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Being a caregiver to a spouse with advanced heart failure : a Ricoeurian phenomenology

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BEING A CAREGIVER TO A SPOUSE WITH ADVANCED HEART FAILURE: A RICOEURIAN PHENOMENOLOGY

by

Heide Christine Bursch

An Abstract

Of a thesis submitted in partial fulfillment
of the requirements for the Doctor of
Philosophy degree in Nursing
in the Graduate College of
The University of Iowa

July 2012

Thesis Supervisors: Professor Keela Herr
Associate Professor Howard Butcher

ABSTRACT

There are an estimated 5 million family caregivers supporting persons suffering from advanced heart failure (AHF) which constitutes the final stage of cardiovascular disease and is the primary cause of death for 1 in 8 Americans. AHF caregivers are instrumental in monitoring symptoms, promoting adherence, communicating with healthcare providers and making treatment choices for their care recipients (CRs) at the end of life. What little is known about the AHF caregiver experience comes from surveys, instruments and structured interviews and tends to exclude caregivers of CRs with advanced disease. The purpose of this interpretive phenomenology was to elicit the meaning of caring for a spouse with AHF and is the first of its kind in the US. Seven older spouses caring for persons with NYHA class III-IV HF recruited by the Advance Practice RN of a large regional hospital participated in 3 reflective interviews over the course of 2 months. Grounded in the Philosophy of Ethics by Paul Ricoeur and using a method based on his Theory of Interpretation, their reflections revealed the essence of the caregiver experience as “being fearfully vigilant, at the mercy of the disease while worrying about that which remains unspoken”. Separate inquiries invited participants to explore the meaning of symptom interpretation which was likened to “a walk in the fog on the rocky shore by a treacherous river”; and communication which illuminated caregivers’ ethical intention in caring for themselves and their loved ones. The fourth and final research question explored caregivers’ meaning making in the experience, symptom interpretation and communication over time which uncovered several missed opportunities for advance care planning. Findings support and add to recent models in palliative care, shared care and advance care planning in AHF. This study gives healthcare providers insight into the challenges to respect, self esteem and autonomy encountered by aging couples in the context of AHF. Participants identified personal learning needs related to being a caregiver, symptom interpretation, and managing clinical and emotional manifestations of AHF. Naming specific barriers in communication with their CRs as well as with healthcare providers they called for relationship counseling for the CG-CR dyad, and to be respected as part of the team by healthcare providers. Participants gave moving examples of how current models of care failed to meet their needs, with urgent implications for coordinated care by an interdisciplinary team of healthcare providers. This study identified the need for more phenomenological inquiry to understand (1) implications of CR's cognitive fluctuations on decision making for preferences of care, (2) CRs' personality changes attributed to an awareness of death being near, (3) the need to retain a purpose in living both as individuals and as a couple, and (4) how CRs reconcile daily choices in illness management and adherence with preferences for care at the end of life.

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CERTIFICATE OF APPROVAL

PH.D. THESIS

This is to certify that the Ph.D. thesis of

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has been approved by the Examining Committee
for the thesis requirement for the Doctor of Philosophy
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To Oma, Elmer, TC, Chewey, Lee, Librarian and Smiley

You are so young, so much before all beginning, and I would like to beg you, dear Sir, as well as I can, to have patience with everything unresolved in your heart and to try to love the questions themselves as if they were locked rooms or books written in a very foreign language. Don't search for the answers, which could not be given to you now, because you would not be able to live them. And the point is, to live everything. Live the questions now. Perhaps then, someday far in the future, you will gradually, without even noticing it, live your way into the answer.

