew, or Cousin

**Q36** Who else can help you care for your family member?

☐ No one

☐ There is at least one child under the age of 18

☐ There is at least one unpaid adult over the age of 18

☐ There is paid help

**Q37** How long have you been caring for your family member since they found out they had heart failure?

☐ Less than 6 months

☐ 6 months – 1 year

☐ 1 – 4 years

☐ 5 – 9 years

☐ More than 9 years

**Q38** Do you feel that your finances are enough to help you take care of your family member where they live?

☐ Yes

☐ No

**Q39** What is your current work status?
Q40 Have you had to change your work schedule because you care for your family member?
   ○ Yes
   ○ No

Q41 Do you get spiritual support to help you?
   ○ Yes
   ○ No

Q42 What is your gender identify?
   ○ Female
   ○ Male
   ○ Nonbinary
   ○ Other

Q43 What is your race?
   ○ American Indian or Alaska Native
   ○ Asian
   ○ Black or African American
   ○ Native Hawaiian or Other Pacific Islander
   ○ White

Q44 What is your ethnicity?
   ○ Hispanic/Latino
○ Not Hispanic/Latino

Q45 What is your age in years? (Please write in the number.)

______

Q46 What is your marital status?

○ Married

○ Single

○ Divorced

○ Widowed

Q47 What region of the United States are you from?

○ Northeast (Connecticut, Maine, Massachusetts, New Hampshire, New Jersey, New York, Pennsylvania, Rhode Island, or Vermont)

○ Midwest (Indiana, Illinois, Iowa, Kansas, Michigan, Minnesota, Missouri, Nebraska, North Dakota, Ohio, South Dakota, or Wisconsin)

○ South (Alabama, Arkansas, Delaware, District of Columbia, Florida, Georgia, Kentucky, Louisiana, Maryland, Mississippi, North Carolina, Oklahoma, South Carolina, Tennessee, Texas, Virginia, or West Virginia)

○ West (Alaska, Arizona, California, Colorado, Hawaii, Idaho, New Mexico, Oregon, Montana, Nevada, Utah, Washington, or Wyoming)

Q48 How has COVID-19 affected your caregiving routines since March 2020?

○ Negatively

○ Somewhat negatively

○ Neither negatively nor positively

○ Somewhat positively

○ Positively

Q49 What are some ways COVID-19 has affected your caregiving routines?

____________________________________________________________________________________

____________________________________________________________________________________

____________________________________________________________________________________

____________________________________________________________________________________

92
**Q50** Where did you hear about this survey?

- Facebook
- Linked In
- Twitter
- Instagram
- Craigslist
- Clinic
- Caregiver Support Group
- Other

**INTRO BCOS** You are more than half way done! This group of questions is about possible changes in your life from providing care for your family member. For each possible change, move the slider to the number that indicates the degree of change.

**Q51** As a result of providing care for my family member with heart failure:

<table>
<thead>
<tr>
<th>Changed for the worst</th>
<th>Did not change</th>
<th>Changed for the best</th>
</tr>
</thead>
<tbody>
<tr>
<td>-3</td>
<td>-2</td>
<td>-1</td>
</tr>
<tr>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>3</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

My self-esteem

<table>
<thead>
<tr>
<th>Changed for the worst</th>
<th>Did not change</th>
<th>Changed for the best</th>
</tr>
</thead>
<tbody>
<tr>
<td>-3</td>
<td>-2</td>
<td>-1</td>
</tr>
<tr>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>3</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Q52** As a result of providing care for my family member with heart failure:

<table>
<thead>
<tr>
<th>Changed for the worst</th>
<th>Did not change</th>
<th>Changed for the best</th>
</tr>
</thead>
<tbody>
<tr>
<td>-3</td>
<td>-2</td>
<td>-1</td>
</tr>
<tr>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>3</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

My physical health

**Q53** As a result of providing care for my family member with heart failure:

<table>
<thead>
<tr>
<th>Changed for the worst</th>
<th>Did not change</th>
<th>Changed for the best</th>
</tr>
</thead>
<tbody>
<tr>
<td>-3</td>
<td>-2</td>
<td>-1</td>
</tr>
<tr>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>3</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Q54
**As a result of providing care for my family member with heart failure:**

