STRAIN, SATISFACTION, AND HOSPITALIZATION IN CAREGIVER/VETERAN WITH HEART FAILURE DYADS: A SECONDARY ANALYSIS

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by

JANET M DELGADO

Dissertation Co-Supervisors:

Dr. Bonnie J. Wakefield and Deirdre D. Wipke-Tevis

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The undersigned, appointed by the dean of the Graduate School, have examined the [dissertation] entitled

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presented by Janet M. Delgado

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and hereby certify that, in their opinion, it is worthy of acceptance.

Deidre D. Wipke-Tevis, Associate Professor

Bonnie J. Wakefield, Adjunct Associate Professor

Maithe Enriquez, Adjunct Professor

David Mehr, Professor Emeritus

Todd Ruppar, Professor

DEDICATION

I dedicate this work to Father in Heaven, Almighty God, who guides and shows me the way. He has broken down barriers for me to simply walk through in completing this work, not with ease, but with gratitude and grace.

I am grateful to my husband, Charles M. DeGeneres and my son, Christopher C DeGeneres who provided encouragement and support during my doctoral studies. Chuck lived with endless nights of me with the light on studying, in an untidy home, and having me decline family and social activities to focus on schoolwork. He also helped me with the ups and down of my health challenges, serving as my much-needed caregiver.

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Janet M Delgado

Dissertation Co-supervisors: Bonnie J. Wakefield & Deidre D. Wipke-Tevis

Support provided by informal (unpaid) caregivers (CG) contributes to the overall health of Veterans living with heart failure. Using Kramer's model of the caregiving experience, this secondary analysis of 137 dyads examined the prevalence of strain and satisfaction in the CGs, the relationship between and Veteran characteristics and strain and satisfaction, and if CG strain and satisfaction were associated with Veteran self-reported hospitalizations. A total of 70.1% CGs were identified as having low strain, with an overall prevalence of CG strain of 88.3%. The prevalence for high CG satisfaction was 67.9%. The overall multiple regression model for CG strain was significant, $F(13, 119) = 12.48$, $p < .001$, $R^2 = .577$, with 57.7% of the variance explained by CG age, Veteran self-reported health, CG and Veteran depressive symptoms, CG coping strategies used, CG choice in taking on the CG role, CG sources of/uses unpaid and paid help as well as CG and Veteran perception of the Veteran needing assistance with activities of daily living and instrumental activities of daily living. The overall multiple regression model for CG satisfaction was significant, $F(4,128) = 9.70$, $p < .001$, $R^2 = .233$, with 23.3 % of the variance explained by CG perceived quality of the relationship, CG perceived social support, and CG choice in taking on the CG role. CG strain was positively related to Veteran self-reported hospitalizations in the past year ($r_{pbs} = .20$, $p = .022$); however, CG satisfaction was not ($r_{pbs} = .004$, $p = .960$). These findings have implications for caregiving research and clinical practice.

CHAPTER ONE:

INTRODUCTION

Cardiovascular diseases, consist of a variety of health conditions affecting the heart and the blood vessels. Conditions affecting the heart and blood vessels are responsible for 31% of all deaths worldwide and make up 1 in 3 deaths annually (Heron, 2019; Mendis et al., 2011; Virani et al., 2021). In the United States (U.S.), heart disease continues to be the leading cause of death at 23.1% of all total deaths (Kochanek et al., 2019). Heart failure, which is defined by Bozkurt and colleagues (2021) as "a clinical syndrome with current or prior symptoms and/or signs caused by a structural and/or functional cardiac abnormality and corroborated by *at least one* of the following: elevated natriuretic peptide levels and/or objective evidence of cardiogenic pulmonary or systemic congestion by diagnostic modalities…" (p.363), is a prevalent, progressive, and debilitating cardiovascular syndrome which primarily affects older adults. In 2017, there were over 6 million adults in the U.S. living with the challenges of heart failure, with 1 in 8 deaths associated with heart failure and more than 550,000 new cases reported yearly (Benjamin et al., 2019; Chaudhry, 2019; Virani et al., 2021). The increasing prevalence and debilitating nature of HEART FAILURE has a major effect on the heart failure patient living in the community, their family, as well as the U.S. healthcare budget (Heidenreich et al., 2013; Jones et al., 2019; Soundarraj et al., 2017; Ziaeian & Fonarow, 2016).

In the U.S., military Veterans (Veterans) are at a higher risk of heart disease, in general, and report higher rates (11.4%) of heart conditions as compared to the general population older than age 50 (8.3%) (Hinojosa, 2019a; 2019b). Additionally, almost 50% of Veterans report at least one heart condition as compared to non-Veterans studied (Hinojosa, 2019b; Piette et al., 2015a). Similarly, heart failure prevalence in Veterans is higher (5%) (Groeneveld et al., 2018)

compared to the general U.S. population (~2.4%) (Heidenreich et al., 2013; Tsao et al., 2022). Of note, Veterans with heart failure seeking care in Veterans Affairs Medical Centers (VAMC) are aging (mean age 72 years), live with multiple chronic comorbid conditions, including diabetes mellitus, hypertension, ischemic heart disease, pulmonary disease, kidney disease, and obesity; have higher 30-day hospital readmission rates, and experience impaired physical and psychological functioning (Early et al., 2022; Groeneveld et al., 2018; Nuti et al., 2016). The impaired physical functioning includes a decline in the ability to carry out personal Activities of Daily Living and Instrumental Activities of Daily Living (DeGeest et al., 2003). As such, Veterans and non-veterans with heart failure often have significant self-care management needs that require the assistance of informal (unpaid) CGs (AARP & NAC, 2020; Family Caregiver Alliance, 2016). Accordingly, studying the effects of informal caregiving in the U.S. Veteran has been identified as a healthcare national priority for nearly 20 years (Jha et al., 2003).

Informal Caregiving for Patients with Heart Failure

Informal caregiving provided by family members aids individuals with chronic conditions, such as heart failure, to meet their basic daily, social, and medical needs (Berry et al., 2017). The informal caregiver (CG) is instrumental at assisting the patient with heart failure to successfully live in the community rather than becoming a resident in an assisted living or long-term care facility. The management of symptoms and daily activities to maintain patients with heart failure in the community is associated with decreased hospital readmissions and improved clinical outcomes (Ziaeian & Fonarow, 2016). The strategies used to reduce hospital readmissions of patients with heart failure include medical management, early reassessment, health literacy, cognition, financial, and functional status. The functional status of the patient

with heart failure improves with the use, improvement and partnering with available community resources including those available to the patient and the informal CG (Molloy et al., 2008).

The informal CG's own personal health and appraisal of their caregiving abilities helps them to be successful in their role and serve as an advocate for the patient with heart failure (Burke et al., 2014; Reinhard et al., 2019). Caregivers for patients with heart failure have a wide range of needs varying and depending on the progression of the disease status of the patient with heart failure; this perception by the CG regarding the patient with heart failure includes that the healthcare needs are not being adequately addressed by healthcare providers (Dionne-Odom et al., 2017). For example, the needs of the CGs assisting patients with heart failure, which may include the intergenerational CG, have been identified as resources, roles, relationships, responsibilities, personal benefits, and challenges (Alonso et al., 2018). Recent research examining the informal CGs of stroke survivors and patients with heart failure has demonstrated that failure to meet the needs of the CG may lead to poor health as well as detrimental physical and mental effects on the CG (Hodson et al., 2019; Krieger et al., 2017).

The Caregiver and Patient with Heart Failure Dyad

Adaptation to the CG role is affected by perceptions of the informal CG while providing care to patients with heart failure, including their perceptions of burden, perceived control over managing heart problems, perceived difficulty with tasks, perceived mental health, and psychological distress (Bakas et al., 2006; Garlo et al., 2010). A more comprehensive approach to optimize and evaluate care is to examine characteristics and outcomes of the CG and patient dyad. In a meta-analysis of the well-being of CGs and resultant heart failure patients' outcomes, Bidwell, and colleagues (2017) identified that even though the CG and patient dyad is transactional and bidirectional in influence; historically, the most studied is the effect of

caregiving on the patient's physical and mental health (Bidwell, Lyons, et al., 2017). Even though higher levels of CG strain were associated with worsening Veteran symptoms and quality of life measures, the authors found it challenging to evaluate the relationship between the CG's well-being and patient outcomes (Bidwell, Vellone, et al., 2017). The challenges in evaluating the CG and patient dyad outcomes are logically explained as the original research studies did not focus on the dyad, but rather on the individual CG or on the patient living with heart failure (Bidwell, Vellone, et al., 2017).

Regardless of the chronic condition studied, recognizing that the CG/patient dyad is an interactive relationship that may lead to either positive and/or adverse health outcomes is likely to improve overall outcomes (Berry et al., 2017). Considering the CG/patient dyad as interconnected components of heart failure care is likely to lead to identification of unmet needs, or even predictable beneficial or adverse outcomes, for both members of the dyad (Hooker et al., 2015). Therefore, heart failure disease-state variables, physical and mental health outcomes, and the transactional nature of the relationship of the CG/patient dyad are all worthy of study in order to improve heart failure care.

Caregiver Strain and Satisfaction in the Caregiver and Veteran Dyads

Community-based care of chronically ill patients, particularly care of the Veteran with heart failure is now provided by families and other informal CGs (Wakefield et al., 2012; Wakefield & Vaughan-Sarrazin, 2017). Two previous studies by Wakefield and colleagues (2012; 2107), which provided the datasets for this secondary data analysis dissertation, have examined CG strain and CG satisfaction in Veteran and their CGs living with chronic illnesses. The first study by Wakefield and colleagues (2012) examined CG strain and satisfaction in a sample of Veteran with a variety of chronic illnesses (diabetes, heart failure, hypertension,

depression, and chronic obstructive pulmonary disease) and their CGs enrolled in a Veterans Health Administration telehealth program. In a subsequent study by Wakefield and Vaughn-Sarrazin (2017), CG strain and CG satisfaction were evaluated in a sample of Veteran with either heart failure or diabetes mellitus and their CGs, of which some were enrolled in a Veterans Health Administration telehealth program and others were not. In both studies, higher levels of CG strain were associated with CG use of professional counseling or prayer as coping strategies, greater self-reported dependency of the Veteran in Instrumental Activities of Daily Living, greater levels of CG depressive symptoms, and receiving less unpaid assistance from family and friends in the last 12 months. Additionally, both studies found that higher levels of social support were predictors of CG satisfaction. In contrast, although Wakefield and Vaughn-Sarrazin (2017) found no Veteran characteristics were associated with the development of CG satisfaction, Wakefield and colleagues (2012) study found both the CG taking medication as a coping strategy and the CG assisting the Veteran with equipment for Activities of Daily Living and Instrumental Activities of Daily Living were associated with higher CG satisfaction.

Collectively, these studies suggest that caregiving of Veterans with heart failure is multifaceted and contributes to negative and positive outcomes for both the Veterans and their caregivers. Although some of the findings are consistent between the two studies, other findings were contradictory. Given that both studies had samples of Veterans with heterogenous chronic illnesses (e.g., diabetes, heart failure, hypertension, depression, and chronic obstructive pulmonary disease); it is unknown if there are specific characteristics that may be uniquely independently associated with CG strain and GG satisfaction when caring for Veterans with heart failure. Additionally, the relationship between CG strain and Veteran hospitalization has not been explored in a homogenous sample of dyads.

Nurse researchers need to identify which characteristics of the dyad are associated with the development of CG strain and CG satisfaction in providing care to Veterans living with heart failure. When we are armed with the information about the characteristics that best predict CG strain and CG satisfaction, we can develop and test interventions to minimize CG strain and maximize CG satisfaction. The informal CG often identifies their confidence or success in caregiving by the health and need for medical intervention for the Veteran to occur less often (Bidwell et al., 2020; Bidwell, Vellone, et al., 2017; Evangelista et al., 2016). Given the high healthcare costs associated with heart failure hospitalizations, it is essential to understand the relationship between CG strain, CG satisfaction, and hospitalization of the community-based Veteran living with heart failure. Information regarding these dyadic relationships and outcomes will contribute to learning more about the interactive processes of the dyad. Identifying the relationships between and amongst these CG and Veteran variables will assist future researchers to focus on developing and testing interventions to improve the interactions within the dyad, mental and physical health, and potentially decrease healthcare costs. The dissertation purpose and research questions follow below.

Purpose and Research Questions

Thus, the purpose of this study was to examine the relationship between the characteristics and caregiving outcomes in caregiving dyads of Veterans with heart failure. We addressed three research questions.

Research Questions

1. What is the prevalence of strain and satisfaction in CGs of Veterans with heart failure?
2. Among Veterans with heart failure, what is the relationship between CG characteristics, Veteran characteristics, CG strain and CG satisfaction?
3. Are strain and satisfaction in CGs of Veterans independently associated with self-reported VAMC hospitalizations from all causes?

Conceptual Framework

This study was completed by analyzing an existing deidentified dataset collected by principal investigators who evaluated Veterans and CGs in previous diabetes and chronic illness research (Wakefield et al., 2012; Wakefield & Vaughan-Sarrazin, 2017). The conceptual model guiding the primary research and this secondary analysis was adapted from Kramer's model of the caregiving experience (Kramer, 1997; Wakefield et al., 2012). Kramer's model of the caregiving experience continues to be useful and adapted by other researchers such as Broese van Groenou et al. (2013) and Kyei-Arthur et al. (2022) to examine the detrimental and beneficial aspects of CG appraisal as partial outcomes of CGs and CG/patient dyads in various chronic illnesses. For example, other researchers have examined those providing care to patients with dementia, palliative care, cancer, eating disorders, and the elderly needing care in resource-limited urban settings (Hauser & Kramer, 2004; Hovland & Kramer, 2019; Kyei-Arthur et al., 2022; Li & Loke, 2013; Padierna et al., 2013).

Wakefield and colleagues (2012) adapted Kramer's (1997) model of caregiving adaptation experience (Figure 1.1) in order to delve deeper and evaluate the characteristic traits

affecting CG and the care receiver (CR) with heart failure. The Wakefield and colleague's (2012) adaptation of Kramer's conceptual model allows for objective testing of components/outcomes of CG appraisal and the outcomes health and well-being for both the CG and the CR. Taking the model a step further, the unit of study used in this dissertation to evaluate the caregiving experience is the dyads; dyads consisting of a Veteran with heart failure and their CG, hereafter referred to as dyads. The instruments used for the primary data collection and previous studies were developed and selected based on Wakefield and colleague's adaptation conceptual model (Wakefield et al., 2012; Wakefield & Vaughan-Sarrazin, 2017). The caregiving context, the resources available to the dyad, the CGs appraisal of caregiving, and the health and well-being of the dyad all contribute to the measurable outcomes of the caregiving experience. The unique characteristics of the CG and Veteran's demographic variables and health status as well as the challenges the CG needs to manage, all play a pivotal role in the care provided. Strain and satisfaction, initially described as strain and gain by (Kramer, 1997), are opposite poles of the caregiving appraisal continuum. The CG appraisal of strain and satisfaction are determined by multiple factors, which include: the type of relationship between the Veteran and CG, the quality of the relationship, the duration and severity of illness, as well as the type and severity of Veteran symptoms to be managed (Wakefield et. al., 2012).

Resources available offer key insights into the variation in strain experienced by the CG. The resources available to the CG may include expected support from the health care system as well as individual resources, which may be internal (coping, knowledge of resources, caregiving skills and self-efficacy) or external in nature. The external resources may include use of additional help and social support systems available to the CG. The CG can appraise their experience on a continuum by evaluating their level of strain and satisfaction. The health and

well-being of both the Veteran and CG is affected by the overall caregiving process and experience.

Significance of the Study to Nursing and Health Care Innovation

The unique experience of the dyads living with heart failure is the focus of this study. The appraisal of the CG experience is important to the outcomes experienced by the Veteran with heart failure, but it is also of value to the informal CG (Kramer, 1997). Noting the prevalence of CG strain and CG satisfaction in this sample of CGs for Veterans with heart failure will help identify the positive and negative aspects of the CG appraisal process versus examining a group of dyads where the Veteran has a non-specified chronic illness. With this additional knowledge, training, support, and resources can be additionally tested and provided to the CG to support them in the role of providing care for the Veteran living with heart failure.

Identifying what variables and to what degree they contribute to CG strain and satisfaction while caring for a Veteran with heart failure is a great contribution to nursing science. If in nursing science, we can identify key or predictor variables, we can, through testing and training provide a precision health (other than genetics) to informal CGs and Veterans living with heart failure. As heart failure has a notable impact on the patient living with heart failure as well as on the CG of the heart failure dyad, examining the heart failure dyad specifically in this secondary analysis, will provide nurse researchers with additional information regarding the CG experience in Veteran dyads who live with heart failure.

(Wakefield et al., 2012; Wakefield & Vaughan-Sarrazin, 2017). The results yielded in this research may be used in clinical practice as well as in planning testable interventions. Expanding the knowledge base that would assist CGs and the Veterans affected with heart failure

places the nurse researcher in a unique position to collaborate with other members of the Veterans Health Administration healthcare team (Wyse et al., 2020).

Definitions of Key Variables

The following definitions provided uniformity and understanding of terms employed throughout the dissertation study.

Activities of Daily Living (ADL): The Activities of Daily Living refer to activities central to caring for oneself and living socially. They enable basic survival and wellbeing, such as getting in and out of beds and chairs, dressing, toileting, bathing, and feeding (AARP & NAC, 2020; Pashmdarfard & Azad, 2020).

Caregiver: According to the AARP and NAC (2020), "Caregivers provide care to people who need some degree of ongoing assistance with everyday tasks on a regular or daily basis" (p.5). The individuals who are assisted may have a chronic illness or debilitating condition (AARP & NAC, 2020).

Caregiver and Veteran Characteristics: In this study, CG and Veteran characteristics include demographic information, health status and depression, caregiving context, and resources (Kramer, 1997; Wakefield et al., 2012).

Caregiver Appraisal: In this study, CG appraisal refers to the process by which a CG estimates the amount or significance of caregiving (Hunt, 2003).

Caregiver Strain: In this study, CG strain is defined as the threats and trials in everyday lives that affect the emotional well-being of CG s (Pearlin et al., 1990; Pearlin & Schooler, 1978; Robinson, 1983).

Caregiver Satisfaction: In this study, CG satisfaction is gain or perceived positive aspects of caregiving (Hunt, 2003; López et al., 2005; Shirai et al., 2009).

Caregiving Context: In this study, caregiving context includes CG-Veteran relationship, living arrangement, CG-Veteran relationship quality, CG choice in taking on the CG role, hours of CG assistance/week and type of caregiving assistance provided such as Activities of Daily Living and Instrumental Activities of Daily Living (Kramer, 1997; Wakefield et al., 2012).

Depression: Depression is defined as a mood disorder characterized by lethargy, slow thinking, and a decreased interest in normal activities. In this study, we screened for the presence of depressive symptoms using the Geriatric Depression Scale -Short Form (Yesavage et al., 1982), Depression is often diagnosed late and overlaps with the symptoms of heart failure (Aloisi et al., 2019; Zhang et al., 2018).

Heart Failure: Tsao et al. (2022) define heart failure as "a chronic, progressive condition in which the heart muscle is unable to pump enough blood to meet the body's needs for blood and oxygen" (p. e547).

Informal Caregiver: An informal CG is a family member or friend providing care, usually focused on Activities and Instrumental Activities of Daily Living, and they are usually not paid for the services they provided (AARP & NAC, 2020).

Instrumental Activities of Daily Living (IADL): The Instrumental Activities of Daily Living support daily life in the home and community. The Instrumental Activities of Daily Living as noted by the Caregiving Alliance include transportation, grocery or other shopping, housework, preparing meals, managing finances, medication management, and arranging outside services (AARP & NAC, 2020; Pashmdarfard & Azad, 2020).

Prevalence: Prevalence is the percentage of a population that is affected with a particular characteristic or disease at a given time (Polit & Beck, 2020).

Resources: In this study, resources include CG skills and self-efficacy, coping strategies, social support, sources of/use of paid help, and sources of/use of unpaid help (Kramer, 1997; Wakefield et al., 2012).

Veteran: "A veteran *is* a person who served in the active military, naval, air, or **space** service and who was discharged or released under conditions other than dishonorable" (Cornell Law School., n.d.). In this study, a Veteran will refer to a person who receives their healthcare from a Veterans Administration Medical Center.

Veteran Resource Utilization: In this study, the Veteran's use of resources was defined as a self-reported Veteran hospitalization from all causes (B. Wakefield, personal communication. September 2021).

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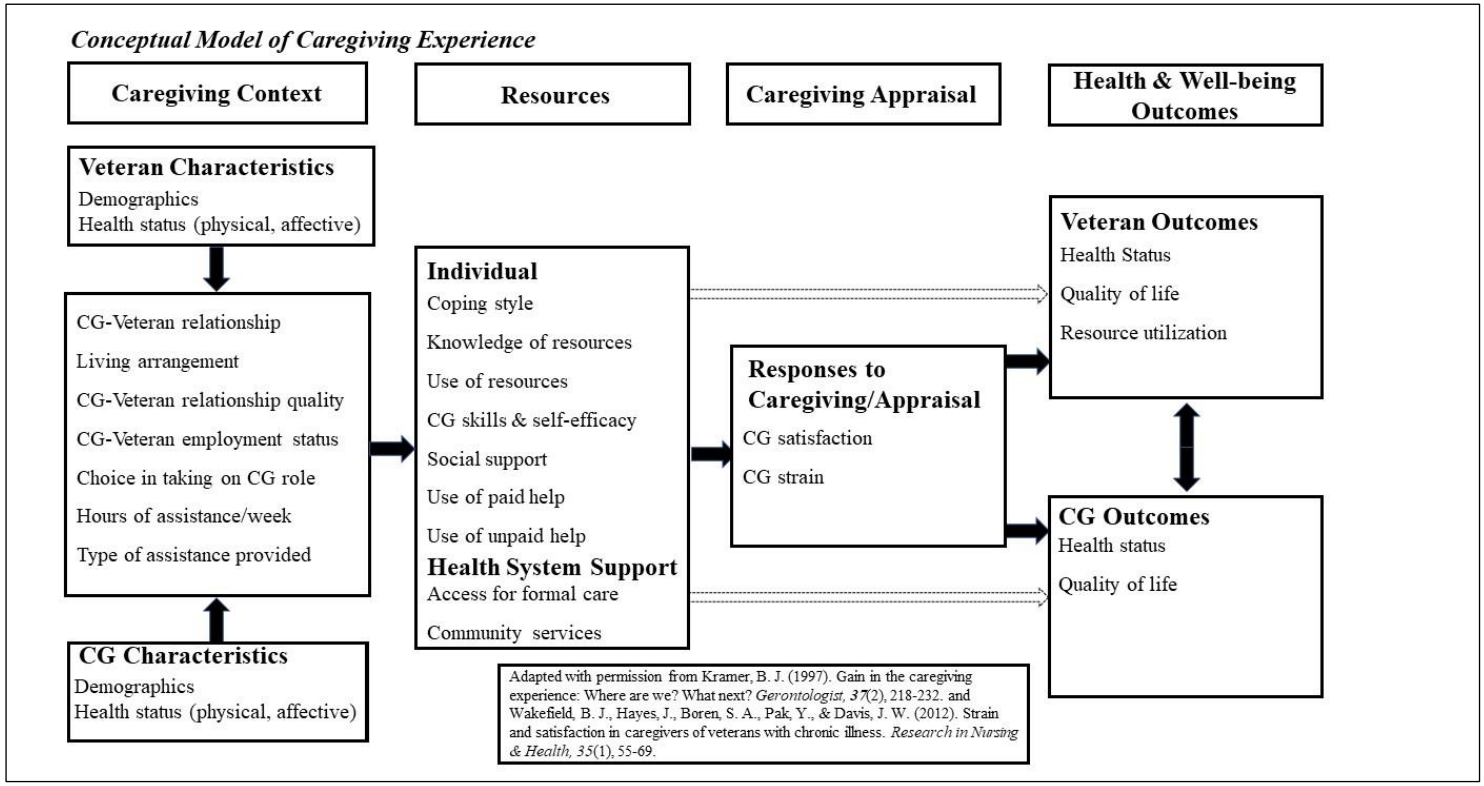
Figure 1. 1

Conceptual Model of the Caregiving Experience



CHAPTER TWO:

REVIEW OF LITERATURE

Informal Caregiving of Adults

In 2015, about 43.5 million informal CGs, friends or family members who provide care, reported providing from 19 to 41 hours a week of care for persons older than 50 years of age (Dunbar et al., 2018). The prevalence of informal CG is now approximately 53 million, caring for 38.9 million adults in the United States (U.S.) (AARP & NAC, 2020). The efforts of these informal CGs are instrumental in keeping the chronically ill person residing in the community (Utz et al., 2021). For example, research has examined informal caregiving in community-dwelling persons living with a variety of chronic illnesses such as cancer (Yang et al., 2019), mild cognitive dysfunction or Alzheimer's dementia (Hayashi et al., 2013; Kajiwara et al., 2018; Yu et al., 2015), heart failure (Dirikkan et al., 2018; Hooker et al., 2018; Lyons et al., 2021) and stroke (Berry et al., 2017; Krieger et al., 2017; Morelli et al., 2019). In addition to the data available for the U.S., there are approximately 6.5 million informal CGs in the United Kingdom, influencing the health and functioning of chronically ill persons and illustrating the effects of informal caregiving throughout the world (Egan et al., 2022). Each CG plays a significant role in society, as the CG supports the overall health and well-being of individuals who are acutely or chronically ill, mentally, or physically incapacitated, or even older persons who need ongoing support and assistance (Egan et al., 2022).