Rainer Maria Rilke
Letters to a Young Poet: The Fourth Letter

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ABSTRACT

There are an estimated 5 million family caregivers supporting persons suffering from advanced heart failure (AHF) which constitutes the final stage of cardiovascular disease and is the primary cause of death for 1 in 8 Americans. AHF caregivers are instrumental in monitoring symptoms, promoting adherence, communicating with healthcare providers and making treatment choices for their care recipients (CRs) at the end of life. What little is known about the AHF caregiver experience comes from surveys, instruments and structured interviews and tends to exclude caregivers of CRs with advanced disease. The purpose of this interpretive phenomenology was to elicit the meaning of caring for a spouse with AHF and is the first of its kind in the US. Seven older spouses caring for persons with NYHA class III-IV HF recruited by the Advance Practice RN of a large regional hospital participated in 3 reflective interviews over the course of 2 months. Grounded in the Philosophy of Ethics by Paul Ricoeur and using a method based on his Theory of Interpretation, their reflections revealed the essence of the caregiver experience as “being fearfully vigilant, at the mercy of the disease while worrying about that which remains unspoken”. Separate inquiries invited participants to explore the meaning of symptom interpretation which was likened to “a walk in the fog on the rocky shore by a treacherous river”; and communication which illuminated caregivers’ ethical intention in caring for themselves and their loved ones. The fourth and final research question explored caregivers’ meaning making in the experience, symptom interpretation and communication over time which uncovered several missed opportunities for advance care planning. Findings support and add to recent models in palliative care, shared care and advance care planning in AHF. This study gives healthcare providers insight into the challenges to respect, self esteem and autonomy encountered by aging couples in the context of AHF. Participants identified personal learning needs related to being a caregiver, symptom interpretation, and managing clinical and emotional manifestations of AHF. Naming specific barriers in communication with their CRs as well as with healthcare providers they called for relationship counseling for the CG-CR dyad, and to be respected as part of the team by healthcare providers. Participants gave moving examples of how current models of care failed to meet their needs, with urgent implications for coordinated care by an interdisciplinary team of healthcare providers. This study identified specific areas for more phenomenological inquiry to understand (1) implications of CR's cognitive fluctuations on decision making for preferences of care, (2) CRs' personality changes attributed to an awareness of death being near, (3) the need to retain a purpose in living both as individuals and as a couple, and (4) how CRs reconcile daily choices in illness management and adherence with preferences for care at the end of life.

TABLE OF CONTENTS

LIST OF TABLES

Table

LIST OF FIGURES

Figure

CHAPTER 1

INTRODUCTION

Heart failure (HF) constitutes the final stage of heart disease, the number one cause of death in America. In 2008, HF was the primary contributory cause in one in eight, or more than 290,000 deaths in the US (Roger et al., 2011). Advanced heart failure (AHF) is defined as "a state in which patients have significant cardiac dysfunction with marked symptoms of dyspnea, fatigue, or symptoms relating to end-organ hypoperfusion at rest or with minimal exertion despite maximal medical therapy" (Goodlin et al., 2004, p. 200). In managing AHF, both patients and healthcare providers (HCP) rely heavily on an estimated 5 million family caregivers (Saunders, 2008b) who monitor symptoms, communicate with HCPs about treatment options and frequently have to assume the role of surrogate decision maker for their care recipient at the end of life.

Although much is known about the course of AHF in general it is difficult in the case of individual patients to recognize when symptoms of living with AHF become the symptoms of dying from AHF. There is little use of hospice or palliative care in AHF. Patients either die suddenly or “unexpectedly”, and/or experience hospital admissions, where family caregivers (CG) have to choose between options for aggressive care and costly interventions, often within days and hours of death. There is a documented lack of conversations with HCPs to prepare family CGs for their role of surrogate decision maker on behalf of the patient with AHF and little is known about how family CGs frame their intentions for monitoring symptoms and making treatment choices at the end of life with AHF.

A better understanding of the AHF CG experience is necessary to develop evidence-based recommendations for conversations about treatment options that include hospice and palliative care earlier in the disease trajectory (Goodlin, Quill, & Arnold, 2008). This study conducted a longitudinal phenomenological description of seven AHF family CGs as they interpreted and communicated about their patients' symptoms in AHF towards the end of life and reflected about their own role in managing symptoms and negotiating treatment options under specialized AHF care in a regional medical center.