<table>
<thead>
<tr>
<th>Changed for the worst</th>
<th>Did not change</th>
<th>Changed for the best</th>
</tr>
</thead>
<tbody>
<tr>
<td>-3</td>
<td>-2</td>
<td>1</td>
</tr>
</tbody>
</table>

### Q55
**As a result of providing care for my family member with heart failure:**

<table>
<thead>
<tr>
<th>Changed for the worst</th>
<th>Did not change</th>
<th>Changed for the best</th>
</tr>
</thead>
<tbody>
<tr>
<td>-3</td>
<td>-2</td>
<td>1</td>
</tr>
</tbody>
</table>

### Q56
**As a result of providing care for my family member with heart failure:**

<table>
<thead>
<tr>
<th>Changed for the worst</th>
<th>Did not change</th>
<th>Changed for the best</th>
</tr>
</thead>
<tbody>
<tr>
<td>-3</td>
<td>-2</td>
<td>1</td>
</tr>
</tbody>
</table>

### Q57
**As a result of providing care for my family member with heart failure:**

<table>
<thead>
<tr>
<th>Changed for the worst</th>
<th>Did not change</th>
<th>Changed for the best</th>
</tr>
</thead>
<tbody>
<tr>
<td>-3</td>
<td>-2</td>
<td>1</td>
</tr>
</tbody>
</table>
### Q58
As a result of providing care for my family member with heart failure:

<table>
<thead>
<tr>
<th>Changed for the worst</th>
<th>Did not change</th>
<th>Changed for the best</th>
</tr>
</thead>
<tbody>
<tr>
<td>-3</td>
<td>-2</td>
<td>0</td>
</tr>
</tbody>
</table>

My emotional well-being

![Bar Chart for My emotional well-being]

### Q59
As a result of providing care for my family member with heart failure:

<table>
<thead>
<tr>
<th>Changed for the worst</th>
<th>Did not change</th>
<th>Changed for the best</th>
</tr>
</thead>
<tbody>
<tr>
<td>-3</td>
<td>-2</td>
<td>0</td>
</tr>
</tbody>
</table>

My roles in life

![Bar Chart for My roles in life]

### Q60
As a result of providing care for my family member with heart failure:

<table>
<thead>
<tr>
<th>Changed for the worst</th>
<th>Did not change</th>
<th>Changed for the best</th>
</tr>
</thead>
<tbody>
<tr>
<td>-3</td>
<td>-2</td>
<td>0</td>
</tr>
</tbody>
</table>

My time for social activities with friends

![Bar Chart for My time for social activities with friends]

### Q61
As a result of providing care for my family member with heart failure:

<table>
<thead>
<tr>
<th>Changed for the worst</th>
<th>Did not change</th>
<th>Changed for the best</th>
</tr>
</thead>
<tbody>
<tr>
<td>-3</td>
<td>-2</td>
<td>0</td>
</tr>
</tbody>
</table>

My relationship with my family

![Bar Chart for My relationship with my family]

### Q62
As a result of providing care for my family member with heart failure:

<table>
<thead>
<tr>
<th>Changed for the worst</th>
<th>Did not change</th>
<th>Changed for the best</th>
</tr>
</thead>
<tbody>
<tr>
<td>-3</td>
<td>-2</td>
<td>0</td>
</tr>
</tbody>
</table>

My financial well-being

![Bar Chart for My financial well-being]
Q63 As a result of providing care for my family member with heart failure:

<table>
<thead>
<tr>
<th></th>
<th>Changed for the worst</th>
<th>Did not change</th>
<th>Changed for the best</th>
</tr>
</thead>
<tbody>
<tr>
<td>My relationship with my family member</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Q64 As a result of providing care for my family member with heart failure:

<table>
<thead>
<tr>
<th></th>
<th>Changed for the worst</th>
<th>Did not change</th>
<th>Changed for the best</th>
</tr>
</thead>
<tbody>
<tr>
<td>My physical functioning</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Q65 As a result of providing care for my family member with heart failure:

<table>
<thead>
<tr>
<th></th>
<th>Changed for the worst</th>
<th>Did not change</th>
<th>Changed for the best</th>
</tr>
</thead>
<tbody>
<tr>
<td>My general health</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Q66 In general how has your life changed as the result of taking care of your family member with heart failure?