Financial Impact of Informal Caregiving

The informal CG provides direct care and assists with indirect care of the adult care recipient. The support the CG provides may include the management of medications, activity, nutrition, mental health, worsening cognitive impairment, social assistance, and physical health

(Dunbar et al., 2018). In 2013, the financial value of overall informal unpaid care in the U.S. was estimated to be $470 billion dollars per year, exceeding the value of total Medicaid spending and paid home care (*Caregiver Statistics: Demographics*, 2022). Not considering the financial impact of informal (unpaid) care of patients with heart failure, it is critical to note that almost 2% of the U.S. healthcare budget is spent on providing heart failure care, resulting in lifetime costs of over $126,000 per patient (Lesyuk et al., 2018). Therefore, the support provided by informal CGs not only supports the optimal health of the patient with heart failure, but also has the potential to decrease the financial burden on the overall healthcare system (Dunbar et al., 2018). The financial effects of caregiving on the person with chronic illness as well as the financial effects associated with the CG's health are both areas of great interest for organizations involved in the effectiveness of national healthcare such as American Association of Retired Persons (AARP), Veterans Health Administration and Medicare (Carey & Stefos, 2016; Dixon & Round, 2019; Shepherd-Banigan et al., 2020a; Urbich et al., 2020; Wyse et al., 2020).

Informal Caregivers and their Care Recipients

A profile of informal CGs and care recipients has been documented by the AARP and the National Alliance for Caregiving (NAC) since 1997 with periodic serial surveys which illustrate the evolving picture of the informal CGs and their care recipients in the U.S. (AARP & NAC, 2020). The most recent report found that informal CGs are providing care to about 41.8 million adults, of which 34% of the CGs are now baby boomers, born from 1946 to 1964 (AARP & NAC, 2020). That said, the demographics of informal CGs have not changed much over the years. Specifically, the typical informal CG is a 49-year-old, married (54%), white (61%), female (61%) that works more than 40 hours/week (60%) caring for one relative (76%). Also, the prevalence of caregiving to those older than 50 years of age has significantly increased from

14.3% in 2015 to 16.8% in 2020. Of note, 24% of those who self-identify as informal CGs provide care for two or more persons. In contrast, the demographic characteristics of the person receiving care has changed since 1997. The typical care recipient is a 70-year-old, member of the silent majority generation, white (61%), male (61%), and is cared for by a relative (89%) of which only 12% is a spouse (AARP & NAC, 2020).

Although informal CGs facilitate persons with chronic illnesses remaining in the community, the experience of providing care also impacts the informal CGs. Comprehensive CG assessment has been used to better understand the impact of caregiving on the informal CG. For example, 36% of CGs reported high emotional stress associated with caregiving, and more female CGs (39%) reported high levels of emotional stress than male CGs (33%) (AARP & NAC, 2020). Positive aspects of caregiving were reported as well. Indeed, 59% of CGs who perceived having a choice in taking on the CG role felt a sense of purpose when providing care whereas only 43% of CGs who perceived that they had no choice in taking on the CG role felt a sense of purpose. Additionally, 57-60% of CGs caring for more distant relatives reported a higher sense of purpose versus the 46-47% of CGs caring for a parent or spouse (AARP & NAC, 2020). These data suggest that it is essential to identify CG characteristics, needs and resources for varied conditions and circumstances to better provide the optimal caregiving experience for the informal CG.

Being knowledgeable regarding the needs of the CGs positions the professional nurse in a strategic position to partner with and provide support for the informal CGs as they carry out their tasks and daily routines of caregiving. Supporting and optimizing the role of the informal CGs requires systematic attention to the identification, assessment, and support of the CG throughout the care delivery process. Unfortunately, there is a dearth of tested and effective interventions to

support informal CGs caring for patients with heart failure in the literature (Dionne-Odom et al., 2017). Thus, researchers and clinicians need to develop tools, protocols, and practice interventions to effectively evaluate, create and expand the skills needed by informal CGs. Through the research process, we can identify and test the interventions needed for CG/patient dyads to incorporate into the daily care routines needed by the patient with heart failure and other chronic illness resulting in organ failure (Nakken et al., 2015).

Informal Caregiving and Heart Failure Self-Management

A well-known approach guiding the care of patients with heart failure and other chronic illnesses is that of self-care or self-management, promoting maximal patient independence in care (Riegel & Jaarsma, 2012). Garland et al. (2022) noted that self-care is also known as self-management, self-monitoring, self-maintenance, and self-help. This overlapping and at times puzzling terminology describes actions and processes that are affected by combining individual, relational, environmental, sociocultural, and economic factors to provide optimal care for patients with heart failure. Also, heart failure self-care ranges from independent self-directed care to directed care requiring maximal assistance. The role of the CG is known to influence self-care and researchers have begun to include the role of the informal CG in participating in heart failure self-care outcomes (Buck et al., 2015; Buck et al., 2018b). The contributions that the CG/patient with heart failure dyad provides to heart failure self-management are known to be crucial to successful self-care to the patient with heart failure (Riegel & Jaarsma, 2021). Although much of the focus of optimal heart failure care is now focused on dyads, including the contribution of the CG to the self-care or self-management concept is important and it is now recognized as a shared experience (Bidwell et al., 2015; Bidwell et al., 2017; Buck et al., 2015).

Caregiving in Heart Failure Dyads

A recent random effects meta-analysis examined the relationship between the well-being of informal CGs and clinical outcomes of patients with heart failure using correlations from observational studies published up through March 2015 (Bidwell et al., 2017). In this meta-analysis, CG well-being was measured as psychological distress and CG strain; heart failure clinical patient outcomes were measured as heart failure patient symptoms, quality of life and clinical event risks. A total of 15 studies met the inclusion criteria and were included in six separate meta-analyses to address the study aims; specifically, 1) CG strain and patient heart failure symptoms (n=601 dyads), 2) CG psychological distress and patient heart failure symptoms (n=752 dyads), 3) CG strain and patient quality of life (n=619 dyads), 4) CG psychological distress and patient quality of life (n=213 dyads), 5) CG strain and patient CER (n=295 dyads), and 6) CG psychological distress and patient clinical events (n=178 dyads). Two key findings were identified: a higher level of CG strain was associated with worse heart failure symptoms (Fisher $z = 0.22$, $p<.001$), and similarly, a higher level of CG strain was associated with worse quality of life in patients with heart failure (Fisher $z = -0.36$, $p<.001$) (Bidwell et al., 2017). No significant relationship was found between CG psychological distress and heart failure symptoms or quality of life. However, these reported findings must be considered with caution given that sample sizes examined for each analysis were small and there was considerable heterogeneity among the studies. Since only four studies examined CG strain and patient clinical outcomes (e.g., hospitalization, mortality, time to events) and only two studies examined CG psychological distress and patient clinical outcomes, a meta-analysis could not be performed for either aim. Nonetheless, based on their meta-analysis, Bidwell and colleagues (2017) conclude

that the CG/patient with heart failure dyads are interactional and in order to obtain optimal caregiving data requires that research be performed at the dyad level.

Three recent studies, published after Bidwell's meta-analysis, used qualitative or mixed method approaches to examine CG/patient with heart failure dyads; two explored dyadic heart failure self-care behavior including self-monitoring and symptom management (Buck et al., 2018a; Kim et al., 2020) while two addressed dyad emotions and mental health in heart failure (Kim et al., 2020; Lyons et al., 2021). Collectively, these studies provide additional insights about CG/patient with heart failure dyads. First, negative emotions and poor mental health (e.g., anger, anxiety, burden, depressive symptoms, fear, frustration, sadness) are common in one or both persons in the dyad (Kim et al., 2020; Lyons et al, 2021). Of note, younger dyads experienced more depressive symptoms than older dyads (Lyons et al, 2021). This difference in age-related CG outcomes supports findings observed in other heart failure studies (Alonso et al., 2018; Bakas et al., 2006). Second, most CG/patient dyads are collaborative or complementary in self-care and symptom management activities (Buck et al., 2018a). This beneficial dyadic teamwork mind set is influenced by the quality of the CG/patient relationship (Kim et al., 2020). Third, CG/patient dyads have established patterns for heart failure self-care at home (Buck et al., 2018a) and health beliefs of the CG/patient dyad help to shape these patterns (Kim et al., 2020). One problematic pattern that has been observed is the patient with heart failure intentionally concealing heart failure symptoms and the need for care from the CG (Lyons et al., 2021). Fourth, dyads with "adequate" scores in self-efficacy and self-management, tend to stay the course and often do not seek clinical provider help with exacerbation of the heart failure symptoms (Buck et al., 2018a). Concealment of heart failure symptoms or failure to seek help

during a heart failure exacerbation is a major health concern which may contribute to heart failure exacerbations that result in costly rehospitalization.

Informal Caregiving in Veterans with Heart Failure

A total of ten studies published since 2012 that specifically examined aspects of informal caregiving in dyads were identified for this focused review (Bouldin et al., 2019; Burke et al., 2016; Hooker et al., 2018, Lee et al., 2020; Piette et al., 2015a; Slightam et al., 2022; Trivedi et al., 2012; Trivedi et al., 2016; Trivedi et al., 2019; Wooldridge et al., 2019). The beginning timeframe was selected to coincide with the publication of the oldest primary research report upon which this secondary analysis was based (Wakefield et al., 2012). No ending date was selected for the search; however, the most recent relevant study included here was published in 2020. All articles were published in peer-reviewed journals.

A variety of study designs were utilized in the studies. Of the 10 studies reviewed, study designs included randomized comparative effectiveness (s=1), pilot/feasibility intervention (s=1), cross-sectional, comparative, or correlational survey (s=4), qualitative (s=3), and mixed methods (s=1). Five of the studies were primary research (Burke et al., 2016; Piette et al., 2015a; Trivedi et al., 2012; Trivedi et al., 2016; Trivedi et. al., 2019). and five studies were secondary analysis of previously collected data (Bouldin al., 2019; Hooker et al., 2018; Lee et al., 2020; Slightam et al., 2022; Wooldridge et al., 2019). Four of the secondary analyses were based on primary research studies examined for this review (Piette et al., 2015a; Piette et al., 2015b; Trivedi et al., 2016; Trivedi et al., 2019; Table 2.1).

The ten dyad studies in this focused literature review were evaluated using Kramer's conceptual model of the caregiving experience (Kramer, 1997). Kramer's model allows for the researcher to examine both the negative and positive appraisal of the caregiving experience.

Aspects of Kramer's model to which the articles were evaluated include CG and Veteran Characteristics, Caregiving Context, Resources, Caregiving appraisal, and Health and Well-being Outcomes. The articles are summarized in Table 2.1

CG and Veteran Characteristics

Except for two studies, participants consisted solely of dyads of informal CGs and Veterans with heart failure. One study included a mixed sample of Veteran and non-Veteran dyads (Hooker et al., 2019). Another study included heart failure clinicians along with the informal CGs/Veteran with heart failure (Trivedi et al., 2019). The sample sizes of the studies reviewed ranged from 22 to 748 participants. The mean age of the informal CGs ranged from 46 to 65 years (two studies did not report CG age) while the mean age of the Veteran/Patient with heart failure ranged from 66 to 69 (two studies did not report Veteran age). The typical informal CG in these studies primarily consisted of white, married females with about one-third of the CGs working outside the home, having completed a high school education. The typical Veteran/patient with heart failure in the dyad primarily consisted of white, married, males not working or retired, having completed some college education. All Veteran participants were recruited from VAMCs; non-Veteran patients in the Hooker et al. (2019) study were recruited from an academic health center. All studies occurred in the U. S. (Table 2.1).

Caregiving Context

In most studies, the usual dyadic relationship was spousal (60-100%); yet, whether the dyad members lived in the same household often was not explicitly discussed. However, in a sub-set of two studies, the researchers specifically recruited out-of-home CGs, and in these studies, the dyadic relationship was typically parent/adult child (Piette et al., 2015a; Bouldin et al., 2019). Only two studies measured hours of assistance provided with the typical CG hours of

assistance/week ranging from zero to greater than 13 hours per week (Lee et al., 2020; Piette et al., 2015a). CGs provided a variety of types of assistance such as preparing meals, household chores, accompanying to doctor visits as well as assistance with self-care support activities such as medication adherence (Piette et al., 2015a; Trivedi et al., 2012).

Of the 10 studies reviewed, seven addressed relationship quality, using both qualitative and quantitative methods (Bouldin et al., 2019; Burke et al. 2016; Hooker et al., 2018; Trivedi et al., 2012; Trivedi et al., 2016; Trivedi et al., 2019; Wooldridge et al., 2019). Various aspects of relationship quality have been examined including communal coping/dyadic coping, dyad communication/communication patterns, emotional closeness, mutuality, relationship characteristics, and relationship satisfaction. Quantitative tools utilized to measure relationship quality included the Dyadic Adjustment Scale, Mutuality Scale of the Family Caregiving Inventory, Mutuality Psychological Development Questionnaire, and study-specific rating scales or qualitative, semi-structured interviews based on the Dyadic Health Behavior Change Model.

Although the different aspects of relationship quality were evaluated using various approaches, these studies consistently suggest that quality of the dyadic relationship is an important aspect of the caregiving context and impacts caregiving appraisal as well as CG and Veteran/patient health and well-being outcomes. From a qualitative perspective, relationship stress within the dyad hinders heart failure self-management while a strong affectionate dyadic relationship provides an opportunity for better dyad communication and positively influences heart failure self-care as well as the experience of the illness for the dyad (Burke et al., 2016; Trivedi et al., 2019; Wooldridge et al., 2019). For example, Hooker and colleagues (2019) found that Veterans/patients with heart failure perceiving better mutuality reported more confidence in their self-care abilities and engaged in more self-management activities while CGs who reported

greater mutuality had less perceived CG burden, increased CG confidence, as well as increased confidence in providing the patient's heart failure care ($p<.05$). Accordingly, one single arm pilot intervention study specifically aimed to increase mutuality as a strategy to improve self-care (Trivedi et al., 2016). Collectively, these data demonstrate the key role that mutuality (dyadic relationship) has in the dyads, particularly as it relates to patient heart failure self-care and CG burden.

Resources

The resources examined in these studies addressed both the individual participant and/or the health care system. Examples of individual resources examined include knowledge and skills related to collaboration, heart failure self-care, medication adherence, shared illness appraisal, self-care confidence/self-efficacy, social support, stress management, and symptom management. Interestingly, having paid help was often used as an exclusion criterion for many of these studies. Health system support resources addressed included self-care support via phone calls and emails. One study specifically identified institutional barriers to caregiving resources such as fragmented care and CG exclusion from information related to change in health status (Trivedi et al., 2019). Examples of instruments utilized to measure these resources are Caregiver Contributions to Self-Care of Heart Failure Index, Multidimensional Scale of Perceived Social Support, the Norbeck Social Support Questionnaire, Self-Care of Heart Failure Index, the Self-management Scale, and study specific self-report questions or semi-structured qualitative interview guide questions.

Interventions in these studies were typically designed to enhance individual and/or health system resources and, ultimately, improve CG appraisal and/or health and well-being of both members of the dyad. For example, Piette et al. (2015a) examined the effects of an enhanced

mHealth intervention that included weekly email updates to the CG about Veterans status with suggestions for supporting Veteran self-care. Indeed, for CG with higher baseline strain and more depressive symptoms, the enhanced mHealth intervention significantly decreased CG strain and the number of depressive symptoms ($p<.05$). Additionally, for CG with low baseline self-care support, the enhanced mHealth intervention resulted in the CG spending significantly more time in self-care support for the Veteran ($p<.05$). Other interventions in these studies were designed to provide resources such as CG skills, symptom management skills, coping skills, communication skills, and/or relationship skills/mutuality (Burke et al., 2016; Trivedi et al., 2016).

Caregiving Appraisal

Of the 10 studies reviewed, seven evaluated the negative aspects of caregiving appraisal (Bouldin et al., 2019; Hooker et al., 2018; Lee et al., 2020; Piette et al., 2015; Trivedi et al., 2012, Trivedi et al., 2016; Wooldridge et al., 2019). Caregiving appraisal concepts evaluated in the studies were burden, strain, and stress. Caregiving appraisal was typically assessed with a multidimensional tool that measured intensity/severity of the concept. Specifically, CG burden was measured using one of two different tools: Zarit Burden Inventory-Short Form or the Caregiver Reaction Assessment. At times, CG burden was also measured using the Caregiver Strain Index and the Modified Caregiver Strain Index (Piette et al., 2015a; Lee et al., 2020). Caregiver strain was measured using one tool, the Caregiver Strain Index. In contrast, CG stress was evaluated qualitatively in one study (Wooldridge et al., 2019). CG satisfaction, the positive component of CG appraisal, was not measured in any of the 10 studies. Although the Caregiver Reaction Assessment instrument has one sub-scale that measures CG Esteem, to assess the value attributed to caregiving, CG Esteem findings were not reported in the studies using this tool.

CG and Veteran Health & Well-being Outcomes

Mental health was most common health and well-being outcome measured in both CGs and Veterans. In particular, depressive symptoms (60%), such as loneliness, sadness, and lack of sleep, were the most frequent aspect of mental health evaluated in these studies (Bouldin et al., 2019; Burke et al., 2016; Lee et al., 2020; Piette et al., 2015a; Trivedi et al., 2012; Trivedi et al., 2016). Instruments used to measure depressive symptoms included the Centers for Epidemiologic Studies Depression Scale (CES-D-10) and the Patient Health Questionnaire (PHQ-9). Although many of these studies had small dyadic samples sizes, findings from these studies suggest depression is common in dyads with heart failure regardless of their dyadic relationship and communication characteristics (Bouldin et al., 2019). Depressive symptoms appear to have adverse impacts on CG burden and Veteran relationship satisfaction (Trivedi et al., 2012). Consequently, intervention studies for heart failure dyads have aimed to improve depressive symptoms and some preliminary evidence exists to support intervention efficacy at decreasing depression in CGs (Piette et al., 2015a; Trivedi et al., 2016) but no change has been observed in the Veteran depressive symptoms (Trivedi et al., 2016).

In contrast, few studies have directly addressed physical health of CGs or Veterans. Indicators of physical health that were evaluated included co-morbid conditions, health complaints, and NYHA classification (Hooker et al., 2018; Lee et al., 2020; Slightham et al., 2020; Trivedi et al., 2018; Trivedi et al., 2019). For studies that did address CG physical health, the most common measure was mean number of comorbidities, and they were reported as a descriptive demographic of the sample rather than a health outcome. Generally speaking, CGs had fewer comorbidities than their Veteran with heart failure. Only the qualitative study by

Wooldridge and colleagues (2019) acknowledged that collaboration within the dyads requires managing the health of both members of the dyad.

The final health and well-being outcome evaluated in these studies was health-related quality of life, which encompasses both physical and mental health. Health related quality of life was only measured in one study (Trivedi et al., 2016). Both members of the dyad completed the multidimensional, Medical Outcomes Study Short Form-12 version 2.0 and Veterans also completed the Minnesota Living with Heart Failure Questionnaire. Interestingly, the small pilot intervention study that measured quality of life found a trend toward decreased quality of life in both CGs and Veterans (Trivedi et al., 2016).

Gaps in the Science

The literature reviewed in this chapter highlights the accomplishments that have been made in the caregiving research related to patients with heart failure, most specifically in the CG/Veteran dyads. Despite these achievements, there are several limitations to this body of work. The majority of the studies were small qualitative studies or secondary data analyses of previously published work. Indeed, since half of the studies were secondary analyses, it should be remembered that the same study participants appeared in two or more studies. More primary studies, in general, and more interventional studies, in particular, are needed to move the science forward. A variety of instruments have been used to measure CG concepts of interest which makes it more difficult to compare study findings. Moreover, a variety of terms have been used interchangeably to describe the negative aspects of CG appraisal –such as strain, stress, burden, and burnout (Irwin et al., 2018; Lee & Li, 2021; Rombough et al., 2006; Saleh et al., 2006; Swan et al., 2022; Wakefield et al., 2012). Clarity and consistency in the use of this terminology is necessary to help inform researchers and clinicians alike. The study samples are quite

homogenous with most Veterans being older white men and most CGs being older white women. The lack of sex/gender and racial/ethnic diversity in the samples limit the generalizability of the findings and prevents us from addressing existing health disparities of this vulnerable and growing population of CGs and Veterans.

Discussion

Collectively, the studies reviewed in this chapter demonstrate some of the key components in the body of research related to dyads. Accomplishments include revealing the intersectionality of the dyad which, depending on the relationship quality, can positively or negatively impact CG burden, CG strain, depressive symptoms, heart failure symptoms, quality of life, and self-care confidence as well as dyadic participation in self-care activities. Generally speaking, these studies have primarily focused on the psychosocial aspects of with heart failure dyads and their impact on heart failure self-care and mental health. While these are very important contributions, additional research is needed to address the impact of being part of a dyad on the CG and Veteran physical health outcomes and healthcare utilization. Moreover, few studies have evaluated the full spectrum of CG appraisal, from negative to positive aspects of the CG experience, as well as the quality of the relationship between members of the dyad. Reviewing all these aspects will promote successful development of the dyads.

Conclusion

Kramer's (1997) conceptual model of caregiving experience was a useful tool for examining the recent studies regarding dyads. The model helped to highlight that these studies have primarily focused on the caregiving context, resources, the negative appraisal of caregiving and mental health outcomes. Less attention has been given to addressing the positive aspects of caregiving, physical health outcomes, quality of life outcomes, and resource utilization

outcomes. This dissertation will help to address these knowledge gaps by providing dyad-specific evidence related to the comprehensive appraisal of caregiving, which is both the positive aspects of caregiving (CG satisfaction) and negative aspects of caregiving (CG strain) as well as examine their relationships with Veteran resource utilization (self-reported hospitalization in the last 12 months).