The Medical Model as Context for Family Caregiving in AHF

The American Heart Association estimates that more than 5,700,000 Americans suffer from HF, afflicting 1 in 100 over the age of 65. HF was associated with more than 1 million hospital discharges in 2009, with the direct cost of care estimated at $39.2 billion for the year 2010 (Lloyd-Jones et al., 2010), a number that does not include the costs associated with informal family caregiving. AHF patients experience fatigue, breathlessness, anorexia, pain, insomnia, confusion, depression and anxiety (Janssen, Spruit, Wouters, & Schols, 2008; Solano, Gomes, & Higginson, 2006). Beyond optimal medical management, treatment guidelines for AHF recommend implantation of increasingly sophisticated pacing and defibrillating devices, home inotrope infusion and more recently, consideration of a ventricular assist device as a bridge to transplant or destination therapy, or palliative care (Hunt et al., 2009). There is no evidence supporting aggressive care beyond optimal medical management in the oldest patients, those with multiple co-morbidities, or those at the end-stage of the disease (J. Kirkpatrick & A. Kim, 2006). Despite this lack of evidence for aggressive interventions in older populations, data from the Centers for Medicare and Medicaid Services document ever increasing acuity of care for older persons in terminal hospitalizations before death (Barnato, McClellan, Kagay, & Garber, 2004) and continued lack of access to palliative care (Hunt et al., 2009).

Along with cancer and/or chronic lung disease, HF affects two thirds of Medicare patients who consume 30 to 35 percent of Medicare dollars in the last two years of life. Findings from the Dartmouth Atlas Project on this patient population showed that while

HCPs, patients and their families believed more specialty services and acute care interventions were better, patients did not benefit from “rescue medicine” as currently practiced, and instead fared worse when “everything possible” was done (Center for the Evaluative Clinical Sciences, 2006). As a matter of fact, in a sample of 4,493 patients from a sample of 5% of the entire Medicare beneficiary population for 1998-2002, mean survival was significantly longer for AHF patients who received hospice care compared to those who received traditional aggressive care at the end of life (Connor, Pyenson, Fitch, Spence, & Iwasaki, 2007). However, whether hospice is a useful model to provide the specialized symptom management necessary in AHF, has been questioned (Zambroski, Moser, Roser, Heo, & Chung, 2005).

Palliative care, on the other hand, combines aggressive symptom management with the goal of comfort, not prolongation of life, and offers interdisciplinary psychosocial support to patients and their family CGs. It is widely seen as a model of care that fits the needs of AHF patients and their families (Goodlin et al., 2004). However, difficulties in the interpretation of symptoms and communication about the end of life within the patient-family-HCP triad continue to be a barrier for implementation of palliative care in AHF until the final days or hours before death (Stuart, 2007). This study provides phenomenological understanding of the CG experience and illuminates how symptom interpretation and communication may provide barriers to introducing palliative care from the perspective of family CGs.

Turning to the Ethical Intention in AHF Caregiving

This study was grounded in the philosophical framework of Paul Ricoeur, a 20th century French Philosopher. According to Ricoeur, human beings use narrative to create meaning and coherence for who they are, what they do and what happens to them. Human beings who are autonomous actors in their own life story are able to act in ways that reconcile who they are, want to be and feel they should be. This means the autonomous human being is able to self actualize in his/her search for happiness, or, as Ricoeur calls it, follow his or her ethical intention for “the good life with and for others in just institutions.”