<table>
<thead>
<tr>
<th></th>
<th>Changed for the worst</th>
<th>Did not change</th>
<th>Changed for the best</th>
</tr>
</thead>
<tbody>
<tr>
<td>Move the slider</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

INTRO CPRA You are doing well!

Think about your contact with the medical professional who examined your family member most recently.
Then answer the following questions by checking the answer that best describes how you feel about your recent contact with that medical professional.

Q67 I understand the possible side effects of my family member’s treatment

- [ ] Very strongly disagree
- [ ] Disagree
- [ ] Somewhat disagree
- [ ] Neither agree nor disagree
- [ ] Somewhat agree
- [ ] Agree
- [ ] Very strongly agree

Q68 If this medical professional tells me something that is different from what I was told before, it is difficult for me to ask about it in order to get it straightened out

- [ ] Very strongly disagree
- [ ] Disagree
- [ ] Somewhat disagree
- [ ] Neither agree nor disagree
- [ ] Somewhat agree
- [ ] Agree
- [ ] Very strongly agree

Q69 This medical professional is warm and caring toward me

- [ ] Very strongly disagree
- [ ] Disagree
- [ ] Somewhat disagree
- [ ] Neither agree nor disagree
- [ ] Somewhat agree
- [ ] Agree
Q70 If I do not understand something this medical professional says, I have difficulty asking for more information

- Very strongly disagree
- Disagree
- Somewhat disagree
- Neither agree nor disagree
- Somewhat agree
- Agree
- Very strongly agree

Q71 The medical professional told me what he/she hopes the treatment will do for my family member

- Very strongly disagree
- Disagree
- Somewhat disagree
- Neither agree nor disagree
- Somewhat agree
- Agree
- Very strongly agree

Q72 The medical professional makes me feel comfortable about discussing personal or sensitive issues

- Very strongly disagree
- Disagree
- Somewhat disagree
- Neither agree nor disagree
- Somewhat agree
Q73 It is hard for me to tell the medical professional about my family member’s new symptoms

- Agree
- Very strongly agree

- Very strongly disagree
- Disagree
- Somewhat disagree
- Neither agree nor disagree
- Somewhat agree
- Agree
- Very strongly agree

Q74 It is hard for me to ask about how my family member’s treatment is going

- Very strongly disagree
- Disagree
- Somewhat disagree
- Neither agree nor disagree
- Somewhat agree
- Agree
- Very strongly agree

Q75 This medical professional really respects me

- Very strongly disagree
- Disagree
- Somewhat disagree
- Neither agree nor disagree
- Somewhat agree
- Agree
Q76 I understand pretty well the medical plan for helping my family member

- Very strongly agree
- Very strongly disagree
- Disagree
- Somewhat disagree
- Neither agree nor disagree
- Somewhat agree
- Agree
- Very strongly agree

Q77 After talking to this medical professional, I have a good idea of what changes to expect in my family member’s health over the next weeks and months

- Very strongly disagree
- Disagree
- Somewhat disagree
- Neither agree nor disagree
- Somewhat agree
- Agree
- Very strongly agree

Q78 When I talk to this medical professional, I sometimes end up feeling insulted

- Very strongly disagree
- Disagree
- Somewhat disagree
- Neither agree nor disagree
- Somewhat agree
- Agree
Q79 I have difficulty asking this medical professional questions

- Very strongly disagree
- Disagree
- Somewhat disagree
- Neither agree nor disagree
- Somewhat agree
- Agree
- Very strongly agree

Q80 My family member’s treatment procedure was clearly explained to me

- Very strongly disagree
- Disagree
- Somewhat disagree
- Neither agree nor disagree
- Somewhat agree
- Agree
- Very strongly agree

Q81 This medical professional does not seem interested in me as a person

- Very strongly disagree
- Disagree
- Somewhat disagree
- Neither agree nor disagree
- Somewhat agree
- Agree
- Very strongly agree
INTRO SDS You are doing great! This is the last group of questions. Listed below are a number of statements concerning personal attitudes and traits. Read each item and decide how it pertains to you. Please respond True or False to each item.