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Table 2.1

Focused Literature Review: Informal Caregiver / Veteran with Heart Failure Dyads

Author/Date/ Title	Purpose	Sample / Study Location	Design/Methodology	Key Findings	Study Limitations
Trivedi, Piette, Fihn, & Edelman (2012) Examining the Interrelatedness of Patient and Spousal Stress in Heart Failure Conceptual Model and Pilot Data	1) To present a conceptual model for HF self-management in which spousal CG & Veteran with HF impact one another 2) To examine the utility and validity of the proposed conceptual model among spousal CG & Veterans with HF dyads	Sample: n = 23 CG / Veteran with HF dyads -Spousal dyadic relationship (100%) -Typical CG: Age & Race not reported, Female (100%), Married (100%), Some college (35%), Chronic diseases (1.7) -Typical Veterans: 66 y/o, White (61%), Male (100%), Married (100%), Some college (30%), Chronic diseases (7.9) Study Location: North Carolina, U.S.	Design: Cross-sectional, correlational, observational, study Variables of Interest: -Dyads: --Depressive symptoms --Perceived social support --Relationship satisfaction --IADLs -Veteran: --Health Complaints --Medication adherence --HF self-care -CG: --CG burden	-Dyad Factors (p<.05): --CG burden + correlation with Veteran depressive symptoms --CG burden + correlation with Veteran's heart disease complaints --CG burden negatively correlated with Veteran's relationship satisfaction --CG depressive symptoms negatively correlated with Veteran's relationship satisfaction --CG burden negatively correlated with Veteran's social support	-Racial/ethnic breakdown of GG not provided - All CG female & all Veterans with HF male, which limits generalizability - Self-reported data may introduce recall bias -Only included in home, spousal CGs; applicability of model to out-of-home & non-spousal CGs unknown -Relevance of model may not be generalizable to non-Veterans and/or non-heterosexual couples -Given the small sample size, correlation coefficients may be unstable -The large number of correlational analyses with multiple comparisons

				--dyad's relationship satisfaction positively correlated --Dyad's assessment of Veteran's functional limitations positively correlated --Veteran's self-management confidence negatively correlated with CG depressive symptoms -- Veteran's self-management confidence negatively correlated with CG social support --Veteran's self-management maintenance negatively correlated with CG relationship satisfaction	increases the risk for Type I error
Piette, Striplin, Marinec, Chen & Aikens (2015a)	To determine if feedback to CG of Veterans with HF impacts	Sample: n= 369 CG (Out-of-Home CarePartners)/Veterans dyads with HF	Design: 2 Group Randomized comparative effectiveness trial over 12 months	For CG with ↑er baseline CG strain & > baseline depressive symptoms, the	-Racial/ethnic breakdown of GG not provided & demographics of dyad members not consistent

A randomized trial of mobile health support for heart failure patients and their informal caregivers: Impacts on caregiver-reported outcomes	caregiving burden & assistance with HF self-management	-Dyadic relationship mostly parent/adult child (daughter/ daughter-in-law [41.1%], son/son-in-law [19.7%]) -Typical CG: 47.1 y/o, Female (65.1%), Married (68.9%), ≤High School education (28.1%) -Typical Veteran: 67.9 y/o, White (77.2%), Male (99.2), Married/Partnered (58.9%), Education not reported Study Location: U.S. VA outpatient clinics, location unspecified	-Standard mHealth (control group): --weekly automated self-care support calls --clinicians notified re: problems –mHealth+CP (treatment group): --identical services as control group PLUS --weekly updates re Veterans status with suggestions for supporting self-care emailed to CarePartners Variables of Interest: -CG strain (burden) -CG depression -CG support for HF self-care	mHealth+CP intervention group had significantly decreased CG strain & significantly fewer CG depressive symptoms at both 6 & 12 months -For most CG with low baseline self-care support (median 1 hr/week), the mHealth+CP intervention group spent significantly more time in self-care support for the Veteran including more frequently attending MD visits & greater involvement in medication adherence at both 6 months & 12 months	-Most CG female & most Veterans with HF male, which limits generalizability -Only included out-of- home, non-spousal CGs; impact of intervention on in-home, spousal CGs unknown -CG were designated by researcher based on Veteran preference of 4 CG nominated & highest social support score. Once CG selection was made by researcher, Veteran may not choose to express concerns regarding choice, this may influence results -Self-reported data may introduce recall bias -Study purpose addresses CG burden but used Caregiver Strain Index instrument; burden & strain are different concepts

Trivedi, Slightam, Fan, Rosland, Nelson, Timko, Asch, Zeliadt, Heidenreich, Hebert & Piette (2016) A couples' based self-management program for heart failure: Results of a feasibility study	-Develop & pilot test the SUCCEED program, a program designed to improve CG / Veteran with HF dyad communication, & promote HF self-management	Sample: n = 17 CG / Veterans dyads with HF -Typical CG: 64 y/o, White (79%), Working (29%), Some college or degree (71%) -Typical Veteran: 68 y/o, White (79%) Working (21%), Some college or degree (71%) Study location: VAMC Palo Alto, CA USA, HF clinic	Design: Single arm pre-post pilot intervention Intervention: Six sessions delivered via telephone to dyad: <u>Session1</u>: skills to manage disease and CG burden <u>Sessions 2-3</u>: skills to manage negative emotions <u>Sessions 4-5</u>: skills to manage interpersonal relationship and relationship stress <u>Session 6</u>: Building a successful life with HF Variables of Interest: -<u>CG / Veteran Dyad</u>: --Dyadic coping/ Relationship quality --Dyad illness communication --Relationship mutuality -<u>CG</u>: --Burden & Self-esteem --Depression --Quality of Life -<u>Veteran</u>: --HF self-care (maintenance, management, confidence) --Depression --Quality of Life	-Both dyad members reported high feasibility & acceptability of the SUCCEED sessions given -Veteran outcomes after SUCCEED: --Trend toward ↑HF self-management --Trend toward ↑ communication --Trend toward ↑relationship quality --Trend toward ↓quality of life --No change in depressive symptoms -CG Outcomes after SUCCEED: --Trend toward ↓depressive symptoms --Trend toward ↓CG burden --Trend toward ↑mutuality --Trend toward ↓quality of life --Trend toward ↓communication --Trend toward ↓dyadic coping	-Sex/gender not reported for CG or Veteran -Homogenous sample with little racial/ethnic diversity -Acceptability/feasibility/ outcomes of intervention may not be generalizable to non-Veterans and/or non-heterosexual couples -Given the small sample size post-intervention change scores may not be reliable and correlation coefficients may be unstable -45 to 60 minute sessions via telephone is lengthy & may be burdensome to members of the dyad -Self-reported data may introduce recall bias

Burke, Johnson-Koenke, Nowels, Silveira, Jones, & Bekelman, (2016) Can we Engage Caregiver Spouses of Patients with Heart Failure with a Low-Intensity, Symptom-Guided Intervention?	To develop and pilot an intervention designed to engage CGs of Veterans in HF symptom management	Sample: (n =22), CG / Veteran with HF dyads -Spousal dyadic relationship (100%) -Typical CG (n=7): 65 y/o, White (57%), Female (100%), Not working/disability (57%), Completed some college (43%), Lived with Veteran (100%) -Typical Veteran (n=15): 69 y/o, White (80%), Male (93%), Completed some college (73%), HF duration (10.5 yrs.) Study location: VAMC -inpatient & outpatient settings, Colorado USA	Design: Emergent qualitative, descriptive evaluation guided by naturalistic inquiry & social constructivist epistemology Intervention: -Paper-based HF symptom management modules --Depression --Pain --Breathlessness --Fatigue -Semi-structured separate interviews of Veterans & CG incorporating utilization-focused evaluation principles -Mixed inductive & deductive team based thematic analysis of individual CG & Veteran interviews Variables of Interest: -Intervention acceptability -Intervention feasibility -Dyad's contextual nuances	-Recruitment was challenging Barriers to intervention use: -<u>Quality of dyadic relationship</u> --Opportunity for better communication --May ↑CG burden --CG may be overprotective -<u>Timing & structure of the intervention</u> --Difficult to recruit inpatients --Veterans preferred telephone & paper modules --CG preferred Internet & paper modules --Few read/used modules due to being busy, fatigued or readmitted to hospital -<u>Veteran's belief in ability to control HF</u> --Some had sense of control & knowledgeable about symptom management --Some had sense of control but needed more knowledge to better manage symptoms --Some felt symptoms out of their control	-8 of 15 CGs dropped out of study before being interviewed; thus only 7 actual dyads -Employment status of Veterans not reported -Most Veterans male; all CG were female plus limited Racial/ethnic diversity -All CGs were spouses; perspectives of non-spousal CGs remain unknown -Small pilot study -Only focused on barriers to intervention module usage; facilitators not examined

Hooker, Schmiege, Trivedi, Amoyal & Bekelman, 2018 Mutuality & Heart Failure Self-Care in Patients and their Informal Caregivers	To examine the relationships among mutuality, patient self-care confidence, self-care maintenance, CG confidence in patient self-care maintenance, & CG burden	Sample: n = 99 CG / Veteran & non-Veteran patient with HF dyads -Mixed sample of Veteran & non-Veteran patients with HF -Dyadic relationship mostly spousal (60%) -Typical CG: 57 y/o, White (70%), Female (81%), Married/ Significant Other (82%), Less than high school graduate (36%), Retired (32%) -Typical Patient: 66 y/o, White (73%), Male (79%), Married/ Significant Other (71%), Some college (41%), Retired (52%), Co-morbidities (4.4) Study Location: Participants from a VAMC & academic health center in Colorado USA	Design: Secondary data analysis; Cross-sectional, correlational survey design using path analysis Primary study was a multi-site RCT of a symptom management & psychosocial care intervention in persons with HF (Bekelman et al., 2016; 2018) Variables of Interest: -<u>Patient</u>: --Relationship mutuality --HF self-care (confidence, maintenance) -<u>CG</u>: --Relationship mutuality --CG contributions to HF self-care (confidence, maintenance) --CG burden -<u>Co-variates</u>: --Patient age --Patient gender --CG age --CG gender --Spousal vs non-spousal CG	-Proposed path analysis model actor effects (with a person) were significant --Patient mutuality positively correlated with confidence in self-care abilities ($p<.05$) --Patient confidence positively correlated with patient self-care maintenance ($p<.05$) --CG mutuality correlated with confidence in patient self-care ($p<.05$) -No path analysis partner effects (across the dyad) were significant -Regression analyses suggest CG with more mutuality have less perceived CG burden ($p<.05$)	-Limitations of secondary research -Since sample was mixture of Veteran/non-Veteran patients, unique aspects of mutuality & HF self-care in dyads is unknown -Most CG were female, most Veterans/patients were male, most CG were spouse/partner & limited racial/ethnic diversity which may limit generalizability -Cross-sectional design limits ability to determine temporal linkage between variables -Self-reported self-care behavior may introduce bias -CG that completed surveys at home may have discussed survey with patient -Insufficient power to examine differences between spousal & non-spousal CGs

Bouldin, Aikens, Piette & Trivedi (2019) Relationship and Communication Characteristics Associated with Agreement between Heart Failure Patients and Their CarePartners on Patient Depressive Symptoms	To identify groups of HF patients & their out-of-home informal CG (Care Partner) based on relationship & communication characteristics & compare how groups agree on patient's depressive symptoms	Sample: n=201 CG (Out-of-Home CarePartners)/ Veteran dyads with HF -Typical CG: 46 y/o, White (75%), Female (69%), Married (68%), More than High School education (75%), Working (66%), Depressive symptoms (51%) -Typical Veteran: 68 y/o, White (76%), Male (99%), Married (60%), High School or less education (50%), Working (14%), Depressive symptoms (12%) Study Location: Cleveland, Ohio, USA	Design: Secondary data analysis; Cross-sectional, comparative survey design using latent class analysis Primary study was a comparative effectiveness trial of a technology-based intervention for Veterans with HF (Piette et al., 2015a; Piette et al., 2015b) Variables of Interest: -Dyad depressive symptoms -Dyad agreement on Veteran depressive symptoms -Dyadic relationship characteristics -Dyad communication patterns -Dyad demographics -CG strain	4 dyad groups identified: -Collaborative Dyad (51%): Close relationship, visit in person frequently & talk about HF; 46% of Veterans had depressive symptoms -Avoidant Dyad (16%); Phone contact 2X/week; Visit in person less often & prefer not to discuss HF; 61% of Veterans had depressive symptoms -Distant Dyad (17%): Infrequent phone or in person contact & do not discuss HF often; 34% of Veterans had depressive symptoms -Antagonistic (15%): CG tended to be adult child; Frequent in person & phone contact; Discussing HF with each other is frustrating; 74% of Veterans had depressive symptoms -Depressive symptom agreement highest in the Distant dyad group (r =0.39) -CG strain highest in Antagonistic (26%) and Avoidant (30%) dyad groups	-Limitations of secondary research -Only dyads where the CG & Veteran rated the depressive symptoms of Veterans in primary studies were included in this study (n=168 were excluded) -Reason for lack of CG rating of depressive symptoms of the Veteran in primary studies may have influenced results - Dyadic relationship characteristics measure was not previously validated -Time frames on different variables not consistent (e.g., 4 weeks vs 3 months vs 6 months) -CG strain instrument used not described in article -CG strain scores of excluded CG may yield valuable information -Limited gender/sex & racial/ethnic diversity which may limit generalizability

Trivedi, Slightam, Nevedal, Guetterman, Fan, Nelson, Rosland, Heidenreich, Timko, Asch & Piette (2019) Comparing the barriers and facilitators of heart failure management as perceived by patients, caregivers, & clinical providers	1) To compare the barriers & facilitators of HF management as perceived by CG-Veteran dyads with HF and clinicians 2) To examine the degree of alignment of CG, Veterans, and providers perceptions of HF self-management	Sample: n = 17 Dyads with & 13 VAMC clinical providers for people with HF Typical CG: 64 y/o, White (65%), Female (100%), Married (89%) with 3 co-morbid conditions Typical Veteran: 68 y/o, White (65%), Male (100%), Married (89%) with 8 co-morbid conditions Clinical Providers: Physician (50%), Nurse practitioner (42%), nurse (8%), social worker (8%) Study Location: VAMC Palo Alto, CA USA, HF clinic	Design: Qualitative study with semi-structured interviews based upon the Dyadic Health Behavior Change Model 2-part dyadic interviews: -30- to 45-minute joint dyadic interview followed by -5-to-10-minute confidential interview with CG and Veteran separately -30-minute individual interview with each clinician -Data analyzed using latent thematic analysis informed by Dyadic Health Behavior Change Model Variables of Interest: -Barriers to HF self-management -Strategies to overcome barriers -Alignment of CG, Veteran, provider perceptions of HF self-management	<u>Three common themes identified by CG, Veterans & providers:</u> 1) Lack of knowledge is major barrier to HF self-management 2) Communication between HF dyad & clinician is essential to successful HF self-management, but barriers still exist 3) Strong dyad relationship & family social support improves HF self-management whiles stress hinders HF self-management CG specific barriers: Feeling disempowered when excluded from new health status information & decision-making Veteran specific barriers: Quality of relationship & communication with CG adversely impacted by stress & conflict Provider specific barriers: Institutional barriers such as lack of standardized protocols & information sheets & care fragmentation Dyad facilitators: -Stress-management & hobbies	-Unable to determine if clinician interviewed cared for dyads interviewed -3 of 17 dyads did not return demographic questionnaire -No demographics reported for the clinical providers -All Veterans male; all CG were female plus limited Racial/ethnic diversity -Single center study -45-to-60-minute session via telephone is lengthy and may be burdensome to members of the dyad -Positive aspects of CG appraisal was not described; only negative emotions were described

Wooldridge, Gray, Pukhraj, Geller & Trivedi (2019) Understanding communal coping among patients and informal caregivers with heart failure: A mixed methods secondary analysis of patient-caregiver dyads	-To examine illness appraisal by Veterans or non-Veterans with HF and their CGs -To explore how by Veterans or non-Veterans with HF and their CGs describe HF self-management collaboration -To explore how dyads describe HF self-management given their shared illness appraisal	Sample: n = 34 Veteran (n=17) or Non-Veteran (n=17) with HF and their CG Typical CG: 62 y/o. White (76%), Female (93%), Married/ Partnered (83%), Working, (32%), Education - some college (64%), Typical Veteran/Patient: 67 y/o, White (67%), Male (78%), Married/Partnered (73%), Working (15%) Education – some college (52%) Study Location: VAMC and academic HF clinic, USA	Design: Secondary data analysis; Mixed methods design Primary studies were two mixed methods studies that examined barriers of HF self-management & perception of CG role in HF (Trivedi et al., 2016) -Illness appraisal examined with Linguistic Inquiry Word Count text analysis program -Dyad self-management collaboration explored using thematic analyses -Shared illness appraisal & self-management collaboration concordance explored using thematic analyses Variables of Interest: <u>CG</u>: -Shared Illness (stressors) appraisal (I, we) -Collaboration -Communal coping <u>Veteran/Patient with HF</u>: -Shared Illness (stressors) appraisal (I, we) -Collaboration -Communal coping	Shared illness appraisal: --CG had higher average we- ratio than Veterans/patients ($p<.05$) Within-dyad concordance in we-ratio: --Both dyad members' we-ratios in upper 50% of sample: 29.6% --Both dyad members' we-ratios in lower 50% of sample: 33.3% -Three Emergent Themes related to Collaboration within Dyads: 1) Collaboration depends on specific HF self-management behavior --More collaboration with diet, medications & appointments; less with physical activity 2) Collaboration includes managing health of both members --Comorbidities, including mental health, require more collaboration 3) Collaboration depends on dyads' level of agreement that HF is a shared problem --Dyads concordant on high we-ratio highly collaborative --Dyads concordant on low we-ratios require more social support --Discordant dyads with CG high we-ratio & Veteran/patient low we-ratio had poor patient health & high CG stress	-Limited racial/ethnic diversity of sample -Limitations of secondary research -No citation for primary study conducted at academic HF clinic -Small sample size required analysis of concordance on we-ratio using median split rather than upper & lower quartiles -Most CG were female, most Veterans/patients were male, & most CG were spouse/partner -Interview guides for the primary studies were not identical -Measure of shared illness appraisal not able to consider the context in which (singular or plural) pronouns were used or the tone of voice the speaker used

Lee, Aikens, Janevic, Rosland & Piette (2020) Functional support and burden among out-of-home supporters of heart failure patients with and without depression	To compare out-of-home CG hours of weekly support in Veterans with HF with & without depression To examine whether Veteran's depression associated with CG strain (burden)	Sample: n= 348 (Out of Home - CarePartners) dyads -Typical CG: 47 y/o, White (79%), Non-Hispanic (99%), Female (64%), Married (70%), Some college education (73%), & Employed (63%) -Typical Veteran: 68 y/o, White (79%), Non-Hispanic (99%), Male (99%), Married (59%), Some college education (51%), Employed (12%), with comorbid CV diseases (76%), chronic pain conditions (50%), chronic lung diseases (42%), & gastrointestinal disease (49%) Study location: VAMC outpatient clinics, location unspecified	Design: Secondary data analysis; Cross-sectional, correlational survey design Primary study was a comparative effectiveness trial of a technology-based interventions for Veterans with HF (Piette et al., 2015a) Variables of Interest: -<u>CG</u>: --Hours of CG in-person support/week (social support) --Hours of CG telephone support/week (social support) --CG strain (burden) -<u>Veteran</u>: --Depressive symptoms -<u>Control Variables</u>: --CG emotional closeness to Veteran --CG geographic proximity to Veteran --Veteran comorbid conditions --Veteran living serial situation	-Controlling for confounding variables, CG provided 35% more hours of in-person support for Veterans with HF & depressive symptoms (p<.05) -Controlling for confounding variables, CG 42% more hours of telephone support for Veterans with HF & depressive symptoms (p<.05) -Veteran depression not associated with CG strain (burden) (p = .984) -In person support associated with higher CG strain (burden) (p <.05) -Telephone support hours not associated with CG strain (burden) (p=.34)	-Observational design prevents determining causation -Did not differentiate types of functional support provided by CG -Diagnosis of depression not verified by provider -Quality of telephone support not assessed - CG were designated by researcher based on Veteran preference of 4 CG nominated and highest social support score. -Most CG non-Hispanic, White, females & most Veterans non-Hispanic, White, males which limits generalizability -Only included out-of- home, non-spousal CGs, relevance to spousal CG unknown Title & abstract address CG burden but instrument used in study measures CG strain

Slightam, Risbud, Guetterman, Nevedal, Nelson, Piette & Trivedi (2020) Patient, caregiving partner, & clinician recommendations for improving heart failure care in the Veterans Health Administration	To understand & identify shared recommendations to improve HF self-care from the perspective of Veterans with HF, CGs, & clinicians	Sample: 16 CG / Veteran dyads with HF & 13 clinician providers for persons with HF Triad defined as CG, Veteran, and the clinician. Typical CG: White (79%), Female (100%), Married (89%) with 3 co-morbid conditions Typical Veteran: White (79%), Male (100%), Married (89%) with 5-year history of HF & 8 co-morbid conditions Clinical Providers: 54% male; Physician (50%), Nurse practitioner (42%), nurse (8%), social worker (8%) Study location: VAMC Palo Alto, CA USA, HF clinic	Design: Secondary data analysis; Qualitative research design Primary studies were designed to understand barriers & facilitators of HF self-care (Trivedi et al., 2016; Trivedi et al., 2019) Variables of Interest: -HF self-care strategies -Information, training, & skills for couples managing HF -Ways VHA can help dyads manage HF	Three themes identified: 1) Dyads & clinicians believe improvements needed to existing HF education, tailored to learning style & culture --Additional classes, additional teaching strategies, & additional referrals/resources needed 2) Dyads & clinicians believe technology can facilitate better HF self-care --Trainings needed on multiple technologies available for tracking self-care & communicating with providers 3) Dyads & clinicians believe that CG are part of self-care team & should be involved in care management to support Veteran with HF --Dyads & clinicians recognize importance of CG receiving support & respect --Dyads & clinicians recognize benefits of CG providing care to Veterans	-Dyads and clinicians were not matched -Sex/gender and racial/ethnic diversity of dyads limited in the 2 primary studies -Limitations associated with secondary research, specifically unable to collect additional data to support emerging themes -Limited by the scope of the original interview -Single center study -45-to-60-minute sessions via telephone is lengthy and may be burdensome to members of the dyad -Recommendations may not be relevant to non-integrated health systems

Note: CG – caregiver, HF – heart failure, VA – Veterans Affairs, VAMC – Veterans Administration Medical Center, VHA – Veterans Health Affairs, CCHT[a]: Care Coordination and Home Telehealth program, SUCCEED[b]: Self-management Using Couples' Coping EnhancEment in Diseases

CHAPTER THREE:

METHODOLOGY

Research Design

This study was a secondary analysis of quantitative data obtained from two previous cross-sectional survey research studies (Wakefield et al., 2012; Wakefield & Vaughan-Sarrazin, 2017) and employed a retrospective, descriptive, correlational design using a deidentified dataset. The deidentified dataset consisted of self-reported data from CG and Veterans with diagnosed heart failure and excluded participants with other diagnoses from the primary research (Wakefield et al., 2012; Wakefield & Vaughan-Sarrazin, 2017). Variables of interest for this secondary analysis research included in the deidentified data set to answer the research questions are described below.