There is a small but growing body of literature describing physical and psychosocial outcomes in AHF CGs to begin to answer the questions of who they are, what they do and what happens to them. Caregiving is broadly defined as providing physical and/or emotional support to the patient (Saunders, 2003). CGs described in the literature are most often spouses but may also be children, siblings or friends of the patient (Usher & Cammarata, 2009). They administer complex medication regimens, obtain daily weights, supervise sodium and fluid restrictions, ensure adequate nutrition, encourage physical activity and assist with basic and instrumental activities of daily living (Molloy, Johnston, & Witham, 2005). In the course of caregiving, they experience impaired physical, emotional and social well-being (Usher & Cammarata, 2009).

To answer the questions of who do CGs want to be or feel they should be in the role of caregiving, there are three distinct lines of inquiry that especially merit insight from the phenomenological perspective. First, small descriptive studies showed that increased perceived control supported the ethical intention in terms of satisfaction and engagement in caregiving (Bakas, Pressler, Johnson, Nauser, & Shaneyfelt, 2006; Bull, Hansen, & Gross, 2000a; Chubinski, 2007; Dracup et al., 2004; Molloy et al., 2008) and by lowering CG burden (Ãgren, Evangelista, & Stramberg, 2010) and depression (Chung, Pressler, Dunbar, Lennie, & Moser, 2010). Second, shared care between care recipients and CGs, a concept developed by Riegel and others (2009), included communication and decision making and was thought to influence how CGs were able to remain true to themselves and confident in their caregiving ability. Third, Foster and McLellan (2002) pointed out that caregiving and decision making at the end of life must include family members’ perspective and ethical considerations. Fundamental questions about responsibility, guilt and commitment needed to be addressed to help CGs keep the promise of their ethical intention to their care recipients.

While symptom interpretation and communication were central to all, these studies were not designed to illuminate how symptom interpretation and communication might affect CGs' ethical intention in accompanying the care recipient to the end of life with AHF. CG communication at the end of life with AHF is understudied. Perceptions and experiences of CGs involved in shared decision making about treatment options in AHF are missing. In order to develop recommendations for EOL communication in AHF based on evidence of what human beings experience, feel and believe, it is necessary to understand how symptom interpretation and communication surrounding AHF shape CGs' ethical intention for the kind of care their family members should receive at the end of life.

Definition of Symptom Interpretation

CG symptom interpretation plays a key role in AHF management. For the purpose of this study, symptoms are those signs which are presumably related to the illness process, subjectively experienced and observed by the CG, and not necessarily measurable. The act of interpretation assigns meaning to these symptoms through the process of explanation and understanding. Symptom interpretation as a medical analysis leads to the act of diagnosing, i.e. identifying the nature or cause of some phenomenon. It therefore implies prognostication as a prediction of the symptom's outcome for the future, and is a call for action (Ricoeur, 2007). Although not from the same clinical reference point, the same act of diagnosis and prognostication is required of family CGs who are involved in managing the symptoms of the disease. Symptom interpretation therefore refers to the process by which CGs make meaning of their care recipients' experiences related to illness, and shapes CGs' intentions in how they are to act or who they are to be in response to the anticipated outcome.

CGs must observe their patients for various representations of angina, shortness of breath, lethargy and/or confusion or change in appetite (Clark et al., 2008), symptoms which become refractory to intervention toward the end of the disease trajectory. Additional symptoms include pain from other causes such as arthritis, or functional or cognitive decline for any reason. AHF patients themselves generally fail to recognize, interpret or respond to worsening symptoms due to progressive cognitive decline and their ability to accommodate to decreased activity tolerance (Jurgens, Hoke, Byrnes, & Riegel, 2009). Symptom interpretation in AHF is challenging because objective signs often do not correlate with the patient's subjective illness experience (Shah et al., 2001). For example, patients and their CGs may attribute increasing fatigue and functional losses to the natural aging process rather than an AHF exacerbation (Levenson, McCarthy, Lynn, Davis, & Phillips, 2000). Conversely, increasing depression may herald worsening AHF before there is evidence in cardiac function tests (Moser, 2002).