Q82 It is sometimes hard for me to go on with my work if I am not encouraged.
   ○ True
   ○ False

Q83 I sometimes feel resentful when I don’t get my way.
   ○ True
   ○ False

Q84 On a few occasions, I have given up doing something because I thought too little of my ability.
   ○ True
   ○ False

Q85 There have been times when I felt like rebelling against people in authority even though I knew they were right.
   ○ True
   ○ False

Q86 No matter who I am talking to, I’m always a good listener.
   ○ True
   ○ False

Q87 There have been occasions when I took advantage of someone.
   ○ True
   ○ False

Q88 I’m always willing to admit it when I make a mistake.
   ○ True
   ○ False

Q89 I sometimes try to get even rather than forgive and forget.
   ○ True
Q90 I am always courteous, even to people who are disagreeable.
    ○ True
    ○ False

Q91 I have never been irked when people expressed ideas very different from my own.
    ○ True
    ○ False

Q92 There have been times when I was quite jealous of the good fortune of others.
    ○ True
    ○ False

Q93 I am sometimes irritated by people who ask favors of me.
    ○ True
    ○ False

Q94 I have never deliberately said something that hurt someone’s feelings.
    ○ True
    ○ False

DRAWING Q Would you like to enter an optional drawing for a tablet?
    ○ Yes  [Skip to DRAWING]
    ○ No   [Skip to End of Survey]

DRAWING Please complete your Email for notification of drawing and name and mailing address for mailing purposes only. Survey responses will remain anonymous.
    ○ Email______________________________________________
    ○ Name____________________________________________
    ○ Address___________________________________________
    ○ Address 2 _________________________________________
Circle the appropriate box:

- City ____________________________
- State __________________________
- Postal code ______________________
Appendix B

Participant Responses

Participants accessed survey  
(n = 290)

Did not move on  
(n = 6)

Participants completed consent = YES  
(n = 282)

Participants completed consent = NO  
(n = 2)

Participants met criteria as FCG end-stage HF = YES  
(n = 198)

Did not move on  
(n = 34)

Did not meet criteria  
(n = 50)

Participants proceeded with online option  
(n = 186)

Indicated paper survey  
(n = 11)

Did not provide address  
(n = 10)

Mailed with no return  
(n = 1)

Participants proceeded with survey / partial  
(n = 167)

Did not move on  
(n = 19)

Did not complete entire survey / skipped questions (allowed)  
(n = 40)

Completed survey through end  
(n = 127)

Final  
(n = 127)
Biographical Sketch of Author

Lisa A. Cross

EDUCATION

1993  Bachelor of Arts, Political Science, Northeastern University, Boston

1996  RN Diploma, Lawrence Memorial Hospital School of Nursing, Medford

2014  Master of Science Nursing, Education focus, Salem State University, Salem

2017 – current  Candidate, Doctor of Philosophy Nursing, Health Promotion focus, University of Massachusetts Lowell, Lowell

PROFESSIONAL EXPERIENCE

2021 – current  Part-Time Visiting Lecturer, Salem State University, Salem

2017 – current  Part-Time Clinical Instructor, North Shore Community College, Danvers

2020 – 2021  Virtual Clinical Instructor, University of Massachusetts Lowell, Lowell

2019 – 2020  Adjunct Clinical Instructor, University of Massachusetts Lowell, Lowell

2019 – 2020  Per Diem Clinical Liaison, Beth Israel Lahey Health at Home, Woburn

2015 – 2017  Quality Improvement Specialist, Hallmark Health VNA and Hospice, Malden

2013 – 2015  Information Systems Support Clinician/Weekend Scheduler/Hospice Nurse/Team Support, VNA Middlesex East Visiting Nurse Hospice, Wakefield

2012 – 2013  Hospice Nurse/Weekend Scheduler/Weekend On-Call Supervisor, VNA Middlesex East Visiting Nurse Hospice, Wakefield

2011 – 2012  Registered Nurse, On-Call Evening Supervisor, VNA Middlesex East Visiting Nurse Hospice, Wakefield
GRADUATE RESEARCH

PUBLICATIONS