Sample and Setting

The population of interest are Veterans with heart failure and their CGs. The sample consisted of English speaking, community-dwelling Veterans with a diagnosis of heart failure and their informal (unpaid) CG, over age 18, who had access to a working telephone and agreed to participate. In the two primary studies, data were collected from 364 Veterans and their informal CGs with a one-time cross-sectional survey (Wakefield et al., 2012; Wakefield & Vaughan-Sarrazin, 2017). Of the 364 dyads in the primary research studies, 137 Veterans were identified that had a diagnosis of heart failure. Thus, the final sample in the deidentified dataset for this secondary data analysis included 137 dyads associated with the Veterans Health Administration's Care Coordination/Home Telehealth program following Veterans with heart failure (Darkins et al., 2008). Sampling techniques and recruitment strategies have been previously published

(Wakefield et al., 2012; Wakefield & Vaughan-Sarrazin, 2018). In the two primary studies, the data were collected via telephone by trained research assistants from the community-dwelling dyads associated with outpatient VAMC facilities across 9 states in the Midwest.

Protection of Human Subjects

The two primary studies were approved by the University of Missouri Institutional Review Board (Wakefield et al., 2012), University of Iowa Institutional Review Board (Wakefield & Vaughan-Sarrazin, 2017) and local Veterans Affairs Medical Center (VAMC) Research & Development Committees at each site. The principal investigator of the two primary studies obtained permission from the Iowa City VAMC Healthcare System to use the previously collected data to examine the newly listed specific aims of this secondary research study. Because the current study used deidentified data, the Institutional Review Board of the University of Missouri deemed it exempt from review.

Instruments and Variables

The CG and the Veteran surveys for the two primary studies were based upon the Kramer Conceptual Model of Caregiving Experience (Kramer, 1997), which was described in Chapter 1 and portrayed visually in Figure 1.1. Variables included in the CG survey and the Veteran survey emanated from items published in the 2004 questionnaire from the *Caregiving in the U.S.* research study (National Alliance for Caregiving [NAC] & American Association of Retired Persons [AARP], 2004) as well as additional standardized instruments which are

summarized in Table 3.1. The CG survey, Veteran survey, and data dictionary utilized in the two primary studies can be found in Appendices A, B, and C.

The 2004 questionnaire from the *Caregiving in the U.S.* study was developed by research collaborators from the AARP, Belden Russonello & Stewart (a market research agency); NAC, and Research / Strategy / Management (NAC & AARP, 2004, p. 4). The 2004 questionnaire, available on the NAC website (https://www.caregiving.org/wp-content/uploads/2020/05/04questionnaire.pdf), contains 98 survey questions that cover a wide range of topics associated with the experience of caregiving. The eight domains of the 2004 questionnaire include: characteristics of the relationships, characteristics of the recipient (includes Activities of Daily Living and Instrumental Activities of Daily Living, medications, other CG support, stress on working CGs; physical, emotional, and financial stress of caregiving; information/services, and demographics. For the purposes of this secondary analysis, stress on working CGs; physical, emotional, and financial stress of caregiving data were not analyzed from the 2004 questionnaire (NAC & AARP 2004). No psychometric data are available for the overall 2004 questionnaire (NAC & AARP 2004; Wakefield et al., 2012; Wakefield & Vaughn-Sarrazin, 2017). Additional variables were evaluated using validated instruments described below and in Table 3.1.

Caregiver and Veteran Surveys

Within the caregiver and Veteran surveys (See Appendix A and Appendix B), items were organized according to Wakefield and colleague's (2012) adaptation of Kramer's (1997) Conceptual Model of Caregiving Experience using the following conceptual headings: Caregiving Context which included CG and Veteran Characteristics, Resources (Individual or Health Systems) available to the CG and

Veteran, Caregiving Appraisal consisting of CG strain and satisfaction, and CG and Veteran Health and Well-Being Outcomes (Wakefield et al., 2012). The CG and Veteran survey items are described in detail in the primary studies (Wakefield et al., 2012; Wakefield & Vaughn-Sarrazin, 2017) and summarized below by conceptual headings.

Caregiving Context Items

Caregiving context items were measured on both the CG and Veteran surveys using questions from the 2004 Caregiving in the U.S. questionnaire (AARP & NAC 2004). Both the CG and the Veteran provided information about the CG relationship to the Veteran (1 question), CG and Veteran living arrangement (1 question), perception of CG and Veteran relationship quality (1 question), and role demands/employment status (1 question). On the CG survey only, CG were asked about their choice (yes/no) in taking on the CG role (1 question), and perceived hours of assistance provided to the Veteran (1 question). The question about CG choice in taking on the CG role was coded as "yes" = 1 or "no" = 2. For this secondary analysis, the perceived hours of assistance provided to the Veteran and the role, and the role demands employment status were not analyzed.

CG and Veteran Characteristics Items

Demographics.

Both the CG and Veteran surveys used in the primary research included five demographic questions from the 2004 Caregiving in the U.S. questionnaire (NAC & AARP 2004). The Veteran survey included an additional question about their chronic disease. For the purposes of this study, only Veterans with a diagnosis of heart failure were included in the dataset.

General Self-Rated Health (GSRH).

Perception of General Health was evaluated on both the CG and Veteran surveys with a single-item, self-rated question. The General Self-RatedHealth Status was derived and tested from the 36-item Medical Outcomes Study Short form (SF-36) and asked, "In general would you say your health is: Excellent, Very Good, Good, Fair, Poor?" In a sample of 21,732 Veterans, the predictive validity and discriminatory ability of the General Self-Rated Health Status has been demonstrated as comparable to the SF - 36 physical component score and the Seattle index of Comorbidity in predicting mortality (Area Under the Curve [AUC] ,74), hospitalization (AUC .63) and high outpatient use (AUC .63) and high outpatient use (AUC .61) (deSalvo et al., 2005).

Geriatric Depression Scale – Short Form (GDS – SF)

The presence of depressive symptoms was measured using the 15 yes/no questions from the GDS-SF (Sheikh & Yesavage, 1986), developed from the original 30-item GDS (Yesavage et al., 1982), on both the CG and Veteran surveys. The GDS-SF screens for depressive mood symptoms in older adults, has been used both clinically and in research in a variety of patient populations and settings, and has established construct validity, sensitivity (81%-92%), specificity (75%-89%), internal consistency (Cronbach's alpha 0.74-0.94), and test-retest reliability (r = 0.84-0.85) (Koenig et al., 1988, Sheikh & Yesavage, 1986; Smarr & Keefer, 2011). One of the primary studies (Wakefield et al., 2012) reported Cronbach's alpha values of 0.82 (CGs) and 0.86 (Veterans) for the GDS-SF.

Types of Assistance.

Both the CG and Veteran surveys included questions from the 2004 Caregiving in the U.S. questionnaire (NAC & AARP 2004) about the perceived types of assistance the CG *provided to* the Veteran and the types of assistance the Veteran perceived they *needed from* the CG. The types of assistance were broken down into Activities of Daily Living, Instrumental Activities of Daily Living, assistance with medications, and other types of assistance.

Activities of Daily Living. The eight questions about Activities of Daily Living addressed the perception of assisting the Veteran with the following functions: bathing/showering, dressing, toileting, transfer in/out of bed/chair, incontinence/diapers, eating/feeding, walking, and taking medication. Each item was scored as 0 (none of the time, 1 (some of the time) or 2 (all of the time). All items were summed for a total score ranging from 0 to 16. One of the primary studies (Wakefield et al., 2012) reported a Cronbach's alpha for the ADL items (0.80 for CGs perception of assistance provided; 0.83 for Veteran perception of assistance received).

Instrumental Activities of Daily Living. The six questions about Instrumental Activities of Daily Living evaluated the perception of assisting the Veteran with the following activities: managing finances, grocery shopping, housework, meal preparation, arranging/supervising agency services, and transportation. Each Instrumental Activities of Daily Living item was scored on a 3-point scale ranging from none of the time (0) to all of the time (2) with all items

being summed for a total score ranging from 0 to 12. One of the primary studies (Wakefield et al., 2012) reported a Cronbach's alpha for the IADL items (0.71 for CGs perception of assistance provided; 0.71 for Veteran perception of assistance received).

Assistance with Medications. The original CG and Veteran surveys of the primary research had three questions that addressed assistance with medications: whether the Veteran took medications (yes/no), whether the *Veteran needed,* or CG *provided* assistance to take medications properly (need help/manages on their own), and if the CG or Veteran had enough information about the Veteran's medications (know enough/need to know more). The variables regarding medication assistance were not analyzed in this secondary analysis.

Other Types of Assistance. In the original CG and Veteran surveys used in the primary research, six questions addressed other types of medical assistance the CG provided, or the Veteran received: going with the Veteran to doctor appointments (yes/no), dressing/bandage changes (yes/no), helping with medical equipment (yes/no), helping with rehabilitation/exercise (yes/no), other types of medical support (yes/no). A narrative text box was provided to describe other types of medical support. None of the data on other types of medical assistance were analyzed in this secondary analysis**.**

Resources Items

Coping Strategies Score

Eight coping strategy questions were included on both the CG and Veteran surveys using questions from the 2004 Caregiving in the U.S. questionnaire (NAC & AARP 2004). The coping style questions addressed advice from family/friends (yes/no),

exercising (yes/no), taking medication to cope (yes/no), professional/spiritual counselling (yes/no), praying (yes/no), reading books about the Veteran's chronic illness (yes/no), using the Internet to find information (yes/no), and talking with a VAMC worker (such as a nurse, physician, social worker) (yes/no). The Coping Strategies Score, achieved by adding the total number of "yes" answers, ranged from 0 to 8 with higher scores indicating the use of a larger number of coping strategies (Wakefield & Vaughn-Sarrazin, 2017).

Caregiving Self-Efficacy/Confidence

The CG survey assessed perception of CG self-efficacy/confidence using one question from the 2004 Caregiving in the U.S. questionnaire (NAC & AARP 2004). The single self-report question was, ''How confident are you in your ability to provide assistance to [Veteran]?'' The item was scored using a 4-point scale ranging from Very confident (1) Not at all confident (4).

Other Support Received (paid/unpaid assistance)

The CG survey assessed other support the CG received using two questions from the 2004 Caregiving in the U.S. questionnaire (NAC & AARP 2004). Other CG support received was assessed by asking the CG if others provided unpaid assistance with caregiving in the last year (yes/no) and if others provided paid assistance in the last year (yes/no).

Social Support

The Personal Resource Questionnaire 2000 (PRQ2000), a multidimensional measure of perceived social support (Weinert, 2003), was included on the CG survey. An adaptation of earlier iterations of the instrument

(Brandt & Weinert, 1981; Weinert, 1987), each item on the 15-item PRQ2000 is rated using a Likert-type scale ranging from 1 (strongly agree) to 7 (strongly disagree). The total score ranges from 15 to 105 with lower scores indicating lower levels of social support. The PRQ2000 has been utilized in studies of individuals and families with chronic illness and has demonstrated construct divergent validity and internal consistency reliability (Cronbach's alpha of .0.87-0.93) (Weinert, 2003; Weinert et al., 2008). One of the primary studies (Wakefield et al., 2012) reported a Cronbach's alpha of 0.85 for the PRQ2000 in a sample of CGs of Veterans with various chronic illnesses.

Outcome Items

Caregiver Strain

Caregiver Strain Index (Robinson, 1983), a 13-item instrument measuring the CG's perspective of strain, was incorporated into the CG survey. The Caregiver Strain Index addresses five domains of CG strain, employment, financial, physical, social, and time, using "yes"/"no" type questions. All the "yes" answers are summed to achieve a total score. Scores of 7 or greater on the Caregiver Strain Index indicate high levels of strain. The Caregiver Strain Index has been used with CGs of patients experiencing hospitalization for recent hip surgery, heart disease, stroke, and recent survivors of critical illness and has established construct and convergent validity and internal consistency reliability (Cronbach's alpha .83-.86) (Kruithof et al., 2015; McPeake et al., 2016; Robinson, 1983). One of the primary studies (Wakefield et al., 2012) reported a Cronbach's alpha of 0.88 for the Caregiver Strain Index in a sample of CGs of Veterans with various chronic illnesses.

Caregiver Satisfaction

The CG survey measured caregiving satisfaction with the 11 original items from the Positive Aspects of Caregiving Scale (Tarlow et al., 2004). The Positive Aspects of Caregiving Scale was built on the previous work of Lawton and colleagues (1989; 1991) with the Caregiving Satisfaction Scale (a subscale of the Caregiver Appraisal Scale) that examined positive aspects of caregiving. Each of the 11 original items of the Positive Aspects of Caregiving Scale were scored on a 4-point Likert-type scale where 1 = strongly agree and 4 = strongly disagree. The total score is the sum of all items and ranges from 11 to 44, with lower scores indicating greater satisfaction with caregiving. For this analysis, this scale was reverse scored to make higher scores equal higher satisfaction. In the two primary studies of caregiving of Veterans with chronic illness, the reported internal consistency reliability of the original 11-item Positive Aspects of Caregiving Scale was $\alpha = .90$ (Wakefield et al., 2012) and $\alpha = .94$ (Wakefield & Vaughan-Sarrazin, 2017), respectively. In a secondary analysis examining caregiving of Veterans with diabetes, Wakefield and Vaughan-Sarrazin (2018) reported $\alpha = 0.94$ for the 11-item Positive Aspects of caregiving Scale used in the research. Tarlow and colleagues (2004) established construct validity, convergent validity, and discriminant validity as well as internal consistency reliability (Cronbach's alpha .89) of their final 9-item Positive Aspects of caregiving Scale in CGs of persons living with Alzheimer's Disease.

Veteran Resource Utilization

The Veteran survey measured Veteran resource utilization of healthcare based on one self-reported question about whether or not they had been admitter to a VAMC

hospital in the last 12 months. The Veteran's response was recorded as "yes" or "no" . "Yes" was coded as 1 and "no" was coded as 0.

Data Management

The deidentified data set for this secondary analysis was received from the principal investigator of the two primary studies as an Excel document which was originally shared in Box and later migrated to Microsoft OneDrive, a secure, password protected, cloud-based data management system available to faculty, students, and staff at the University of Missouri. In addition to the raw data, the CG and Veteran surveys used to interview the CG and Veteran participants, and the data dictionary used in the original studies research were provided to this investigator as well. Box and Microsoft OneDrive are safe and convenient replacement for departmental file servers, allowing for monitored access. Research data have fully maintained and backed-up storage, reducing the risk of catastrophic data loss and security breaches. Both Box and Microsoft OneDrive provide compliance with HIPAA, FINRA and FedRAMP and offers access permissions and advanced security capabilities like watermarking, data governance and device trust.

Data Collapsing and Coding

The deidentified data sets from both studies (Wakefield, et al., 2012; Wakefield & Vaughan-Sarrazin, 2017) were shared in an electronic format. To prepare the final combined dataset from the two primary studies for analysis required collapsing and recoding of categories for selected items with small numbers and/or zeros in cells. The following decision rules were made for re-coding of selected variables. Marital status categories were collapsed and coded as "married" = 1 or "not married" = 2. Level of education categories were collapsed and coded as "less than high school" = 1, "high

school graduate" = 2, "some college or college graduate" = 3, and "graduate school" = 4. The variable of race was collapsed into the categories of "white" = 1 and "non-white" = 2. The variable of employment was coded into the categories of "working full- or part-time" = 1, "retired" = 2, or "other" = 3. Self-rated health status was collapsed and dichotomized as "excellent/good" or "fair/poor" = 2. The relationship to the Veteran variable was recoded as "spouse" = 1 or "other" = 2. The lives together in the same household variable was dichotomized to "yes" = 1 or "no" = 2. The perceived quality of the dyadic relationship categories were collapsed and coded as "very good/good" = 1 or "fair/poor" =2. The variable addressing caregiving self-efficacy (confidence) was recategorized as "very confident" = 1 or "not confident" = 2. With regard to paid and unpaid sources of CG help, both variables were dichotomized to has sources/used paid help "yes" = 1 and "no" = 2 and has sources/used unpaid help "yes" = 1 and "no" = 2.

Data Analysis

The deidentified data set was imported and programmed into the Statistical Package for the Social Sciences (*IBM SPSS Statistics for Windows*, Version 27.0) for analysis. The following research questions were analyzed by implementing the SPSS analytical features of descriptive statistics, bivariate correlations, and stepwise multiple linear regression for model prediction.

Research Question 1: What is the prevalence of strain and satisfaction in CGs of Veterans with heart failure?

The prevalence of CG strain and CG satisfaction were reported as point prevalence (Tenny, 2021). The point prevalence of this cross-sectional study was

calculated based on the responses provided at the specific time of the telephone interview with the CG as there was only a one-time measure. For a representative sample at a specific time, period prevalence is the number of people in the sample with the characteristic of interest, divided by the total number of people in the sample.

$$\text{Period Prevalence} = \frac{\text{Number of people in sample with characteristic}}{\text{Total number of people in sample}}$$

The individual values of strain and satisfaction were reported as overall scores of 0-13 and 4-34, respectively. Scores of 7 or greater in the Caregiver Strain Index indicate high levels of strain, as lower score reflect less strain. The satisfaction score demonstrates higher satisfaction with a higher reported number. These measures of CG appraisal were reported with descriptive statistics, including the means and standard deviations.

Research Question 2: Among Veterans with heart failure what is the relationship between CG characteristics, Veteran characteristics, CG strain and CG satisfaction?

The associations were examined by examining bivariate correlations (Akoglu, 2018). A correlation quantifies the strength of the linear relationship between paired variables, expressing this association as a correlation coefficient. The characteristics of the Veteran as well as the characteristics of the CG were examined as to how they affect the CG strain and satisfaction, both in direction and strength. A scatterplot for each of the variables of interest and the outcome variables (strain and satisfaction) was developed to determine normalcy of the relationship. Those relationships showing a linear distribution

in the scatter plots were quantified using a Pearson's correlation coefficient. If a normal distribution was not identified, or if one of the variables was of ordinal scale, then the Spearman's rank correlation coefficient was used to determine the direction and strength of the relationships (Hazra & Gogtay, 2016).

All variables were summarized using descriptive statistics and assessed for normality. Caregiving strain and satisfaction were reported as individual total scores. The initial data analysis was bivariate correlations to examine the relationship between potential explanatory variables and the total score of each outcome measure (strain and satisfaction). The relationships were examined via bivariate correlation statistics (Pearson's or Spearman's correlation). The direction and strength of the relationships (characteristics and CG strain and satisfaction) were established.

Multiple linear regression models were used to evaluate potential explanatory variables of CG strain and CG satisfaction. CG and/or Veteran characteristics that had statistically significant bivariate correlations ($p<.05$) with CG stain or CG satisfaction for the respective models, were evaluated as potential explanatory variables. Prior to analysis, the assumptions of normality, homoscedasticity, and absence of multicollinearity were tested.

Research Question 3: Are strain and satisfaction in CGs of Veterans independently associated with self-reported VAMC hospitalizations?

Since Veteran self-reported hospitalization was a dichotomous variable, the relationships between the Veteran's self-report of a VAMC hospitalization of all causes and the CG strain and satisfaction were examined using point bi-serial

correlational coefficients. The scores of CG strain and satisfaction were correlated with the occurrence of Veteran hospitalizations to determine direction and strength of the bivariate associations.

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Table 3.1

Concepts, Instruments and Scoring of Instruments

Concept	Instrument	Scoring
General Health Status	GSRH (DeSalvo et al., 2005)	1 item, 5-point Likert-type 0=poor, 4=excellent, lower score=worse health
Mental Health Status (Depressive Symptoms)	GDS-SF (Koenig et al., 1988; Sheikh & Yesavage, 1986; Smarr & Keefer, 2011)	15 items, Yes/No format, Total score = number of "Yes" answers, No depression 0–4, Mild depression 5-9, Moderate to Severe 10–15
Activities of Daily Living	ADL (Wakefield et al., 2012)	6 items, Scored as 0-2, Help given/received: none, some, or all of the time
Instrumental Activities of Daily Living	IADL (Wakefield et al., 2012)	12 items, Scored as 0-2, Help given/received: none, some, or all of the time
Perceived Social Support	PRQ-2000 (Brandt & Weinert, 1981; Weinert, 1987; Weinert, 2003; Weinert et al., 2008)	15 items, Likert-type 1-7, total scores 15-105, Higher score = more support
CG Strain	CSI (Robinson, 1983; Kruithof et al., 2015; McPeake et al., 2016)	15 items, Yes/No Dichotomous questions, 1 point for each Yes, Scores >7 = high strain
CG Satisfaction	PACS (Lawton et al, 1989 & 1991, 2000; Tarlow et al., 2004)	11 items; Likert-type 1-4 for each item, Scored as 11-44, higher score = higher satisfaction[1]

Note: CG – Caregiver, GSRH – General Self Rated Health Status, GDS-SF – Geriatric Depression Scale-Short Form, PRQ-2000 – Personal Resource Questionnaire 2000, CSI – Caregiver Strain Index, PACS – Positive Aspects of Caregiving Scale, [1]The PACS scale was reverse scored in this confused.

CHAPTER FOUR:

RESULTS

Sample Demographics

The sample consisted of a total of 137 dyads (n=274 participants). The typical Veteran with heart failure was a 73-year-old, married (79%), White (96%), retired (68%), male (94%), with a high school degree (38%). In contrast, the typical CG was a married (88%), White (97%), college-educated (45%), retired (39%), female (96%), who was, on average, was about 7 years younger than the Veteran with heart failure. The sample demographics for the dyads are presented in Table 4.1.

CG and Veteran Characteristics

Table 4.2 portrays the CG and Veteran characteristics for health, coping, and caregiving context. Most were spousal dyads, living in the same home, and reported having good-very good relationship quality. The majority of Veterans and their CGs rated their general health as good-excellent. On average, both Veterans and their CGs had less than four symptoms of depression. Additionally, both members of the dyad typically used three to four coping strategies (such as prayer, exercise, talking with or seeking advice from friends/relatives, and seeking information from the internet about condition and treatment) to deal with the demands of the dyad. CGs perceived that the Veteran required more assistance with both Activities of Daily Living and the Instrumental Activities of Daily Living than the Veteran perceived they needed.

With regard to resources for caregiving, CGs reported having good perceived social support with M = 88.6 and SD = 11.7. More than half of the CGs (54.1%, 73/135) chose to take on the caregiving role for their Veteran. Most CGs (83.9%, 115/137) felt

very confident about their caregiving skills. Additionally, the majority of CGs had access to resources to assist them with caregiving; specifically, unpaid help (67.9%, 93/137) and paid help (77.4%, 106/137).

Research Question 1: What is the prevalence of strain and satisfaction in CGs of Veterans with heart failure?

Caregiver strain scores ranged from 0 to 13, with $M = 4.57$, $Med = 4.00$, and $SD = 3.48$. Of the total of the 137 CG, 96 CG participants (70.1%) were identified as having low strain (Caregiver Strain Index ≤ 6), of these 96 participants categorized with low strain, 16 CG participants had no strain. A total of 41 CG participants (29.9%) were identified as having high strain (Caregiver Strain Index ≥ 7). Thus, the overall prevalence of strain in CGs of Veterans with heart failure was 88.3%.

Caregiving satisfaction scores ranged from 20 to 44, with $M = 34.57$, $Med = 33.00$, and $SD = 5.50$. A total of 43 CG participants (31.6%) had low satisfaction levels (Positive Aspects of Caregiving Scale ≤ 32) and 93 CG participants (68.4%) had high satisfaction levels (Positive Aspects of Caregiving Scale ≥ 33). Thus, the prevalence of high satisfaction in CGs of Veterans with heart failure was 68.4%.