Intentions of professional HCPs in response to symptom interpretation in AHF generally aim to integrate symptom relief with life-prolonging interventions. In this process, it is difficult for family CGs to recognize when care shifts from aggressive interventions to maintain life, to palliative care, managing the symptoms of dying (Barnes, Gott, Payne, Seamark et al., 2006c; K. J. Boyd et al., 2004). Most CGs will have accompanied their care recipients through one or more life-threatening exacerbations from which the patient recovered to near baseline functional ability earlier in the disease trajectory. While contemporary HF care may successfully treat each crisis as an isolated event, CGs need to create meaning and coherence out of the cumulative occurrences of these events to understand progression of the disease towards death. There are no descriptions in the literature of how AHF-specific repeat experiences with near death shape CGs' symptom interpretation, or how communication surrounding these events affects the appraisal of their own role in providing physical and emotional support to the AHF care recipient over time.

It is important to note that this study aims to explore the CG's experience of these symptoms, not the care recipient's. Symptom interpretation can be conceptualized within the hermeneutic arc of explanation and understanding, and for the purpose of this study, involves CG reflections on the meaning they construct for their own role of CG as they observe patient symptoms. This conceptualization of symptom interpretation does not require congruence between CG and CR, or validation of symptoms through objective measurement. It is only the CG's subjective experience and attribution of meaning which is of interest. By focusing on CGs' internal processing of their personal symptom experience, this study sought to externalize feelings, emotions and ethical or moral thought processes that may affect their engagement in the CG role and ultimately shape participation in making treatment choices for their patients.

Definition of Communication

Communication is "any act by which one person gives to or receives from another person information about that person's needs, desires, perceptions, knowledge, or affective states. Communication may be intentional or unintentional, may involve conventional or unconventional signals, may take linguistic or nonlinguistic forms, and may occur through spoken or other modes" (National Joint Committee for the Communication Needs of Persons With Severe Disabilities, 1992, p. 2). In this study, communication is understood to be the process by which information about symptom interpretation is conveyed between family CGs and others. Communication in AHF caregiving requires CGs to have an understanding of the disease and its symptoms as well as the natural course of the disease towards death, in order to participate in implementing symptom management therapies, weigh their patient's symptom burden against burden of treatment and act as surrogate decision maker towards the end of life. Even when CGs would choose to remain the passive recipients of action (i.e. to avoid making decisions for their patients), the nature of AHF care and models of shared decision making generally require them to assume some degree of active surrogacy. The challenges surrounding prognosis and communication of EOL (EOL) status, in general (Hancock, Clayton et al., 2007b) and AHF status in particular (Goodlin, Quill, & Arnold, 2008; Zapka, Moran, Goodlin, & Knott, 2007), between CRs, CGs and HCPs have been well-documented. Because it is possible to communicate about the observation of symptoms without actually sharing the experience or assigned meaning of symptoms; and because one might convey the action in response to symptoms without sharing an understanding of the prognosis that prompted the action (Ricoeur & Kearney, 1996), it can be difficult for CGs to determine what their intention should be in caring for their family member with AHF. This leads to action that is seemingly disconnected from the circle of explanation and understanding.

According to Kvale (1996), communication occurs within three different contexts: Conversation as (1) human ontology, (2) epistemology, that is a way to gain knowledge, and (3), method or technique to achieve a purpose, such as a therapeutic intervention. Frederiksson and Eriksson have added as a fourth dimension that of "conversation as something good", that is conversation towards realizing Ricoeur's ethical intention (Fredriksson & Eriksson, 2003, p. 139). This study therefore seeks to explore (1) how CGs use communication to share their own world; (2) how they seek knowledge; (3) what kind of communication they engage in to create meaning and coherence for their own lives; and (4) how they use communication to enact their ethical intention in the CG role.