Research Question 2: Among Veterans with heart failure, what is the relationship between CG characteristics, Veteran characteristics, and CG strain and satisfaction?

Bivariate Correlations with CG Strain

Statistically significant relationships were noted between CG strain and the characteristics of CG age, Veteran self-reported health, CG and Veteran depressive symptoms, CG coping, CG perceived quality of the relationship, choice in taking on CG role, CG resources, and CG and Veteran perceptions of needed assistance with Activities of Daily Living.

Activities of Daily Living, and Instrumental Activities of Daily Living (see Table 4.3). Caregiver age was inversely related with CG strain, Veterans self-rated health was associated with CG strain. Both CG depressive symptoms and Veteran depressive symptoms were positively related to CG strain. Caregiver coping was positively related to CG strain. Caregiver perceived quality of the relationship was positively related to CG strain. Likewise, CGs who did not choose to take on the CG role was associated with strain. Not having or using sources of unpaid help and paid help were both associated with CG strain. Caregiver and Veteran's perceptions of the Veteran needing assistance with Activities of Daily Living and Instrumental Activities of Daily Living were associated with CG strain. All these significant variables were retained for the multiple linear regression analysis to examine their independent association with CG strain.

Bivariate Correlations with CG Satisfaction

Statistically significant relationships were noted between CG satisfaction and CG depressive symptoms, CG perceived quality of the relationship, choice in taking on the CG role, and CG perceived social support (see Table 4.4). Caregiver depressive symptoms were inversely related to satisfaction. Caregivers with poor perceived quality of relationship with their Veteran was negatively associated with CG satisfaction, Not choosing to take on the CG role were inversely related to satisfaction. Caregiver perceived social support was positively related to CG satisfaction. All these significant variables were retained for the multiple linear regression analysis to examine the independent association with CG satisfaction.

Multiple Linear Regression Analysis with CG Strain

A multiple linear regression was conducted to assess whether various *CG* and Veteran characteristics were independently associated with CG strain. Prior to analysis, the assumptions of normality, homoscedasticity, and absence of multicollinearity were tested. Normality was assessed with a normal P-P scatterplot. As seen in Figure 4.1 the data closely followed the normality trend line, indicating that the assumption of normality was supported. The assumption of homoscedasticity was tested with visual inspection of a residual scatterplot (see Figure 4.2). The scatterplot depicted a non-recurring pattern, suggesting that the assumption of homoscedasticity was supported. Absence of multicollinearity was tested with variance inflation factors (VIFs). According to (Kim, 2019), VIFs below 10 indicate a low association among the predictor variables and the assumption for absence of multicollinearity will be met. All the VIFs in the regression model were below 10, providing evidence that the assumption was supported.

The findings of the overall regression model were statistically significant, $F(13, 119) = 12.48$, $p < .001$, $R^2 = .577$ indicating that approximately 57.7% of the variance in CG strain could be attributed to the explanatory variables. The individual explanatory variables were examined next which included: CG age, Veteran self-rated health, CG and Veteran depressive symptoms, CG coping, CG perceived quality of the relationship, choice in taking on the CG role, having sources of/uses unpaid and paid help; as well as the CG and Veteran's perception of needing assistance with Activities of Daily Living and Instrumental Activities of Daily Living. Caregiver age ($B = -0.08$, $t = -3.55$, $p < .001$) was negatively associated with CG strain. Veterans who self-rated health as fair to poor ($B = 1.03$, $t = 2.24$, $p < .027$) was positively associated with CG strain. CG

depression (B = 0.50, t = 4.11, p < .001) was positively associated with CG strain. Caregiver coping strategies (B = 0.44, t = 3.45, p < .001) was positively associated with CG strain. Not choosing to take on the caregiving role (B = 1.06, t = 2.46, p = .015) was associated with CG strain. Caregiver's perception of the Veteran's need for assistance with Instrumental Activities of Daily Living (B = 0.26, t = 2.15, p = .033) was positively associated with CG strain. Table 4.4 presents the findings of the CG strain regression model.

Multiple Linear Regression Analysis with CG Satisfaction

A multiple linear regression was conducted to assess whether various CG characteristics were independently associated with CG satisfaction scores. Prior to analysis, the assumptions of normality, homoscedasticity, and absence of multicollinearity were again tested. The data approximately followed the normality trend line, indicating that the assumption of normality was supported (see Figure 4.3). The residuals scatterplot depicted a non-recurring pattern, suggesting that the assumption of homoscedasticity was supported (see Figure 4.4). All the VIFs in the regression model were below 10, providing evidence that the assumption for absence of multicollinearity was supported.

The findings of the overall regression model were statistically significant, F(4, 128) = 9.70, p < .001, R^2 = .233, indicating that approximately 23.3% of the variance in satisfaction scores could be attributed to the explanatory variables. The individual explanatory variables were examined next which included: CG perceived quality of relationship, CG choice in taking on the role, CG perceived social support, and CG depressive symptoms. Caregiver perceived quality of relationship (B = -3.83, t = -1.99, p

= .049) was negatively associated with CG satisfaction. Not choosing to take on the CG role (B = -1.92, t = -2.18, p = .031) was negatively associated with CG satisfaction. CG perceived social support (B = 0.12, t = 2.99, p = .003) was positively associated with CG satisfaction. Table 4.5 presents the findings of the CG satisfaction regression model.

Research Question 3: Are strain and satisfaction in CGs of Veteran independently associated with self-reported VAMC hospitalizations of all causes?

Of the 136 Veterans responding to the survey question regarding self-reported hospitalization in the last 12 months, 37.5% (51/136) reported being hospitalized and 62.5% (85/136) denied being hospitalized. The Veterans that self-reported hospitalization had CG strain scores of M = 5.47 with SD = 3.61 in comparison to the Veterans that did not self-report hospitalization with CG strain of M = 4.06 and SD = 3.32. The Veterans that self-reported hospitalization had CG satisfaction scores of M = 34.37 with SD = 4.95 in comparison to the Veterans that did not self-report hospitalizations with a M = 34.32 and SD = 6.82. CG strain was positively related to Veteran self-reported hospitalization (r_{pbs} = .20, p = .022). Caregiver satisfaction, however, was not associated with Veteran self-reported hospitalization (r_{pbs} = .004, p = .960).

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Table 4.1 *Demographics of the CG and Veteran with Heart Failure Dyads*

Variable	Variable Label	Veteran (n =137)	CG (n=137)
Mean age[1] (SD) years	CG AGE VET_AGE	73 (9.1)	65.6 (12.0)
Male, n (%)	CG Gender VET Gender	129 (94%)	6 (4.0%)
Married[2], n (%)	CG Marital VET Marital	108 (79.4%)	121 (88.3%)
Education[2], n (%)	CG EDUC VET_EDUC		
Less than High School		26 (19.1%)	13 (9.5%)
High School Graduate		51 (37.5%)	54 (39.4%)
Some College/College Graduate		50 (36.7%)	62 (45.2%)
Graduate School		9 (6.6%)	8 (5.8%)
Race[2]	CG RACE VET_RACE		
White, n (%)		131 (96.3%)	133 (97.1%)
Non-White, n (%)		5 (3.7%)	4 (2.9%)
Employment Status[2], n (%)	CG_66 VET_36		
Working Full-/Part-time		11 (8.1%)	49 (35.8%)
Retired		92 (67.6%)	54 (39.4%)
Other		33 (24.3%)	34 (24.9%)

*Note***:** [1]Four Veterans did not report, [2]One Veteran did not report

Table 4.2

CG and Veteran Characteristics: Health, Coping, and Caregiving Context

Variable	Variable Label	Veteran (n =137)	CG (n=137)
Health and Coping			
General Self-rated Health, n (%)	VET52 CG119		
Excellent-Good		79 (57.7%)	117 (85.4%)
Fair-Poor		58 (42.3%)	20 (14.6%)
Depression Score, *M* (SD)	CG104-118 VET37-51	3.86 (3.2)	1.97 (1.9)
Coping Strategies Score, *M* (SD)[3]	CG28-CG35 VET23-30	4.34 (1.9)	3.27 (1.9)
Caregiving Context			
Relationship to One Another, n (%)	CG1 VET1		
Spouse		107 (78.1%)	107 (78.1%)
Other		30 (21.9%)	30 (21.9%)
Live in same household, n (%)	CG2 VET2	120 (87.6%)	120 (87.6%)
Perceived Relationship Quality[2], n (%)	CG53 VET31		
Very Good-Good		132 (97.1%)	129 (94.2%)
Fair-Poor		4 (2.9%)	8 (5.8%)

Perceived Assistance with ADLs, *M* (SD)	VETADL	2.69 (2.8)	7.0 (5.1)
	CG/ADL		
Perceived Assistance with IADLs, *M* (SD)	VETIADL	7.7 (2.5)	11.0 (8.0)
	CG/IADL		

Note: [2] One Veteran did not report, [3] Three Veterans did not report

Table 4.3

Bivariate Correlations with CG Strain (0-15)

Variable (coding or score range)	Variable Label	*r*	*P*
Age	**CG AGE**	**-.28**	**<.001**
	VET AGE	-.14	.101
Gender (1=male, 2=female)	CG Gender	.07	.432
	VET Gender	.10	.228
Marital status (1=married, 2=not married)	CG Marital	.12	.172
	VET Marital	.09	.316
Educational level (1=<HS, 2=HS, 3=college, 4=Grad school)	CG EDUC	.11	.200
	VET EDUC	.16	.068
Race (1=White, 2=non-White)	CG RACE	-.02	.853
	VET RACE	.00	.994
Employment status (1=working, 2=retired, 3=other)	CG_66	-.06	.476
	VET_36	.14	.104
Self-rated health (1=excellent/good, 2=fair/poor)	CG119	.02	.803
	VET52	**.27**	**.002**
Depressive Symptoms (0-15)	**CGdepr**	**.47**	**<.001**
	VETdepr	**.35**	**<.001**
Coping strategies (0-8)	**CG COPE**	**.51**	**<.001**
	VET COPE	.12	.159
Dyad relationship (1=spouse, 2=other)	CG1/VET1	.08	.347
Dyad lives together (1=yes, 2=no)	CG2/VET2	-.01	.901

Quality of relationship (1=very good/good, 2=fair/poor)	**CG53**	**.26**	**.002**
	VET31	.05	
			.597
CG confidence with skills (1=very confident, 2=not confident)	CG23	.09	.272
Chose to take on CG role (1=yes, 2=no)	**CG 103**	**.22**	**.010**
CG social support (15-105)	SOCSUPP	-.16	.057
Has sources of/uses unpaid help (1=yes, 2=no)	**CG25**	**.22**	**.011**
Has sources of/uses paid help (1=yes, 2=no)	**CG27**	**.23**	**.006**
Veteran assistance with ADLs (0-12)	**CG ADL**	**.29**	**<.001**
	VET ADL	**.29**	**<.001**
Veteran assistance with IADLs (0-24**)**	**CG IADL**	**.42**	**<.001**
	VET IADL	**.25**	**.004**

Note: n = 137, **Bolded** values are statistically significant, CG = caregiver, HS = high school, Grad = graduate, ADL = Activities of Daily Living, IADL = Instrumental Activities of Daily Living

Table 4.4

Bivariate Correlations with CG Satisfaction (11-44)

Variable (coding or score range)	Variable Label	*r*	*p*
Age	CG AGE	-.10	.250
	VET AGE	.09	.302
Gender (1=male, 2=female)	CG Gender	.00	.998
	VET Gender	-.11	.186
Marital status (1=married, 2=not married)	CG Marital	.14	.112
	VET Marital	.10	.250
Educational level (1=<HS, 2=HS, 3=college, 4=Grad school)	CG EDUC	.02	.858
	VET EDUC	-.02	.818
Race/Ethnicity (1=White, 2=non-White)	CG RACE	-.03	.723
	VET RACE	.09	.292
Employment status (1=working, 2=retired, 3=other)	CG_66	-.05	.529
	VET_36	.01	.928
Self-rated health (1=excellent/good, 2=fair/poor)	CG119	.02	.801
	VET52	-.08	.330
Depressive Symptoms (0-15)	**CGdepr**	**-.24**	**.005**
	VETdepr	-.09	.298
Coping strategies (0-8)	CG COPE	-.08	.331
	VET COPE	-.09	.286
Dyad relationship (1=spouse, 2=other)	CG1/VET1	.11	.213
Dyad lives together (1=yes, 2=no)	CG2/VET2	.08	.346

Quality of relationship (1=very good/good, 2=fair/poor)	**CG53**	**-.24**	**.004**
	VET31	-.10	.273
CG skills self-efficacy (1=very confident, 2=not confident)	CG23	-.07	.424
Chose to take on CG role (1=yes, 2=no)	**CG 103**	**-.25**	**.003**
CG social support (15-105)	**SOCSUPP**	**.33**	**<.001**
Has sources of/uses unpaid help (1=yes, 2=no)	CG25	.08	.381
Has sources of/uses paid help (1=yes, 2=no)	CG27	-.00	.969
Veteran assistance with ADLs (0-12)	CG ADL	.03	.711
	VET ADL	-.07	.389
Veteran assistance with IADLs (0-24)	CG IADL	-.04	.687
	VET IADL	-.02	.788

Note: n = 137, **Bolded** values are statistically significant, CG = caregiver, HS = high school, Grad = graduate, ADL = Activities of Daily Living, IADL Instrumental Activities of Daily Living

Table 4.5

Multiple Linear Regression with Dyad Characteristics Explaining Strain

Explanatory Variable	Variable Label	*B*	*SE*	β	*T*	*P*
CG age	**CG_AGE**	**-0.08**	**0.02**	**-.25**	**-3.55**	**<.001**
VET self-rated health	**VET119**	**1.03**	**0.46**	**.15**	**2.24**	**.027**
CG depressive symptoms	**CG_depr**	**0.50**	**0.12**	**.29**	**4.11**	**<.001**
Veteran depressive symptoms	VET_depr	-0.02	0.08	-.02	-0.19	.848
CG coping strategies	**CG_COPE**	**0.44**	**0.13**	**.24**	**3.45**	**<.001**
CG perceived relationship quality	CG53	1.62	0.94	.11	1.72	.089
Chose to take on CG role	**CG 103**	**1.06**	**0.43**	**.15**	**2.46**	**.015**
Has sources of/uses unpaid help	CG25	0.37	0.47	.05	0.78	.439
Has sources of/uses paid help	CG27	0.72	0.53	.09	1.38	.171
CG perceived ADL assistance	CGADL	0.10	0.10	.09	1.02	.310
Veteran perceived ADL assistance	VETADL	0.12	0.11	.10	1.13	.262
CG perceived IADL assistance	**CGIADL**	**0.26**	**0.12**	**.19**	**2.15**	**.033**
Veteran perceived IADL assistance	VETIADL	-0.01	0.12	-.01	-0.11	.913

Note: n = 137, Significant explanatory variables are **bolded**, B = unstandardized beta coefficient, SE =standard error, β = standardized beta coefficient, T = ratio between coefficient and SE, p = significance level, CG = caregiver, VET = Veteran, ADL = Activities of Daily Living, IADL = Instrumental Activities of Daily Living

Table 4.6

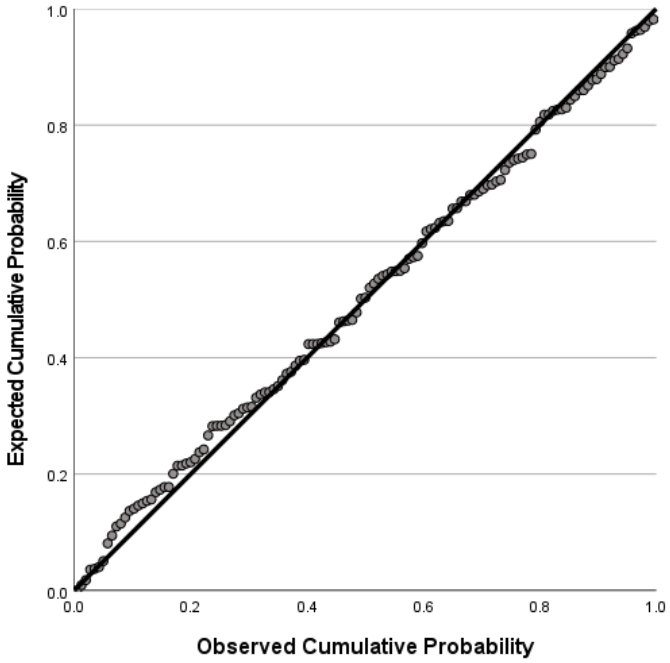
Multiple Linear Regression of Dyad Characteristics Explaining CG Satisfaction

Explanatory Variable	Variable Label	*B*	*SE*	β	*T*	*P*
CG depressive symptoms	CG depr	-0.41	0.23	-.15	-1.77	.079
CG perceived relationship quality	CG53	-3.83	1.92	-.17	-1.99	**.049**
Chose to take on CG role	CG 103	-1.92	0.88	-.17	-2.18	**.031**
CG perceived social support	SOCSUPP	0.12	0.04	.25	2.99	**.003**

Note: Significant explanatory variables are **bolded**, B = unstandardized beta coefficient, SE =standard error, β = standardized beta coefficient, T = ratio between coefficient and SE, p = significance level, CG = caregiver

Figure 4.1

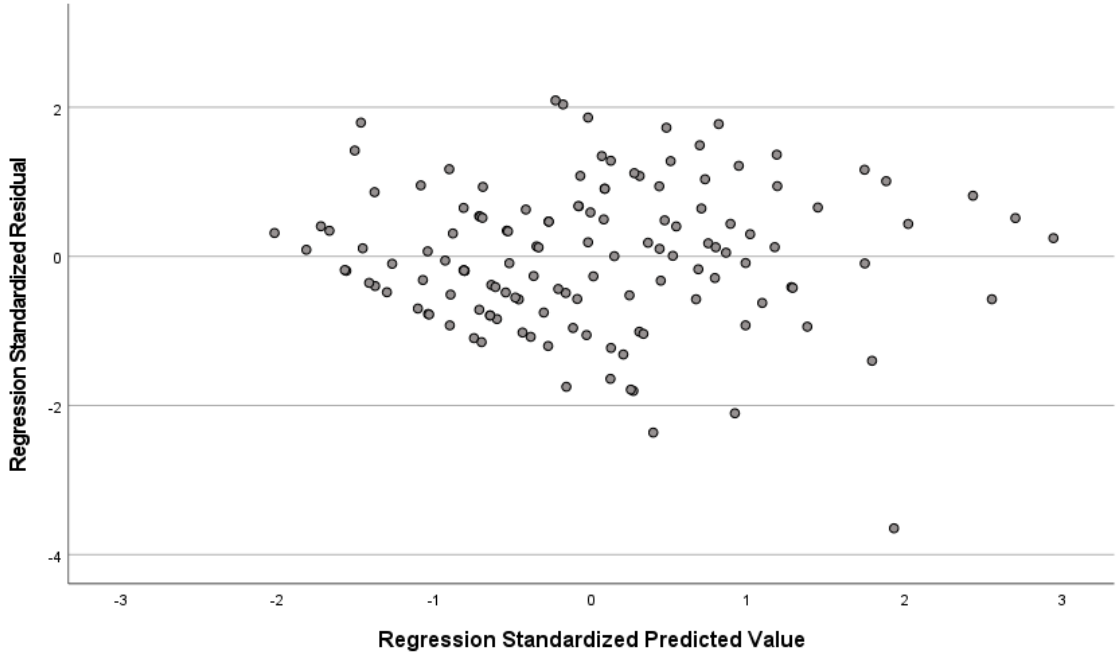
Normal P-P plot for Multiple Linear Regression Model Explaining Strain



Note: Expected and observed probability of predicting caregiver strain, a positive linear association

Figure 4.2

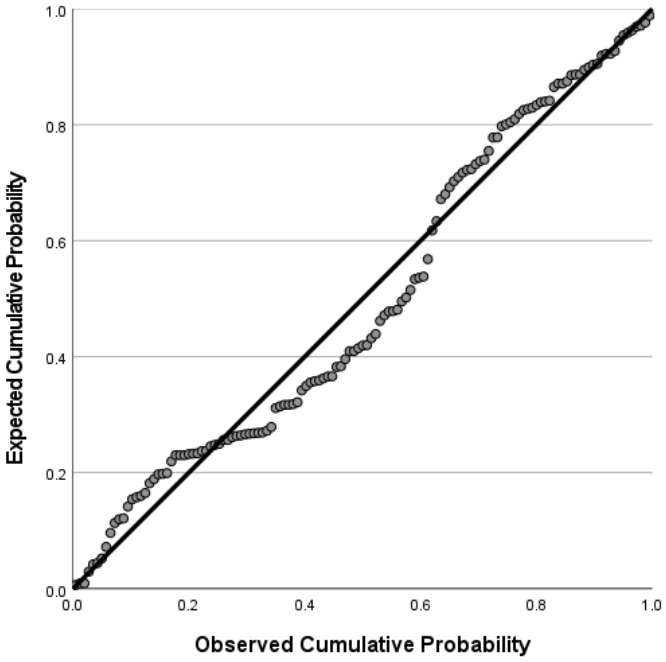
Residuals Plot for Multiple Linear Regression Model Explaining Strain



Note: **Assumption of homoscedasticity supported by non-recurring pattern**

Figure 4.3

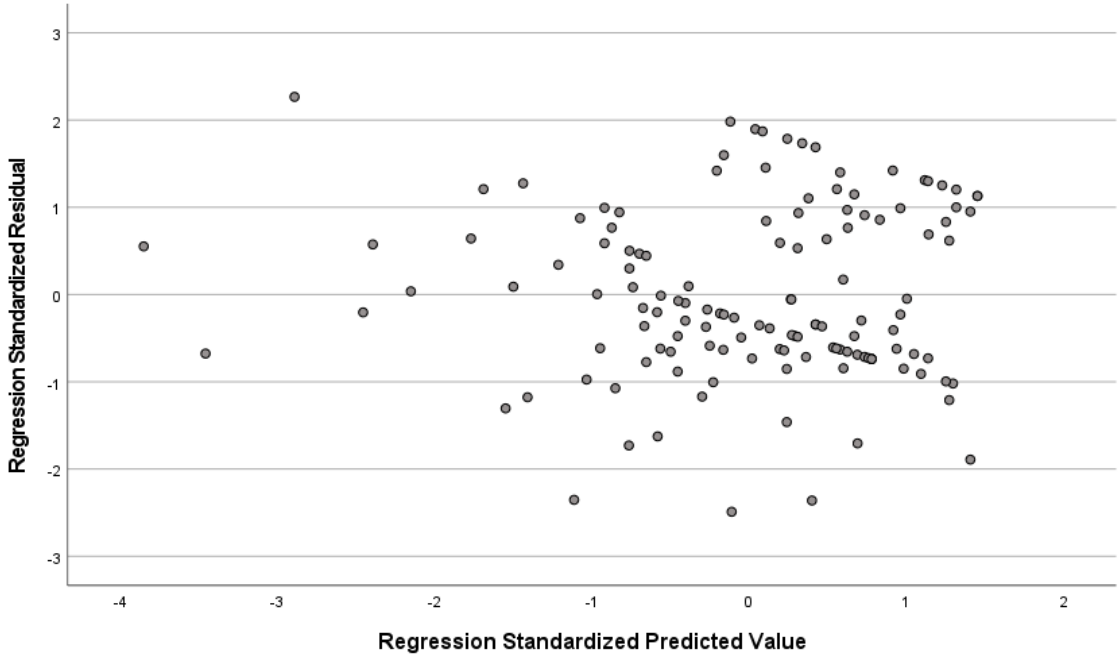
Normal P-P Plot for Multiple Linear Regression Model Explaining Satisfaction



Note: Expected and observed probability of predicting caregiver satisfaction, a positive linear association

Figure 4.4

Residuals Plot for Multiple Linear Regression Model Explaining Satisfaction



Note: Assumption of homoscedasticity supported by non-recurring pattern

CHAPTER FIVE:

DISCUSSION

This secondary analysis examined the relationships between CG and Veteran characteristics, CG strain, and CG satisfaction in the dyads. This dyadic analysis contemplates several key findings based on the results of assessing the concepts described in the research questions identified in Chapter One. First, although the overall prevalence of strain was quite high, when examined by low/high cut-points, most CGs of Veterans with heart failure reported low CG strain. Second, the majority of CGs of Veterans with heart failure recognized the gain or positive aspects of caregiving as demonstrated by their high CG satisfaction scores. Third, a combination of both CG characteristics and Veteran characteristics contributed to CG strain whereas only CG characteristics explained CG satisfaction. Fourth, although CG strain was associated with the health and well-being outcome of self-reported hospitalization in a VAMC in the past year, CG satisfaction was not. Collectively, these findings have implications for both caregiving research and clinical practice.

Interpretation of the Findings

Caregiver Strain

For the majority of CGs in this study, the severity of the strain was categorized as low (CSI≤6). Our CG strain levels were similar to, but on average, about 1.5 points higher than the baseline CG strain levels reported in a large sample of out-of-home CarePartners of Veterans with heart failure (Lee et al., 2020 [secondary analysis, n=348]; Piette et al., 2015a [primary study, n=369]). The average age of the CarePartners was about 20 years younger than our CGs. Based on our multivariate analysis of explanatory

variables associated with strain, one might expect that our older CGs would have *lower* strain levels than the younger CarePartners. However, that was not the case. Several plausible explanations may account for this difference.

One potential explanation for our higher CG strain is that our CGs were primarily spousal CGs who lived with the Veteran whereas the CarePartners were primarily adult child CGs who did not live with the Veteran. Indeed, data from Lee and colleagues (2020) suggest that in-person support of Veterans with heart failure is associated with higher CG strain while telephone support is not associated with strain. Another possibility might be related to the age of our Veterans. Our Veterans were, on average, about five years older than the Veterans in the two aforementioned studies. Increasing age might account for increased Veteran needs for assistance with Instrumental Activities of Daily Living which we have shown to be a predictor of higher CG strain (Table 4.5). Another reason might be related to the severity of heart failure in our sample. Although our dataset did not contain information about the anatomical or functional severity of the heart failure, the stage of heart failure may affect the amount of time, effort and self-care knowledge required by the CG to aid the patient with heart failure (Dionne-Odom et al., 2017). However, other researchers have suggested that disease severity may have limited impact of CG burden (Burton et al., 2012; Luttik et al., 2007) and likewise may have limited impact on CG strain.

Interestingly, the prevalence of high CG strain in our study was lower than the prevalence of high CG strain in one of the primary studies from which this secondary data set was drawn (Wakefield et al. 2012). One potential explanation might be that the study by Wakefield and Vaughan-Sarrazin (2017) contained a mixed sample of

chronically ill Veterans of which the majority had type 2 diabetes mellitus. The difference in the prevalence of high CG strain in persons with diabetes may be due to the unique CG challenges to the CG in supporting diabetes self-care management. Supporting the patient with diabetes is a labor-intensive role for the CG to assume as the CG helps motivate patients to perform the daily self-care needed to manage diabetes and increase therapeutic lifestyle changes and adherence (Wakefield & Vaughan-Sarrazin, 2018).

Although a recent meta-analysis revealed that several studies have investigated the impact of the negative aspects of caregiving, such as strain or psychological distress, on heart failure patient outcomes in CG/patient dyads (Bidwell, Lyons et al., 2017), little work has examined the explanatory variables associated with CG strain in CG/patient with heart failure dyads. In relation to Kramer's model (1997a) of the caregiving experience, we found that, generally speaking, significant explanatory variables associated with CG strain fell within the caregiving context rather than resources. The only resource that was associated with higher CG strain was the use of a greater number of CG coping strategies. One possible explanation for this may be that the CG who experienced higher strain may seek additional coping strategies in an attempt to decrease strain. Alternatively, a measure of the type of coping style, rather than the quantity of the coping strategies might yield different and more informative results. For example, in a sample of CG/patient dyads where the patients had mixed chronic illnesses (including heart failure), Burton and colleagues (2012) found greater use of the helpless-hopeless coping style was associated with increased burden while the anxious preoccupation coping style was associated with poor spiritual well-being. While some explanatory

variables of strain, such as age, are non-modifiable, others may provide opportunity for intervention such as depressive symptoms, stress management, and coping strategies (Burton et al., 2012; Piette et al., 2015a; Trivedi et al., 2016; Trivedi et al., 2019).

Several challenges exist with comparing strain results to prior Veteran or non-Veteran dyadic research. First, the terms/concepts used to describe the negative aspects of caregiving appraisal (e.g., strain, hassles, stress, burden, and burnout) are often used interchangeably in the literature (Gérain & Zech, 2021; Irwin et al., 2018; Lee & Li, 2021; Rombough et al., 2006; Saleh et al., 2006; Swan et al., 2022). Second, researchers have used several different measurement strategies ranging from qualitative themes to study-specific ordinal level questions to validated tools. However, even when a validated tool has been used (e.g., the Caregiver Strain Index), some investigators may state they are measuring a different concept. For example, in the purpose and discussion sections of their research, Piette and colleagues (2015a) indicated that they were investigating caregiving burden; however, they utilized the Caregiver Strain Index to measure burden. Although burden is a concept used to measure negative CG appraisal in providing care for patients with heart failure (Collins & Swartz, 2011; Grigorovich et al., 2017; Hodson et al., 2019; Hooker et al., 2015; Hooker et al., 2018), it is not clear whether CG burden, hassles, emotional stress, and burnout measure the same concept as strain. Thus, examination of caregiving appraisal concepts and typology requires further investigation.

Caregiver Satisfaction

To our knowledge, this is one of the first studies to identify that most dyads experience high CG satisfaction. Indeed, none of the recent dyad articles reviewed as part of this dissertation quantitatively measured CG satisfaction or any other positive measure of CG appraisal (Bouldin et al., 2019; Burke et al., 2016; Hooker et al., 2018, Lee et al.,

2020; Piette et al., 2015a; Slightam et al., 2022; Trivedi et al., 2012; Trivedi et al., 2016; Trivedi et al., 2019; Wooldridge et al., 2019). Satisfaction is a positive component of CG appraisal (Wakefield et al., 2012) and can be seen as a gain by both the CG and the Veteran with] heart failure. Gain is a reward of a CG's well-being consistent with Hunt's (2003) description of the positive outcomes and personal growth aspects of caregiving (Cangelosi, 2009; Shirai et al., 2009). The positive aspects of caregiving include concepts such as CG esteem, uplifts of caregiving, CG satisfaction, finding or making meaning through caregiving, intrinsically rewarding, and finally, to achieve gain in the caregiving experience (Bangerter et al, 2019; Kramer, 1997). Similar in its development as a concept, as CG strain, it is unclear whether CG satisfaction is the same or similar to other concepts focusing on the positive aspects of caregiving.

The concept of CG satisfaction has been evaluated in CG/patient with heart failure dyads (Molloy et al., 2008); however, the Caregiver Reaction Assessment instrument was utlized rather than the Positive Aspects of Caregiving Scale making comparisons of findings difficult. The Caregiver Reaction Assessment instrument does measure both components (negative and positive) of CG appraisal; however, researchers using the instrument often only report on the sub-scales addressing the negative aspects of caregiving (burden) and neglect to address the CG esteem sub-scale which evaluates the positive aspects of caregiving (Burton et al., 2012; Hwang et al., 2011; Trivedi et al., 2016). Our study adds to the body of research as recommended in previous research which focused more on the significance of demographic variables (Hiel et al., 2015). Additional research is needed to increase awareness of the positive effects of caregiving on the CG, establish consensus regarding positive aspect of caregiving terminology, and

identify the best validated instrument(s) for measuring positive aspects of caregiving (Lee & Li, 2021).

Our average CG satisfaction levels were quite similar to the primary study containing a mixed sample of dyads with diabetes mellitus or heart failure (Wakefield & Vaughn-Sarrazin, 2017). In contrast, our mean CG satisfaction levels were nearly 14 points higher than the other primary study containing a mixed sample of dyads with diabetes mellitus, depression, heart failure, hypertension, and chronic obstructive lung disease (Wakefield et al., 2012). It is unclear why this difference exists, but it is possible that unique caregiving needs of patients within each chronic disease may be a factor or independently associated with CG satisfaction.

In our regression analysis for satisfaction, we found explanatory variables associated with higher CG satisfaction also fell predominantly within the caregiving context rather than resources. The only resource that was associated with higher CG satisfaction was greater perceived social support. Our findings are consistent with prior research in CG/patient living with mixed chronic illness dyads who reported wanting more help from family and friends (Burton et al., 2012). Evidence-based strategies to improve the dyad relationship quality (e.g., mutuality) and enhance individual resources, such as increase perceived social support, provide opportunities to intervene to improve CG satisfaction and well-being (Piette et al., 2015a; Trivedi et al., 2016; Trivedi et al., 2019; Wooldridge et al., 2019). It should be noted, however, that our regression model only explained about 25% of the variance in CG satisfaction. This suggests that there are additional important factors that impact CG satisfaction that this study did not address that need to be examined in future research.

Self-reported VAMC Hospitalizations

When examining the effects of the CG appraisal on health and well-being outcomes of the Veteran with heart failure, it was interesting to note that CG strain was associated with hospitalizations in a VAMC during the previous year, but CG satisfaction was not related to hospitalization. Our findings conflict with those of Hwang and colleagues (2011) who found higher CG esteem, a positive aspect of CG appraisal, was associated with less frequent Emergency Department visits. Although CG satisfaction in our research and CG esteem are different concepts, both may affect the perception of success on part of the CG in performing their caregiving duties, as the need for acute medical intervention for the patient with heart failure may be perceived as a negative caregiving outcome (Bidwell et al., 2017). It should be noted that Veteran hospitalization was based on self-reported recall from the last 12 months; thus, recall bias may have influenced results. Future research would be enhanced by obtaining data from electronic health records to confirm hospitalization and/or Emergency Department utilization outcomes.

Strengths and Limitations of the Research

Based on the examination of a previously collected data set, there are advantages to performing secondary research. These advantages include identification of knowledge gaps, less expense as the data has already been collected, consent from the participants has already been obtained, data are deidentified, and earlier reported findings also benefit the researcher to anticipate gaps in the literature (Hutchings et al., 2021; Raman, 2021). A strength to our research was the larger sample size which included 364 participants or 137 dyads; this larger size was achieved by combining the data gleaned from the two primary studies. There are also disadvantages to performing secondary research which

can include discovering missing quantitative data and inaccurate transcription of data into a statistical database (Dunn et al., 2015; Glass, 1976). The primary studies (Wakefield et al., 2012; Wakefield & Vaughan-Sarrazin, 2017) from which the currently used data set was derived was monitored closely by the original investigators and well-trained and supervised research assistants. The data set used for this dissertation was reviewed in depth with the principal investigator of the primary research which helped in validation of the integrity of this data set. Knowing the integrity of this data set gives one confidence in the results obtained. The investigator had the unique opportunity to learn from the principal investigator how decisions regarding the design and process of the research protocol were made, which is not often the case in secondary research (Alvarez et al., 2012; Raman, 2021). The data in the primary research were self-reported and, thus, may have introduced recall or social desirability bias (Cook et al., 2002).

Data from this study may not be generalizable to other populations of CGs of Veterans with heart failure (Frost et al., 2007). The dyads examined were from VAMCs in the Midwest area of the U. S. Based on the racial and ethnic distribution of Veterans overall, the Midwest region has a less racially/ethnically diverse population. This is noted and expected, as 96.3% of the Veteran participants were white. The caregiving context and resources of racially and ethnically diverse populations are likely different than white male Veterans and their spouses. Therefore, predictors of CG strain, CG satisfaction, and Veteran resource utilization may not be generalizable to racially and ethnically diverse dyads.

Not having access to the Veteran's electronic medical record was an additional challenge with this secondary research. For example, it would have been helpful to

evaluate the stages of clinical heart failure as a potential explanatory variables independently associated with CG strain and satisfaction. Patients in the later stages of heart failure are more physically dependent on care from others (Chen-Scarabelli et al., 2015). Data that included Veterans comorbidities would additionally have been helpful to evaluate how non-cardiovascular co-morbidities may have affected results (Correale et al., 2021).

Limitations

This study is a secondary analysis of caregiving in Veterans with heart failure living in communities of the Midwest region of the U.S. The existing data were analyzed from a non-publicly available dataset from the Veterans Health Administration. The primary studies were cross-sectional surveys which included CG and Veterans with chronic illness and some of those were enrolled in an home telehealth program (Wakefield et al., 2012; Wakefield & Vaughan-Sarrazin, 2017). Strengths of the study include its exclusive focus on Veterans with heart failure and their caregivers which is a vulnerable and aging population. Compared to many of the studies reviewed, the sample size is larger which enhances the external validity of the findings. However, a major limitation of the study was use of data from cross-sectional surveys. Limitations of cross-sectional survey designs include: the sample needs to be representative of the entire population in order for the data to be useful, personal biases of the researcher can affect access and approach to the sample as well as how and what questions are asked, Other disadvantages of cross-sectional survey designs include the limitations associated with time-limited measures and that causal relationships are not established with this design.

As a program of research develops, it is important for researchers and clinicians to use clear and consistent language or typology to identify and measure concepts. There are various terms and lack of consistent nomenclature used throughout the caregiving literature to describe both the positive and negative appraisal of the caregiving experience (Hunt, 2003; Lee & Li, 2021). The lack of uniformity of terminology is likely to confuse researchers and clinicians alike. Some of these varying terms describing caregiving concepts include feelings of CG burden, CG role strain, making meaning of the experience of caregiving, caregiving satisfaction, and gain in caregiving experience (Archbold et al., 1990; Ayres, 2000; Kramer, 1997a; Kramer, 1997b; Lawton et al., 1991; Zarit et al., 1980). In heart failure dyadic research and clinical care, we need to consider a consistent and culturally relevant typology as proposed by (Buck et al., 2018). However, in accordance with the 2022-2026 strategic plan from the National Institute for Nursing Research as we consider providing individualized care to populations, we may also consider taking this collaborative effort a step further, and apply it to dyadic care in the community, regardless of diagnosis (Edmonds, 2022). In addition, we need to consider relevant concepts and variables to test and develop more primary heart failure dyadic research.

Recommendations for Future Research and Clinical Care

In the recent past, it was recognized that it was important to not only evaluate the outcomes for the patient living with heart failure but also the effects on the informal CGs whose appraisal of the CG process is strongly linked to the health and well-being of the patient with heart failure (Lyons et al., 2021; Morelli et al., 2019; Wooldridge et al., 2019). The financial, physical, and psychosocial effects on the GG and Veterans can

place a substantial strain as well as affect the health and well-being of the CG and the Veteran. Social support of the CG is an important variable which may affect CG satisfaction. Specific interventions providing dyadic support may be examined in future research studies, Future intervention research may include the testing of strategies which were not available during the primary data collection (Wakefield et al., 2012; Wakefield & Vaughan-Sarrazin, 2017). The results of this research support current intervention studies which test the use of technology to offer social support to the dyad (Egan et al., 2022; Piette et al., 2015a; Utz et al., 2021). The findings of how strain and satisfaction are affected in the dyads reinforces previous literature of how caregiving can be rewarding to the informal and in-home CG (Lee et al., 2020). Additional implications for planning future clinical care and research affects the content of education and skills training provided to dyads. As these educationally focused interventions are planned, researchers need to consider learning styles, culture, health literacy, and the use of technology to achieve optimal outcomes (Delgado & Ruppar, 2017; Slightam et al., 2020).

To enhance generalizability of future research, it would be beneficial to examine heart failure dyads associated with other VAMC settings. Examining the polar components of CG appraisal (strain and satisfaction) process also in non-Veteran populations with heart failure, would be helpful in improving generalizability of the concepts. Identifying the explanatory variables independently associated with CG appraisal in non-Veteran dyads; or even in the caregiving of patients with conditions other than heart failure would lead to expanding the impact of CG research and using the unit of the dyad to explore new testable questions. Additionally, using the CG appraisal

continuum to evaluate the providing of care to other populations and their CGs may be useful to optimize care for dyadic research.

Conclusion

This secondary analysis of data from two existing studies of Veteran and CG which included Veterans with heart failure examined the associations between CG and Veteran characteristics, caregiving context, and resources in dyads and their ability to explain CG strain and satisfaction. Despite a high overall prevalence of strain in this sample, most CGs of Veterans with heart failure reported low intensity of CG strain and high levels of CG satisfaction. Potentially modifiable explanatory variables associated with CG strain include CG depressive symptoms and CG coping strategies, whereas modifying perceived social support may impact CG satisfaction. Additional longitudinal research is needed to further examine associations between CG and Veteran characteristics and hospitalization in, Veterans with heart failure. Given the positive bivariate relationship between CG strain and hospitalization, strategies to minimize CG strain also may help to decrease rehospitalization of Veterans with heart failure. The results of this study may be used to plan research-based nursing care, test interventions to improve caregiving appraisal, dyadic health and well-being outcomes and develop policies to standardize and optimize the informal CG experience.

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Appendix A

Caregiver Survey

Introduction

Hello. My name is _____ and I am an interviewer with the Department of Veterans Affairs. I am calling today because you returned a form indicating your interest and agreement to participate in a survey on helpers of veterans. Are you available to talk right now? [if not, schedule a time for follow up]

This survey is part of an important national study conducted by the Department of Veterans Affairs. The purpose of this survey is to better understand how family and friends help veterans at home. We really appreciate your participation.

I'd like to remind you that your response to any question is voluntary, and you may ask us to skip any question that you do not wish to answer. You can stop this discussion at any time. The survey should take less than 30 minutes of your time.

[Conduct mental status screen]

I'd like to review the definition we use for a helper. A helper is a person who assists a friend / relative 18 years of age or older. Assistance may include help with personal needs, household chores, a person's finances, or visiting regularly to see how they are doing.

Do you have any questions before we proceed?

OK, let's get started.

[CG-CR Relationship]

CG1. What is the (veteran)'s relationship to you? He/she is your . . .

01 SPOUSE

02 PARENT

03 MOTHER/FATHER-IN-LAW

04 SON/DAUGHTER

05 SON/DAUGHTER-IN-LAW

06 BROTHER/SISTER

07 BROTHER/SISTER-IN-LAW

08 GRANDMOTHER/GRANDFATHER

09 GRANDPARENT-IN-LAW

10 AUNT/UNCLE

11 NIECE/NEPHEW

12 NEIGHBOR

13 OTHER FRIEND / /RELATIVE (SPECIFY_____CG1_OTH _____)

14 COMPANION/PARTNER

15 REFUSED

16 DON'T KNOW

[Living Arrangement]

CG2. Does (veteran) live....

01. In the same household as you

02. Within a twenty minute drive of your home

03. Between 20 minutes and an hour drive from your home

04. A one to two hour drive from your home, or

05. More than two hours away?

06. REFUSED

07. DON'T KNOW

[IF NOT IN HOUSEHOLD] IF answer to question 2 is not in the same household, i.e. responses 02 through 05

CG2_1 On average, how often did you visit (veteran) in the last year?

01. More than once a week
02. once a week
03. few times a month
04. once a month
05. few times a year
06. or less often
07. REFUSED
08. DON'T KNOW

CG2_2 Does (veteran) currently live:

01. Alone
02. With her/his spouse
03. With her/his grown children
04 .With other family members
05. With friend
06. With an aide, housekeeper, or other staff,
07. Or with someone else? (SPECIFY _____ CG2_2_OTH_____)
08. REFUSED
09. DON'T KNOW

[Type of assistance provided]

I'm going to read a list of kinds of help that you might do for (name of veteran). I will ask you to answer with one of 3 responses. So, for each activity I read, just tell me if you provide assistance none of the time, some of the time, or all of the time. [note whether they do this, even if the veteran could do it for himself]

Do you help (veteran) with ...

[Activities of Daily Living]

CG3. Taking medicines, pills, or injections

00. None of the time

01. Some of the time

02. All of the time

03. REFUSED

04. DON'T KNOW

CG4. Walking

00. None of the time

01. Some of the time

02. All of the time

03. REFUSED

04. DON'T KNOW

CG5. Getting in and out of beds and chairs

00. None of the time

01. Some of the time

02. All of the time

03. REFUSED

04. DON'T KNOW

CG6. Getting dressed

00. None of the time

01. Some of the time

02. All of the time

03. REFUSED

04. DON'T KNOW

CG7. Getting to and from the toilet

00. None of the time

01. Some of the time

02. All of the time

03. REFUSED

04. DON'T KNOW

CG8. Bathing or showering

00. None of the time

01. Some of the time

02. All of the time

03. REFUSED

04. DON'T KNOW

CG9. Dealing with incontinence or diapers

00. None of the time

01. Some of the time

02. All of the time

03. REFUSED

04. DON'T KNOW

CG10. Eating / Feeding

00. None of the time

01. Some of the time

02. All of the time

03. REFUSED

04. DON'T KNOW

[Instrumental Activities of Daily Living]

Using the same answers, "none, some, or all of the time", please tell me how much help you provide (veteran) for the following activities.

CG11. Managing finances, such as paying bills, or filling out insurance claims

00. None of the time

01. Some of the time

02. All of the time

03. REFUSED

04. DON'T KNOW

CG12 Grocery shopping

00. None of the time

01. Some of the time

02. All of the time

03. REFUSED

04. DON'T KNOW

CG13 Housework, such as doing dishes, laundry, or straightening up

00. None of the time

01. Some of the time

02. All of the time

03. REFUSED

04. DON'T KNOW

CG14 Preparing meals

00. None of the time

01. Some of the time

02. All of the time

03. REFUSED

04. DON'T KNOW

CG15 Transportation, such as driving, or helping arrange other transportation

00. None of the time

01. Some of the time

02. All of the time

03. REFUSED

04. DON'T KNOW

CG16 Arranging or supervising services from an agency, such as nurses or aides

00. None of the time

01. Some of the time

02. All of the time

03. REFUSED

04. DON'T KNOW

Medications

Now I have a few questions about medications (read answer choices)

CG17 Does (Veteran) take any prescription medicine?

01. Yes
02. No
03. REFUSED
04. DON'T KNOW

CG17_1 [IF YES…] Would you say (Veteran) needs someone to oversee giving him/her medicine in the right amount and on time, or that he/she manages this well on his/her own?

01. NEEDS HELP
02. MANAGES ON OWN
03. REFUSED
04. DON'T KNOW

CG17_2 Do you feel you know as much as you need to about the prescription medicine (veteran) takes, or that you need to know more about it?

01. KNOW AS MUCH AS NEED TO KNOW

02. NEEDED TO KNOW MORE ABOUT IT

03. REFUSED

04. DON'T KNOW

[Other types of assistance]

There are many other ways that a helper may provide medical support. Please answer yes or no. Do you:

CG18 Accompany (Veteran) to the doctor?

01. Yes

02. No

03. REFUSED

04. DON'T KNOW

CG19 Change bandages or wound dressings for (Veteran)?

01. Yes

02. No

03. REFUSED

04. DON'T KNOW

CG20 Help (Veteran) with medical equipment, such as a ventilator or oxygen?