There has been a call for earlier incorporation of interdisciplinary palliative care into HF management (Goodlin et al., 2004) and access to hospice care (Zambroski, 2004) to manage AHF symptoms and meet the communication needs of AHF patients and their families. Instead, there is continued lack of conversation surrounding EOL care options within the CR- CG-HCP triad (Bekelman et al., 2009; Harding et al., 2008) and high intensity medical care continues to be associated with poor communication (Teno et al., 2005). More evidence is needed to develop guidelines for communication that reconciles patients' continued need for clinically aggressive symptom management with palliative care needs at the end of life (Goodlin, Quill, & Arnold, 2008; Stuart, 2007; Zapka, Moran, Goodlin, & Knott, 2007). This study explored the circle of explanation and understanding of AHF symptom interpretation and the role of communication in shaping CGs intentions for caregiving.

My Own Personal Orientation and the Ricoeur Framework

As nurse researcher, I view family CGs as holistic biopsychosocial and spiritualcultural entities in interaction with various environments, with the capacity for subjective inner healing through processes located within their own life world. According to nurse philosopher and theorist Watson, the qualitative nurse researcher sees the health status of her human subjects not as objective states to be measured and quantified in a laboratory setting, but inseparable "from self, the other, nature and the larger universe" (Watson, 1997, p. 50). This study therefore explores CGs' personhood from a humanitarian, metaphysical, spiritual-existential and phenomenological orientation and is concerned with "spirit rather than matter, flux rather than form, inner knowledge and power, rather than circumstance" (Watson, 1989, p. 219).

My own personal orientation and framework guiding the research questions is grounded in the hermeneutic phenomenology of the 20th century philosopher Paul Ricoeur. According to Ricoeur, human beings have a fundamental need to ascribe meaning to existence. In ongoing internal reflection about questions of who, what and why, their interpersonal connectedness, and a societal sense of justice based on responsibility and equality they establish meaning and create coherence for their own life and actions. In *Oneself as Another*, Ricoeur (1992) explores how human stories aim to find congruence on three distinct planes:

(1) A human being thinks of himself both in the second and first person: in continuously asking himself “where are you”, he seeks to answer with “here I am, this is who I am.” Questioning the self as another he tries to realize and stay true to himself in changes imposed by the unfolding context of life. His stories connect the facts and events of his physical and psychospiritual self to assign meaning and take ownership of his perceived reality and to direct his actions at fulfilling the *ethical intention*, which is self actualization toward happiness.

(2) Humans use stories to redefine themselves against the past and future. In the process of reconstructing the self from his past, character emerges from sedimentation of traits and experiences. This character guides the projection of the self in a life plan of the future. Character holds the seeds of a promise to be true to oneself and others: when another asks “where are you,” the self can answer with conviction: “here I am, and this is what I stand for”.

(3) Humans interact not only with themselves in the second person, but also with other humans, the singular and plural you and with that which is outside self and other, and may well be thought of as the majestic “You”: society, life world, God or institutions and organizations. Ricoeur calls these *just institutions*.

While the Ricoeurian self acts autonomously, it does so in dialectical relationship with others and guided by an internalized attitude of *solicitude* toward itself and others. Solicitude, or in a more familiar term, *respect,* acknowledges that which is lacking in the self: in order to have self-esteem the self needs not only esteem given by itself, but it also depends on esteem given to it by others. Solicitude presents a continuum between giving and receiving. Movement along this continuum is directed by notions of *friendship,* which imply *reciprocity* and *mutuality, reversibility*, meaning that “I” can become “you”; *non-substitutability* of individuals who are understood by the self to be irreplaceable; and *similitude* as “the fruit of the exchange between esteem for oneself and solicitude for others” in which the self understands that it cannot have esteem for itself without extending the same kind of esteem towards others. Solicitude, then, becomes ontology for the ethical intention towards the other, and defines the self's ethical existence through recognition of the other (Ricoeur, 1992).

Ricoeur's philosophical framework can be used to externalize the previously mentioned conceptualizations of perceived control, shared care and fundamental ethical perceptions of CGs. The framework also fits well with current models of patient-family centered care which place patients and family members at the center of planning care and decision making. Communication is an important antecedent to patient-family participation and is based on an egalitarian system, respect for individuality, reciprocity and willingness to relinquish and assume power, which in turn leads to improved communication and decision making, increased satisfaction and empowerment (Cahill, 1996). Similarly, the concept of partnership requires partners to value cooperation and share accountability and risk. As partners, HCPs, patients and family members communicate and exchange clinical and experiential knowledge, such as symptom interpretation, of a healthcare problem. True understanding and insight arises out of sharing a common language which is derived by sharing stories. Prerequisites for this type of partnership-communication are interpersonal skills of respect, trust, authenticity and courtesy (Gallant, Beaulieu, & Carnevale, 2002), which can all be seen as illustrations of Ricoeur's concept of solicitude on the continuum of friendship.

Explicating Assumptions and Pre-understandings

My own assumptions leading into the study included the belief that caregiving is part of the human condition and family members generally want to meet this obligation. However, they experience burden, stress and a sense of powerlessness in the task and have many unmet communication and palliative care needs at the end of life with AHF (Ward, 2002). In order to meet not only the patient's needs but also to fulfill their own ethical intention as a family member or friend to the patient, CGs require both practical and socioemotional support in their role.

The pre-understandings which originated my research interest in the AHF CG population arose out of a career in intensive care nursing where I cared for AHF patients and their family members through exacerbations and also in the final stage of dying. I found that despite the well-known poor prognosis of the disease in general, patients and their CGs were no more prepared for death than any intensive care patient admitted for a new, acute process (Willems, Hak, Visser, & Van der Wal, 2004). Olshansky et al. (2007) pointed out that unless they experienced sudden death outside the hospital setting, most AHF patients died in the acute care setting in the hospital. In my experience, even if they experienced cardiac arrest outside the hospital, they were resuscitated on scene and transferred to the hospital only to die there once again. I struggled with the fact that current models of care for HF emphasized acute care "rescue medicine" and lacked palliative care options (Hauptman & Havranek, 2005). In my practice, CGs generally had to make rapid decisions under a great deal of stress for life-saving interventions even within hours of death and palliative options were rarely presented (Lynn et al., 1997).

My experiences resonated with an ethnography by Sharon Kaufman. In her book *"…and a time to die: How American Hospitals Shape the End of Life"* she described the *revolving door pathway* as the most common manner of death for patients with chronic illness, specifically HF and lung disease"…conditions for which prognostication, and thus EOL planning, is known to be difficult because those patients can be stable for long periods and any exacerbations of symptoms usually abate with appropriate medical intervention. Most people in those groups, even when they are hospitalized with life-threatening symptoms, are not necessarily assumed to be near death" (p. 132). She observed that "Many factors co-mingle to foster the revolving door- the diffuse fear of sick people, the specific panic caused by insufficient breath, families' lack of knowledge of what to do for their ailing relatives, doctors who do not act as guides to the end of life because they cannot prognosticate well and do not want to discuss death, Medicare and Medicaid reimbursement rules, and nursing home and hospital discharge routines" (p.132). She likened the revolving door pathway to an airport walkway which, once entered, cannot be exited. "While everyone may feel or know that the person is in decline, no one quite knows how to open a space in the hospital routines for sitting with the close of life. Neither the family nor the medical team is able to leave the revolving door pathway, which usually first moves toward aggressive treatment to sustain a precarious condition, even though the patient is in decline and approaching the end of life" (p.100).