01. Yes

02. No

03. REFUSED

04. DON'T KNOW

CG21 Help (Veteran) with rehabilitation, such as exercise?

01. Yes

02. No

03. REFUSED

04. DON'T KNOW

CG22 Are there other ways that you provide medical support to (Veteran)?

01. Yes

02. No

03. REFUSED

04. DON'T KNOW

IF YES What are they?_____ CG22_1_OTH _____

[Caregiving Skills and Self-Efficacy]

CG23 Thinking now of all the kinds of help you provide for (veteran), how confident are you in your ability to provide assistance? (NOTE: Read answer choices)

01. Very confident

02. Somewhat confident

03. Somewhat not confident

04. Not at all confident

05. REFUSED

06. DON'T KNOW

[Hours per week]

CG24 Thinking now of all the kinds of help you provide for (veteran), about how many hours do you spend in an average week [each day x 7], doing these things?

_____hrs/week

01 REFUSED

02 DON'T KNOW

[Other helper support]

CG25 Has anyone else provided unpaid help to (veteran) during the last 12 months?

01. Yes

02. No

03. REFUSED

04. DON'T KNOW

IF YES ANSWER THE FOLLOWING

CG25_1 If so, what relationship are they to (veteran)?

01 SPOUSE

02 PARENT

03 MOTHER/FATHER-IN-LAW

04 SON/DAUGHTER

05 SON/DAUGHTER-IN-LAW

06 BROTHER/SISTER

07 BROTHER/SISTER-IN-LAW

08 GRANDMOTHER/GRANDFATHER

09 GRANDPARENT-IN-LAW

10 AUNT/UNCLE

11 NIECE/NEPHEW

12 NEIGHBOR

13 OTHER FRIEND / /RELATIVE (SPECIFY___CG25_1 _OTH_____)

14 COMPANION/PARTNER

15 MULTIPLE FAMILY MEMBERS

16 VOLUNTEER (E.G., RED CROSS)

17 REFUSED

18 ON'T KNOW

CG26 If for any reason you are unable to care for (veteran) any longer, is there someone else (friend or relative) who is willing to step in for you?

01. Yes

02. No

03. REFUSED

04. DON'T KNOW

CG26_1 IF YES: What relationship is that person to (veteran)?

01 SPOUSE

02 PARENT

03 MOTHER/FATHER-IN-LAW

04 SON/DAUGHTER

05 SON/DAUGHTER-IN-LAW

06 BROTHER/SISTER

07 BROTHER/SISTER-IN-LAW

08 GRANDMOTHER/GRANDFATHER

09 GRANDPARENT-IN-LAW

10 AUNT/UNCLE

11 NIECE/NEPHEW

12 NEIGHBOR

13 OTHER FRIEND / /RELATIVE (SPECIFY_____ CG26_1_OTH _____)

14 COMPANION/PARTNER

15 MULTIPLE FAMILY MEMBERS

16 VOLUNTEER (E.G., RED CROSS)

17 REFUSED

18 ON'T KNOW

CG27 During the last 12 months, did (veteran) receive any paid help?

01. Yes
02. No
03. REFUSED
04. DON'T KNOW

IF YES, then answer the following…

CG27_1 An aide or nurses' aide?

01. Yes
02. No
03. REFUSED
04. DON'T KNOW

CG27_2 A housekeeper hired to clean or cook?

01. Yes
02. No
03. REFUSED
04. DON'T KNOW

CG27_3 Any other people who are paid to help her/him?

01. Yes Who?_____ CG27_3_OTH_____
02. No

03. REFUSED

04. DON'T KNOW

[Coping Style]

I'm going to read a list of ways that helpers such as yourself have coped with the demands of caregiving. For each one, please tell me, yes or no, whether you have used any of these. Have you ever tried to cope with caregiving stress by:

CG28 Talking with or seeking advice from friends / relatives?

01. Yes

02. No

03. REFUSED

04. DON'T KNOW

CG29 Exercising or working out?

01. Yes

02. No

03. REFUSED

04. DON'T KNOW

CG30 Taking any kind of medication to cope with the demands of caregiving?

01. Yes
02. No
03. REFUSED
04. DON'T KNOW

CG31 Talking to a professional or spiritual counselor?

01. Yes
02. No
03. REFUSED
04. DON'T KNOW

CG32 Praying?

01. Yes
02. No
03. REFUSED
04. DON'T KNOW

CG33 Reading about caregiving in books or other materials?

01. Yes
02. No
03. REFUSED
04. DON'T KNOW

CG34 Going on the Internet to find information?

01. Yes

02. No

03. REFUSED

04. DON'T KNOW

IF YES, which of the following things have you looked for on the Internet?

CG34_1 Information about (veteran) condition and treatment?

01. Yes

02. No

03. REFUSED

04. DON'T KNOW

CG34_2 Information about services available for people like your (veteran)?

01. Yes

02. No

03. REFUSED

04. DON'T KNOW

CG34_3 Support or advice from people with similar caregiving experiences?

01. Yes
02. No
03. REFUSED
04. DON'T KNOW

CGHLP35 Talk with a nurse, doctor, or social worker at the VA Medical Center?

01. Yes
02. No
03. REFUSED
04. DON'T KNOW

IF YES, which of the following did you talk to?

CG35_1 VA doctor?

01. Yes
02. No
03. REFUSED
04. DON'T KNOW

CG35_2 VA nurse?

01. Yes
02. No
03. REFUSED
04. DON'T KNOW

CG35_3 VA social worker?

01. Yes

02. No

03. REFUSED

04. DON'T KNOW

CG35_4 Other VA staff or volunteer?

1. Yes

02. No

03. REFUSED

04. DON'T KNOW

[Social Support]

Now I am going to ask you some other questions about sources of support. For each, tell me if you strongly disagree, disagree, somewhat disagree, are neutral, somewhat agree, agree, or strongly agree

CG36 There is someone I feel close to who makes me feel good.

01 strongly disagree

02 disagree

03 somewhat disagree

04 neutral

05 somewhat agree

06 agree

07 strongly agree

08 don't know

09 refused

CG37 I belong to a group in which I feel important.

01 strongly disagree

02 disagree

03 somewhat disagree

04 neutral

05 somewhat agree

06 agree

07 strongly agree

08 don't know

09 refused

CG38 People let me know that I do well at my work (job, homemaking….)

01 strongly disagree

02 disagree

03 somewhat disagree

04 neutral

05 somewhat agree

06 agree

07 strongly agree

08 don't know

09 refused

CG39 I have enough contact with the person who makes me feel special.

01 strongly disagree

02 disagree

03 somewhat disagree

04 neutral

05 somewhat agree

06 agree

07 strongly agree

08 don't know

09 refused

CG40 I spend time with others who have the same interests that I do….

01 strongly disagree

02 disagree

03 somewhat disagree

04 neutral

05 somewhat agree

06 agree

07 strongly agree

08 don't know

09 refused

CG41 Others let me know that they enjoy working with me (job, committees, projects).

01 strongly disagree

02 disagree

03 somewhat disagree

04 neutral

05 somewhat agree

06 agree

07 strongly agree

08 don't know

09 refused

CG42 There are people who are available if I need help over an extended period of time

01 strongly disagree

02 disagree

03 somewhat disagree

04 neutral

05 somewhat agree

06 agree

07 strongly agree

08 don't know

09 refused

CG43 Among my group of friends we do favors for each other.

01 strongly disagree

02 disagree

03 somewhat disagree

04 neutral

05 somewhat agree

06 agree

07 strongly agree

08 don't know

09 refused

CG44 I have the opportunity to encourage other to develop their interests and skills.

01 strongly disagree

02 disagree

03 somewhat disagree

04 neutral

05 somewhat agree

06 agree

07 strongly agree

08 don't know

09 refused

CG45 I have relatives or friends that will help me out even if I can't pay them back.

01 strongly disagree

02 disagree

03 somewhat disagree

04 neutral

05 somewhat agree

06 agree

07 strongly agree

08 don't know

09 refused

CG46 When I am upset, there is someone I can be with who lets me be myself….

01 strongly disagree

02 disagree

03 somewhat disagree

04 neutral

05 somewhat agree

06 agree

07 strongly agree

08 don't know

09 refused

CG47 I know that others appreciate me as a person.

01 strongly disagree

02 disagree

03 somewhat disagree

04 neutral

05 somewhat agree

06 agree

07 strongly agree

08 don't know

09 refused

CG48 There is someone who loves and cares about me.

01 strongly disagree

02 disagree

03 somewhat disagree

04 neutral

05 somewhat agree

06 agree

07 strongly agree

08 don't know

09 refused

CG49 I have people to share social events and fun activities with….

01 strongly disagree

02 disagree

03 somewhat disagree

04 neutral

05 somewhat agree

06 agree

07 strongly agree

08 don't know

09 refused

CG50 I have a sense of being needed by another person

01 strongly disagree

02 disagree

03 somewhat disagree

04 neutral

05 somewhat agree

06 agree

07 strongly agree

08 don't know

09 refused

[Role demands]

OK, now I am going to ask a few questions about other demands on your time, such as working, or caring for others besides (veteran). Please answer yes or no.

CG51 Are there any children or grandchildren living in your household under 18 years of age?

01. Yes

02. No

03. REFUSED

04. DON'T KNOW

CG51_1 IF YES, are you the primary caretaker of the children or grandchildren living in your home?

01. Yes

02. No

03. REFUSED

04. DON'T KNOW

CG52 Does anyone over age 18 live with you (excluding the veteran)?

01. Yes

02. No

03. REFUSED

04. DON'T KNOW

CG52_1 IF YES, Does this person also provide assistance to (veteran)?

01. Yes

02. No

03. REFUSED

04. DON'T KNOW

CG52_2 Do you provide medical/health care to this person in addition to (veteran)?

01. Yes

02. No

03. REFUSED

04. DON'T KNOW

[CG-CR Relationship Quality]

CG53 Now I have a question about the quality of your relationship with (Veteran). Would you say it is: [Read options 1 – 6]

01. Very good
02. good
03. somewhat good
04. somewhat poor
05. poor
06. very poor
07. REFUSED
08. DON'T KNOW

[Health Status & Self-care behaviors]

Now I would like to ask you some questions about your health.

CG54 Have you smoked cigarettes in the past year?

01. Yes
02. No
03. REFUSED
04. DON'T KNOW

CG54_1 IF YES, how many cigarette per day?_____.

CG55 Have you drank alcohol in the past year?

01. Yes

02. No

03. REFUSED

04. DON'T KNOW

CG55_1 IF YES, how many drinks per day?_____.

CG56 In the past 6 months, have you found that you had the time to see your doctor when you thought you should?

01. Yes

02. No

03. REFUSED

04. DON'T KNOW

CG57 Because of any physical or health problem, do you need the help of other persons for your personal care needs, such as eating, bathing, dressing, or getting around the home?

01. Yes

02. No

03. REFUSED

04. DON'T KNOW

CG58 Because of any physical or health problem, do you need the help of other persons in handling your routine needs, such as everyday household chores, doing necessary business, shopping or getting around for other purposes?

01. Yes
02. No
03. REFUSED
04. DON'T KNOW

Do you have appointments at least once per year for any of the following,?

CG59 Eye examination

01. Yes
02. No
03. REFUSED
04. DON'T KNOW

CG60 Dental examination

01. Yes
02. No
03. REFUSED
04. DON'T KNOW

CG61 Blood pressure check-up

01. Yes
02. No
03. REFUSED

04. DON'T KNOW

CG62 Do you get a flu vaccine (flu shot) each year?

01. Yes
02. No
03. REFUSED
04. DON'T KNOW

CG63 Pap smear (if female)

01. Yes
02. No
03. REFUSED
04. DON'T KNOW
05. NA

CG64 Mammogram (if female)

01. Yes
02. No
03. REFUSED
04. DON'T KNOW
05. NA

CG65 Prostate examination (if male)

01. Yes

02. No

03. REFUSED

04. DON'T KNOW

05. NA

[Working helpers]

CG66 Now I have a few questions about working. Are you currently:

01. Working full time

02. Working part time

03. A student

04. Disabled

05. Retired

06. A homemaker

07. Unemployed and looking for work

08. Unemployed and not looking for work, or

09. Something else (SPECIFY _____ CG66_OTH _____)

10. REFUSED

11. DON'T KOW

Now I would like to ask some questions about how you feel about helping (veteran). For each, tell me if you strongly agree, agree, disagree, or strongly disagree.

Providing help to (veteran) has:

CG67 Made me feel more useful.

01. Strongly agree

02. Agree

03. Disagree

04. Strongly disagree

05. REFUSED

06. DON'T KNOW

CG68 Made me feel good about myself.

01. Strongly agree

02. Agree

03. Disagree

04. Strongly disagree

05. REFUSED

06. DON'T KNOW

CG69 Made me feel needed.

01. Strongly agree
02. Agree
03. Disagree
04. Strongly disagree
05. REFUSED
06. DON'T KNOW

CG70 Made me feel appreciated.

01. Strongly agree
02. Agree
03. Disagree
04. Strongly disagree
05. REFUSED
06. DON'T KNOW

CG71 Made me feel important.

01. Strongly agree
02. Agree
03. Disagree
04. Strongly disagree
05. REFUSED
06. DON'T KNOW

CG72 Made me feel strong and confident.

01. Strongly agree
02. Agree
03. Disagree
04. Strongly disagree
05. REFUSED
06. DON'T KNOW

CG73 Given more meaning to my life.

01. Strongly agree
02. Agree
03. Disagree
04. Strongly disagree
05. REFUSED
06. DON'T KNOW

CG74 Enabled me to learn new skills.

01. Strongly agree
02. Agree
03. Disagree
04. Strongly disagree
05. REFUSED
06. DON'T KNOW

CG75 Enabled me to appreciate life more.

01. Strongly agree
02. Agree
03. Disagree
04. Strongly disagree
05. REFUSED
06. DON'T KNOW

CG76 Enabled me to develop a more positive attitude toward life.

01. Strongly agree
02. Agree
03. Disagree
04. Strongly disagree
05. REFUSED
06. DON'T KNOW

CG77 Strengthened my relationships with others.

01. Strongly agree
02. Agree
03. Disagree
04. Strongly disagree
05. REFUSED
06. DON'T KNOW

[ZARIT] CG78 – CG 89 are not included in the secondary analysis

Now, I would like to ask you some questions about the effect that caring for (veteran) has on you. For each, please tell me yes or no.

[CAREGIVING STRAIN INDEX]

To interviewer: Only read out the examples if the interviewee needs explanations.

CG90 Sleep is disturbed (e.g., because veteran is in and out of bed or wanders around at night).

01. Yes
02. No
03. REFUSED
04. DON'T KNOW

CG91 It is inconvenient (e.g., because helping veteran takes so much time or it's a long drive over to help).

01. Yes
02. No
03. REFUSED
04. DON'T KNOW

CG92 It is a physical strain (e.g., because of lifting veteran in and out of a chair; effort or concentration is required).

01. Yes
02. No
03. REFUSED
04. DON'T KNOW

CG93 It is confining (e.g., helping veteran restricts free time or cannot go visiting).

01. Yes
02. No
03. REFUSED
04. DON'T KNOW

CG94 There have been family adjustments (e.g., because helping veteran has disrupted routine; there has been no privacy).

01. Yes
02. No
03. REFUSED
04. DON'T KNOW

CG95 There have been changes in personal plans (e.g., had to turn down a job; could not go on vacation).

01. Yes
02. No
03. REFUSED
04. DON'T KNOW

CG96 There have been other demands on my time (e.g., from other family members).

01. Yes
02. No
03. REFUSED
04. DON'T KNOW

CG97 There have been emotional adjustments (e.g., because of severe arguments).

01. Yes
02. No

03. REFUSED

04. DON'T KNOW

CG98 Some behavior is upsetting (e.g., because of incontinence; veteran has trouble remembering things; or veteran accuses people of taking things).

01. Yes

02. No

03. REFUSED

04. DON'T KNOW

CG99 It is upsetting to find [veteran's name] has changed so much from his/her former self (e.g., he/she is a different person than he/she used to be).

01. Yes
02. No
03. REFUSED
04. DON'T KNOW

CG100 There have been work adjustments (e.g., because of having to take time off)

01. Yes
02. No
03. REFUSED
04. DON'T KNOW

CG101 It is a financial strain.

01. Yes
02. No
03. REFUSED
04. DON'T KNOW

CG102 Feeling completely overwhelmed (e.g., because of worry about veteran; concerns about how you will manage).

01. Yes
02. No
03. REFUSED

04. DON'T KNOW

CG103 We have been talking about the help you provide for your (veteran). Do you feel you had a choice in taking on this responsibility for caring for your (veteran)?

01. Yes

02. No

03. REFUSED

04. DON'T KNOW

[GDS-SF]

We are almost finished. I would like to ask a few more questions about some of your feelings in general. Please answer the following questions based on how you have felt during the past month. Please answer yes or no.

CG104 Are you basically satisfied with your life?

01. Yes

02. No

03. REFUSED

04. DON'T KNOW

CG105 Have you dropped many of your activities and interests?

01. Yes

02. No

03. REFUSED

04. DON'T KNOW

CG106 Do you feel that your life is empty?

01. Yes
02. No
03. REFUSED
04. DON'T KNOW

CG107 Do you often get bored?

01. Yes
02. No
03. REFUSED
04. DON'T KNOW

CG108 Are you in good spirits most of the time?

01. Yes
02. No
03. REFUSED
04. DON'T KNOW

CG109 Are you afraid that something bad is going to happen to you?

01. Yes

02. No

03. REFUSED

04. DON'T KNOW

CG110 Do you feel happy most of the time?

01. Yes

02. No

03. REFUSED

04. DON'T KNOW

CG111 Do you often feel helpless?

01. Yes

02. No

03. REFUSED

04. DON'T KNOW

CG112 Do you prefer to stay at home, rather than going out and doing new things?

01. Yes

02. No

03. REFUSED

04. DON'T KNOW

CG113 Do you feel you have more problems with memory than most?

01. Yes
02. No
03. REFUSED
04. DON'T KNOW

CG114 Do you think it is wonderful to be alive now?

01. Yes
02. No
03. REFUSED
04. DON'T KNOW

CG115 Do you feel pretty worthless the way you are now?

01. Yes
02. No
03. REFUSED
04. DON'T KNOW

CG116 Do you feel full of energy?

01. Yes
02. No
03. REFUSED
04. DON'T KNOW

CG117 Do you feel that your situation is hopeless?

01. Yes
02. No
03. REFUSED
04. DON'T KNOW

CG118 Do you think that most people are better off than you are?

01. Yes
02. No
03. REFUSED
04. DON'T KNOW

CG119 I would like to ask you a question about your health. In general, would you say your health is:

01. Excellent
02. Very Good
03. Good

04. Fair

05. Poor

06. REFUSED

07. DON'T KNOW

Just a few more questions, then we are done

CGAge: What was your age on your last birthday?

____ years

01 REFUSED

02 DON'T KNOW

CGGender: Are you male or female? (DO NOT READ UNLESS YOU ARE UNABLE TO DETERMINE THIS)

01 Female

02 Male

03 REFUSED

CGMarital: What is your current marital status?

01. Married

02. Widowed

03. Separated

04. Divorced

05. Single, that is never been married

06. Living with a partner

07. REFUSED

08. DON'T KNOW

CGEDUC: What is the last grade of school you completed?

01. Less than high school

02. High school graduate / GED

03. Some college or technical school

05. College graduate

06. Graduate school/graduate work

07. REFUSED

08. DON'T KNOW

CGRace/Ethnicity: How would you describe your primary race or ethnicity?

01. White
02. Black or African American
03. Latino or Hispanic/Puerto Rican
04. Latino or Hispanic/Mexican-American
05. American Indian or Alaska Native
06. Asian, Native Hawaiian, Other Pacific Islander, or other (specify)
07. REFUSED

08. DON'T KNOW

I would now like to verify your preferred mailing address for our records.

(If person asks, let them know we need it to mail the incentive; if they refuse to give their, you can state that we will send their incentive to the veteran's address)

Participant address

Thank you very much for your time. Your responses have been very helpful to this research. Please feel free to contact us with any questions about this survey.

Appendix B

Veteran Survey

Introduction

Hello. My name is _____ and I am an interviewer with the Department of Veterans Affairs. I am calling today because you returned a form indicating your interest and agreement to participate in a survey on helpers of veterans. Are you available to talk right now? [if not, schedule a time for follow up]

This survey is part of an important national study conducted by the Department of Veterans Affairs. The purpose of this survey is to better understand how family and friends help veterans at home. We really appreciate your participation.

I'd like to remind you that your response to any question is voluntary, and you may ask us to skip any question that you do not wish to answer. You can stop this discussion at any time. If you decide not to participate your decision will not affect the care you receive from the VA. The survey should take less than 30 minutes of your time.

[Conduct mental status screen]

I'd like to review the definition we use for a helper. A helper is a person who assists a friend / relative 18 years of age or older. Assistance may include help with personal needs, household chores, a person's finances, or visiting regularly to see how they are doing.

Do you have any questions before we proceed?

OK, let's get started.

[CG-CR Relationship]

VET1. What is (Caregiver's) relationship to you? He/she is your . . .

01 SPOUSE

02 PARENT

03 MOTHER/FATHER-IN-LAW

04 SON/DAUGHTER

05 SON/DAUGHTER-IN-LAW

06 BROTHER/SISTER

07 BROTHER/SISTER-IN-LAW

08 GRANDMOTHER/GRANDFATHER

09 GRANDPARENT-IN-LAW

10 AUNT/UNCLE

11 NIECE/NEPHEW

12 NEIGHBOR

13 OTHER FRIEND / /RELATIVE (SPECIFY_ VET1_OTH ___)

14 COMPANION/PARTNER

15. REFUSED

16. DON'T KNOW

[Living Arrangement]

VET2. Does (Caregiver) live....

01. In the same household as you

02. Within a twenty minute drive of your home

03. Between 20 minutes and an hour drive from your home

04. A one to two hour drive from your home, or

05. More than two hours away?

06. REFUSED

07. DON'T KNOW

[IF NOT IN HOUSEHOLD] IF answer to question 2 is not in the same household, i.e. responses 02 through 05

VET2_1 On average, how often did (NAME) visit you in the last year?

01. More than once a week

02. once a week

03. few times a month

04. once a month

05. few times a year

06. or less often

07. REFUSED

08. DON'T KNOW

VET2_2 Does (Caregiver) currently live:

01. Alone

02. With her/his spouse

03. With her/his grown children

04 .With other family members

05. With friend

06. With an aide, housekeeper, or other staff,

07. Or with someone else? (SPECIFY ___VET2_2_OTH___)

08. REFUSED

09. DON'T KNOW

[Type of assistance provided]

I'm going to read a list of kinds of help which your caregiver might provide to you. I will ask you to answer with one of 3 responses. So, for each activity I read, just tell me if you get help none of the time, some of the time, or all of the time. [note whether helper does this, even if the veteran could do it for himself]

Does NAME help you with ...

[Activities of Daily Living]

VET3.Taking medicines, pills, or injections

00. None of the time

01. Some of the time

02. All of the time

03. REFUSED

04. DON'T KNOW

VET4. Walking

00. None of the time

01. Some of the time

02. All of the time

03. REFUSED

04. DON'T KNOW

VET5. Getting in and out of beds and chairs

00. None of the time

01. Some of the time

02. All of the time

03. REFUSED

04. DON'T KNOW

VET6. Getting dressed

00. None of the time

01. Some of the time

02. All of the time

03. REFUSED

04. DON'T KNOW

VET7. Getting to and from the toilet

00. None of the time

01. Some of the time

02. All of the time

03. REFUSED

04. DON'T KNOW

VET8. Bathing or showering

00. None of the time

01. Some of the time

02. All of the time

03. REFUSED

04. DON'T KNOW

VET9. Dealing with incontinence or diapers

00. None of the time

01. Some of the time

02. All of the time

03. REFUSED

04. DON'T KNOW

VET10. Eating / Feeding

00. None of the time

01. Some of the time

02. All of the time

03. REFUSED

04. DON'T KNOW

[Instrumental Activities of Daily Living]

Using the same answers, “none, some, or all of the time”, please tell me how much help NAME provides you for the following activities, regardless of whether you are capable of doing them.

VET11. Managing finances, such as paying bills, or filling out insurance claims

00. None of the time

01. Some of the time

02. All of the time

03. REFUSED

04. DON'T KNOW

VET12. Grocery shopping

00. None of the time

01. Some of the time

02. All of the time

03. REFUSED

04. DON'T KNOW

VET13. Housework, such as doing dishes, laundry, or straightening up

00. None of the time

01. Some of the time

02. All of the time

03. REFUSED

04. DON'T KNOW

VET14. Preparing meals

00. None of the time

01. Some of the time

02. All of the time

03. REFUSED

04. DON'T KNOW

VET15. Transportation, such as driving, or helping arrange other transportation

00. None of the time

01. Some of the time

02. All of the time

03. REFUSED

04. DON'T KNOW

VET16. Arranging or supervising services from an agency, such as nurses or aides

00. None of the time

01. Some of the time

02. All of the time

03. REFUSED

04. DON'T KNOW

Medications

Now I have a few questions about medications.

VET17. Do you take any prescription medicine?

05. Yes
06. No
07. REFUSED
08. DON'T KNOW

If yes…VET17_1

Would you say (NAME) helps to oversee giving you medicine in the right amount and on time, or that you manage this well on your own?

01. NEEDS HELP
02. MANAGES ON OWN
03. REFUSED
04. DON'T KNOW

VET17_2. Do you feel you know as much as you need to about the prescription medicine you take, or that you need to know more about it?

01. KNOW AS MUCH AS NEED TO KNOW
02. NEEDED TO KNOW MORE ABOUT IT
03. REFUSED
04. DON'T KNOW

[Other types of assistance]

For the following questions, answer yes or no. If they don't apply to your situation, you may answer no.

There are many other ways that a helper may provide medical support. Does NAME:

VET18. Accompany you to the doctor?

01. Yes

02. No

03. REFUSED

04. DON'T KNOW

VET19. Change bandages or wound dressings for you?

01. Yes

02. No

03. REFUSED

04. DON'T KNOW

VET20. Help you with medical equipment, such as a ventilator or oxygen?

01. Yes

02. No

03. REFUSED

04. DON'T KNOW

VET21. Help you with rehabilitation, such as exercise?

01. Yes

02. No

03. REFUSED

04. DON'T KNOW

VET22. Are there other ways that NAME provides medical support to you?

01. Yes

02. No

03. REFUSED

04. DON'T KNOW

If YES What are they?_____ _____ VET22_1_OTH _____

[Coping Strategies]

I'm going to read a list of ways that people such as yourself have coped with the demands of chronic illness. For each one, please tell me, yes or no, whether you have used any of these. Have you ever tried to cope with your illness by:

VET23. Talking with or seeking advice from friends / relatives?

01. Yes
02. No
03. REFUSED
04. DON'T KNOW

VET24. Exercising or working out?

01. Yes
02. No
03. REFUSED
04. DON'T KNOW

VET25. Taking any kind of medication (to cope with demands of chronic illness, not to treat the illness)?

01. Yes
02. No
03. REFUSED

04. DON'T KNOW

VET26. Talking to a professional or spiritual counselor?

01. Yes
02. No
03. REFUSED
04. DON'T KNOW

VET27. Praying?

01. Yes
02. No
03. REFUSED
04. DON'T KNOW

VET28. Reading about chronic illness in books or other materials?

01. Yes
02. No
03. REFUSED
04. DON'T KNOW

VET29. Going on the Internet to find information?

01. Yes
02. No
03. REFUSED

04. DON'T KNOW

IF YES, which of the following things have you looked for on the Internet?

VET29_1. Information about (veteran) condition and treatment?

01. Yes

02. No

03. REFUSED

04. DON'T KNOW

VET29_2. Information about services available for people like your (veteran)?

01. Yes

02. No

03. REFUSED

04. DON'T KNOW

VET29_3. Support or advice from people with similar caregiving experiences?

01. Yes

02. No

03. REFUSED

04. DON'T KNOW

VET30. Talking with a nurse, doctor, or social worker at the VA Medical Center?

01. Yes

02. No

03. REFUSED

04. DON'T KNOW

IF YES, which of the following did you talk to?

VET30_1. VA doctor?

01. Yes

02. No

03. REFUSED

04. DON'T KNOW

VET30_2 VA nurse?

01. Yes

02. No

03. REFUSED

04. DON'T KNOW

VET30_3 VA social worker?

01. Yes

02. No

03. REFUSED

04. DON'T KNOW

VET30_4 Other VA staff or volunteer?

1. Yes

02. No

03. REFUSED

04. DON'T KNOW

[CG-CR Relationship Quality]

VET31. Now I have a question about the quality of your relationship with NAME. Would you say it is (read answer choices)?

09. Very good
10. good
11. somewhat good
12. somewhat poor
13. poor
14. very poor
15. REFUSED
16. DON'T KNOW

[Health Status & Self-care behaviors]

Now I would like to ask you some questions about your health.

VET32. Have you smoked cigarettes in the past year?

01. Yes

02. No

03. REFUSED

04. DON'T KNOW

VET32_1 IF YES, how many cigarettes per day? _____.

VET33. Have you drunk alcohol in the past year?

01. Yes

02. No

03. REFUSED

04. DON'T KNOW

VET33_1 IF YES, how many drinks per day?_____.

VET34. During the past 12 months have you been admitted to a VA hospital?

01. Yes

02. No

03. REFUSED

04. DON'T KNOW

VET35. During the past 12 months have you been admitted to a non-VA hospital?

01. Yes

02. No

03. REFUSED

04. DON'T KNOW

VET36. Now I have a question about working. Please answer this question based on your primary role. Are you currently:

01. Working full time

02. Working part time

03. A student

04. Disabled

05. Retired

06. A homemaker

07. Unemployed and looking for work

08. Unemployed and not looking for work, or

09. Something else (SPECIFY ___VET36_2 OTH_____)

10. REFUSED

11. DON'T KOW

We are almost finished. I would like to ask a few more questions about some of your feelings in general. Please answer the following questions based on how you have felt during the past month. You may answer yes or no.

[Depression]

VET37. Are you basically satisfied with your life?

01. Yes

02. No

03. REFUSED

04. DON'T KNOW

VET38. Have you dropped many of your activities and interests?

01. Yes

02. No

03. REFUSED

04. DON'T KNOW

VET39. Do you feel that your life is empty?

01. Yes

02. No

03. REFUSED

04. DON'T KNOW

VET40. Do you often get bored?

01. Yes

02. No

03. REFUSED

04. DON'T KNOW

VET41. Are you in good spirits most of the time?

01. Yes

02. No

03. REFUSED

04. DON'T KNOW

VET42. Are you afraid that something bad is going to happen to you?

01. Yes
02. No
03. REFUSED
04. DON'T KNOW

VET43. Do you feel happy most of the time?

01. Yes
02. No
03. REFUSED
04. DON'T KNOW

VET44. Do you often feel helpless?

01. Yes
02. No
03. REFUSED
04. DON'T KNOW

VET45. Do you prefer to stay at home, rather than going out and doing new things?

01. Yes
02. No
03. REFUSED
04. DON'T KNOW

VET46. Do you feel you have more problems with memory than most?

01. Yes

02. No

03. REFUSED

04. DON'T KNOW

VET47. Do you think it is wonderful to be alive now?

01. Yes

02. No

03. REFUSED

04. DON'T KNOW

VET48. Do you feel pretty worthless the way you are now?

01. Yes

02. No

03. REFUSED

04. DON'T KNOW

VET49. Do you feel full of energy?

01. Yes

02. No

03. REFUSED

04. DON'T KNOW

VET50. Do you feel that your situation is hopeless?

01. Yes

02. No

03. REFUSED

04. DON'T KNOW

VET51. Do you think that most people are better off than you are?

01. Yes

02. No

03. REFUSED

04. DON'T KNOW

[RATEHEALTH]

VET52. I would like to ask you a question about your health. In general, would you say your health is:

01. Excellent

02. Very Good

03. Good

04. Fair

05. Poor

06. REFUSED

07. DON'T KNOW

Just a few more questions, then we are done

VET53. Age: What was your age on your last birthday?

____ years

REFUSED

DON'T KNOW

VET54. Gender: Are you male or female? [DON'T READ UNLESS YOU CANNOT DETERMINE]

01 Female

02 Male

REFUSED

VET55. Marital: what is your current marital status?

01. Married

02. Widowed

03. Separated

04. Divorced

05. Single, that is never been married

06. Living with a partner

REFUSED

DON'T KNOW

VET56. Education: What is the last grade of school you completed?

01. LESS THAN HS

02. HS GRAD/GED

03. SOME COLLEGE or TECHNICAL SCHOOL

05. COLLEGE GRAD

06. GRADUATE SCHOOL/GRAD WORK

REFUSED

DON'T KNOW

VET57. Race/Ethnicity: Please describe your primary race/ethnicity:

01. White
02. Black or African American
03. Latino or Hispanic/Puerto Rican
04. Latino or Hispanic/Mexican-American
05. American Indian or Alaska Native
06. Asian, Native Hawaiian, Other Pacific Islander, or other (specify)
REFUSED

DON'T KNOW

VET58. At which VA site are you being treated?_____

I would now like to verify your preferred mailing address for our records.

(If person asks, let them know we need it to mail the incentive)

Thank you very much for your time. Your responses have been very helpful to this research. Please feel free to contact us with any questions about this survey.

Appendix C

Data Dictionary

SURVEY QUESTION #	VARIABLE NAME	VARIABLE TYPE	NOTES:
ID #	Caregiver ID	NOMINAL	
Q1	CG-CR Relationship	NOMINAL	
Q1.13spec	CG-CR Relationship If 'other'	NOMINAL	
Q2	Living arrangement	NOMINAL	
IFn2.1	visit in last year	NOMINAL	
IFn2.2	who lived with	NOMINAL	
2.2.07spec	who lived with if 'other'	TEXT	
Q3	ADL meds	NOMINAL	ADL includes Q3-10
Q4	ADL walk	NOMINAL	ADL: use responses 1, 2,or 3 indicating level of assistance (4=refused; 5=don't know); then sum for a total ADL score
Q5	ADL chair	NOMINAL	Higher is worse, i.e., more dependent
Q6	ADL dress	NOMINAL	
Q7	ADL toilet	NOMINAL	
Q8	ADL bathing	NOMINAL	

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Q9	ADL incontinence	NOMINAL	
Q10	ADL feed	NOMINAL	
Q11	IADL financial	NOMINAL	IADL includes Q11-16
Q12	IADL grocery	NOMINAL	IADL: sum up responses 1,2,or 3 indicating level of assistance (4=refused; 5=don't know); then sum for a total IADL score
Q13	IADL housework	NOMINAL	Higher is worse, i.e., more dependent
Q14	IADL meals	NOMINAL	
Q15	IADL transport	NOMINAL	
Q16	IADL services	NOMINAL	
Q17	Rx meds	NOMINAL	
IFy17.1	Meds help	NOMINAL	
IFy17.2	Meds knowledge	NOMINAL	
Q18	OTHASSTdoctor	NOMINAL	
Q19	OTHASSTbandages	NOMINAL	
Q20	OTHASSTequip	NOMINAL	
Q21	OTHASSTrehab	NOMINAL	
Q22	OTHASSTother	NOMINAL	
IFy22.1	OTHASST If 'other'	TEXT	
q23	CGCONFIDENCE	NOMINAL	

q24	HRSPERWEEK	CONTINUOUS	REFUSED OR DON'T KNOW will be missing data
q25	OTHERUNPAID	NOMINAL	
IFy25.1	OTHERUNPAID_WHO	NOMINAL	
IFy25.1.13spec	OTHERUNPAID_WHO_SPEC	TEXT	
q26	OTHSTEPIN	NOMINAL	
IFy26.1	OTHSTEPIN_WHO	NOMINAL	
IFy26.1.13spec	OTHSTEPIN_WHO_SPEC	TEXT	
q27	PAIDHELP	NOMINAL	
IFy27.1	PAIDAIDE	NOMINAL	
IFy27.2	PAIDHOUSEKEEPER	NOMINAL	
IFy27.3	PAIDOTHER	NOMINAL	
IFy27.3.1spec	PAIDOTHER_SPEC		
q28	COPEadvice	NOMINAL	
q29	COPEexerc	NOMINAL	
q30	COPEmeds	NOMINAL	
q31	COPEspiritual	NOMINAL	
q32	COPEpray	NOMINAL	
q33	COPEread	NOMINAL	
q34	COPEinternet	NOMINAL	

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IFy34.1	COPEinternet condition	NOMINAL	
IFy34.2	COPEinternet services	NOMINAL	
IFy34.3	COPEinternet support	NOMINAL	
q35	COPEprof	NOMINAL	
IFy35.1	COPEprof MD	NOMINAL	
IFy35.2	COPEprof RN	NOMINAL	
IFy35.3	COPEprof SW	NOMINAL	
IFy35.4	COPEprof vol	NOMINAL	
			Social Support questions; sum scores; range 15-105;
q36	SOCSUPP_FEELGOOD	NOMINAL	higher is better
q37	SOCSUPP_GROUP	NOMINAL	don't include response 8 or 9 as this is don't know or refused
q38	SOCSUPP_WORK	NOMINAL	
q39	SOCSUPP_SPECIAL	NOMINAL	
q40	SOCSUPP_INTERESTS	NOMINAL	
q41	SOCSUPP_ENJOY	NOMINAL	
q42	SOCSUPP_AVAILABLE	NOMINAL	
q43	SOCSUPP_FAVORS	NOMINAL	
q44	SOCSUPP_ENCOTHERS	NOMINAL	
q45	SOCSUPP_HELP	NOMINAL	

q46	SOCSUPP_UPSET	NOMINAL
q47	SOCSUPP_APPREC	NOMINAL
q48	SOCSUPP_LOVESME	NOMINAL
q49	SOCSUPP_SHAREACTIV	NOMINAL
q50	SOCSUPP_NEEDED	NOMINAL
q51	UNDER18_INHOME	NOMINAL
IFy51.1	UNDER18_INHOME_CG	NOMINAL
q52	OVER18_INHOME	NOMINAL
IFy52.1	OVER18_INHOME_HELP	NOMINAL
IFy52.2	OVER18_INHOME_CG	NOMINAL
q53	RELQUAL	NOMINAL
q54	SMK	NOMINAL
IFy54.1	NUMBCIG	CONTINUOUS
q55	DRINK	NOMINAL
IFy55.1	NUMDRINK	CONTINUOUS
q56	SEEDOCTOR	NOMINAL
q57	NEED_ADL_HELP	NOMINAL
q58	NEED_IADL_HELP	NOMINAL
q59	EYE	NOMINAL

q60	DENTAL	NOMINAL	
q61	BLOODPRESSURE	NOMINAL	
q62	FLUSHOT	NOMINAL	
q63	PAP	NOMINAL	
q64	MAMMO	NOMINAL	
q65	PROSTATE	NOMINAL	
q66	WORK	NOMINAL	
q66.09spec	WORKelse	TEXT	
q67	POSCG_USEFUL	NOMINAL	POSCG items are scored using a Likert scale
q68	POSCG_GOOD	NOMINAL	where 1= strongly agree to 4=strongly disagree
q69	POSCG_NEEDED	NOMINAL	items can be added for an overall score
q70	POSCG_APPRECIATE	NOMINAL	where lower scores indicate greater positive aspects of caregiving
q71	POSCG_IMPORTANT	NOMINAL	
q72	POSCG_CONFIDENT	NOMINAL	
q73	POSCG_MEANING	NOMINAL	
q74	POSCG_NEWSKILLS	NOMINAL	
q75	POSCG_APPREC_LIFE	NOMINAL	
q76	POSCG_POS_ATTITUDE	NOMINAL	
q77	POSCG_RELATIONSHIPS	NOMINAL	

q78	ZARIT1	NOMINAL	CALCLUATE two ZARIT scores:
q79	ZARIT2	NOMINAL	RISK SCORE = total of q 78, 79, 82, 87 (ZARIT 1,2,5,10)
			OVERALL SCORE = overall total of q78 through 89
q80	ZARIT3	NOMINAL	(ZARIT 1-12)
q81	ZARIT4	NOMINAL	responses 3 & 4 indicate refuse or don't know so don't use them
q82	ZARIT5	NOMINAL	
q83	ZARIT6	NOMINAL	
q84	ZARIT7	NOMINAL	
q85	ZARIT8	NOMINAL	
q86	ZARIT9	NOMINAL	
q87	ZARIT10	NOMINAL	
q88	ZARIT11	NOMINAL	
q89	ZARIT12	NOMINAL	
q90	STRAIN1	NOMINAL	STRAIN INDEX (Q90-102)
q91	STRAIN2	NOMINAL	SUM UP THE YES RESPONSES (1=YES ON SURVEY)
q92	STRAIN3	NOMINAL	(score of 7 or higher indicates need for assessment)
q93	STRAIN4	NOMINAL	responses 3 & 4 indicate refused, don't know, so don't use them
q94	STRAIN5	NOMINAL	
q95	STRAIN6	NOMINAL	

q96	STRAIN7	NOMINAL		
q97	STRAIN8	NOMINAL		
q98	STRAIN9	NOMINAL		
q99	STRAIN10	NOMINAL		
q100	STRAIN11	NOMINAL		
q101	STRAIN12	NOMINAL		
q102	STRAIN13	NOMINAL		
q103	CHOICE	NOMINAL		
q104	DEP1	NOMINAL	score 1 if no	DEP are q104-118; survey response 1=yes 2=no
q105	DEP2	NOMINAL	score 1 if yes	add score as noted in column D
q106	DEP3	NOMINAL	score 1 if yes them	responses 3 & 4 indicate refuse or don't know so don't use
q107	DEP4	NOMINAL	score 1 if yes	
q108	DEP5	NOMINAL	score 1 if no	
q109	DEP6	NOMINAL	score 1 if yes	
q110	DEP7	NOMINAL	score 1 if no	
q111	DEP8	NOMINAL	score 1 if yes	
q112	DEP9	NOMINAL	score 1 if yes	
q113	DEP10	NOMINAL	score 1 if yes	
q114	DEP11	NOMINAL	score 1 if no	

q115	DEP12	NOMINAL	score 1 if yes
q116	DEP13	NOMINAL	score 1 if no
q117	DEP14	NOMINAL	score 1 if yes
q118	DEP15	NOMINAL	score 1 if yes
q119	RATEHEALTH	NOMINAL	
q120	AGE	CONTINUOUS	
q121	GENDER	NOMINAL	
q122	MARITAL	NOMINAL	
q123	EDUC	NOMINAL	
q124	RACE	NOMINAL	

SURVEY QUESTION #	VARIABLE NAME	VARIABLE TYPE	NOTES:
ID #	Veteran ID	NOMINAL	
PGM_NAME	PGM_NAME		not in Iowa City data set??
Q1	CG-CR Relationship	NOMINAL	
Q1.13spec	CG-CR Relationship If 'other'	NOMINAL	
Q2	Living arrangement	NOMINAL	
IFn2.1	visit in last year	NOMINAL	

IFn2.2	who lived with	NOMINAL	
2.2.07spec	who lived with if 'other'	TEXT	
Q3	ADL meds	NOMINAL	ADL includes Q3-10
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Q7	ADL toilet	NOMINAL	
Q8	ADL bathing	NOMINAL	
Q9	ADL incontinence	NOMINAL	
Q10	ADL feed	NOMINAL	
Q11	IADL financial	NOMINAL	IADL includes Q11-16)
Q12	IADL grocery	NOMINAL	IADL: 1,2, or 3 indicating level of assistance (4=refused; 5=don't know); then sum for a total IADL score
Q13	IADL housework	NOMINAL	Higher is worse, i.e., more dependent
Q14	IADL meals	NOMINAL	
Q15	IADL transport	NOMINAL	
Q16	IADL services	NOMINAL	
Q17	Rx meds	NOMINAL	
IFy17.1	Meds help	NOMINAL	

IFy17.2	Meds knowledge	NOMINAL
Q18	OTHASSTdoctor	NOMINAL
Q19	OTHASSTbandages	NOMINAL
Q20	OTHASSTequip	NOMINAL
Q21	OTHASSTrehab	NOMINAL
Q22	OTHASSTother	NOMINAL
IFy22.1	OTHASST If 'other'	TEXT
Q23	COPEadvice	NOMINAL
Q24	COPEexerc	NOMINAL
Q25	COPEmeds	NOMINAL
Q26	COPEspiritual	NOMINAL
Q27	COPEpray	NOMINAL
Q28	COPEread	NOMINAL
Q29	COPEinternet	NOMINAL
IFy29.1	COPEinternet condition	NOMINAL
IFy29.2	COPEinternet services	NOMINAL
IFy29.3	COPEinternet support	NOMINAL
Q30	COPEprof	NOMINAL
IFy30.1	COPEprof MD	NOMINAL

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IFy30.2	COPEprof RN	NOMINAL		
IFy30.3	COPEprof SW	NOMINAL		
IFy30.4	COPEprof vol	NOMINAL		
Q31	RELQUAL	NOMINAL		
Q32	SMK	NOMINAL		
IFy32.1	NUMBCIG	CONTINUOUS		
Q33	DRINK	NOMINAL		
IFy33.1	NUMDRINK	CONTINUOUS		
Q34	VAADM	NOMINAL		
Q35	NONVAADM	NOMINAL		
Q36	WORK	NOMINAL		
Q36.09spec	WORKelse	TEXT		
Q37	DEP1	NOMINAL	score 1 if no	DEP are q104-114 Survey response 1=Yes, 2=No
Q38	DEP2	NOMINAL	score 1 if yes	Add score as noted on column D
Q39	DEP3	NOMINAL	score 1 if yes not use	responses 3&4 indicate refuse or don't know, do
Q40	DEP4	NOMINAL	score 1 if yes	
Q41	DEP5	NOMINAL	score 1 if no	
Q42	DEP6	NOMINAL	score 1 if yes	

Q43	DEP7	NOMINAL	score 1 if no
Q44	DEP8	NOMINAL	score 1 if yes
Q45	DEP9	NOMINAL	score 1 if yes
Q46	DEP10	NOMINAL	score 1 if yes
Q47	DEP11	NOMINAL	score 1 if no
Q48	DEP12	NOMINAL	score 1 if yes
Q49	DEP13	NOMINAL	score 1 if no
Q50	DEP14	NOMINAL	score 1 if yes
Q51	DEP15	NOMINAL	score 1 if yes
Q52	RATEHEALTH	NOMINAL	
Q53	AGE	CONTINUOUS	
Q54	GENDER	NOMINAL	
Q55	MARITAL	NOMINAL	
Q56	EDUC	NOMINAL	
Q57	RACE	NOMINAL	
Q58	SITE	NOMINAL	

VITA

Janet Maria Delgado was born in Havana, Cuba in 1955. Her mother went into labor during “Janet”, a category 5 hurricane which destroyed much of the Caribbean. You will never see another hurricane named Janet again because of the damage caused, as the name was retired. But that was only the beginning of the story!