I found that AHF CGs who had been through and survived previous exacerbations with their care recipients seemed numb to yet another discussion of the seriousness of the current situation. As nurse, I was entangled in a phenomenon of institutionalized pathways of treatments, a disease trajectory, rules guiding reimbursement, and an attitude of choice limited to aggressive interventions. Upon admission to the intensive care unit, the patient's symptoms were generally presented as an isolated event that could potentially be treated successfully. Death was presented as a choice to the alternative of another procedure, to preserve medical criteria for life: breathing and circulation. The patient's autonomy was emphasized in asking "what would the patient want" and offered the hope that this procedure would also preserve the essence of life: a life worth living. However, as described by Granger and colleagues (2006), there was no time to explore the meaning of the event based on the patient's transition on the disease trajectory, or its implication for future functional status and quality of life.

From my experience as a hospice volunteer, I could also attest to the finding that with the exception of those admitted in their last few days, AHF patients survived longer in hospice care than with continued aggressive care (Connor, Pyenson, Fitch, Spence, & Iwasaki, 2007). Sadly enough, such improvement mandated discharge from the hospice service, until they had to be re-admitted for a future AHF exacerbation. This effectively introduced yet another version of the "revolving door" at the end of life.

Formulating the Phenomenological Question

The phenomenological research question explores the lived experience and meaning of the experience. In an open approach to the meaning of phenomena in the world, phenomenology seeks to understand social phenomena from the actor's own perspective, describing the world as experienced by the subject with the assumption that important reality is what people perceive it to be (Kvale, 1996). The method is therefore intended for use in areas that have not been extensively examined or in which the experience of people being interviewed has not been fully described. According to Ray (1994), researchers must be well-versed in the particular philosophy guiding the entire research process from phrasing the question to discussion of findings; and use the vocabulary of their school of thought, in this case the hermeneutic phenomenological philosophy of Paul Ricoeur. The phenomenological question is sensitive to the meaning of the experience to the CG and not to the researcher's predetermined notion of what might be happening.

The researcher who operates within Ricoeur's philosophical framework would seek to understand about her participant (a) who he is presenting himself to be, (b) what he intends for life with himself, others and the world, (c) what the meaning is which he attributes to his narrative and (d) how this shapes his being in the world.

In granting and receiving solicitude on the continuum of friendship, the self develops self esteem and from there, *capacity to act* which is Ricoeur's definition of true autonomy in the context of human existence. Capacity to act is needed for human self actualization, which according to Ricoeur is expressed as *the ethical intention to aim for the good life with and for others in just institutions* (Ricoeur, 1992). More specifically, my examination of CGs' ethical intention sought to illuminate how CGs experienced solicitude in interaction with the patient, other family members and friends, and HCPs: how did they derive self esteem and capacity to act from these interactions? Confronting multiple choices and models for life and action, where "everything is possible but not everything is beneficial" (Ricoeur, 1992, p. 162), what were the critical reflections of CGs shaping their appropriation of meaning and coherence from the circle of explanation and understanding of AHF symptoms? Could CGs respond to ethical questions of AHF symptom management with self-constancy and character: "I can try anything," to be sure, but "Here is where I stand!" (Ricoeur, 1992, p. 168).

The phenomenological questions for this study were

1. How do caregivers experience themselves in the daily acts of caring for their spouse with AHF?
2. How do caregivers explain and understand AHF symptoms?
3. How do caregivers use communication to explain and understand the caregiving situation?

The final question summarizes findings of symptom interpretation and communication along the timeline of the interview sessions with the intent to identify opportunities for advance care planning (ACP).

4. How does appropriation of symptom interpretation and communication shape caregivers' ethical intention for advocacy and making treatment choices over time?

Purpose of the Research

With these phenomenological questions, the study seeks to describe AHF CGs' self-perception in the role, how they interpret symptoms when their patients transitioned to AHF, what type of communication they look for in order to find meaning and coherence in the transition, how effective they felt in the role of AHF CG based on their experiences with symptom interpretation and communication, and how prepared they were to assume the role of surrogate decision maker. The study explores the phenomenon of meaning making over time based on the evolution of symptoms and ongoing processes of CGs' communication with others.

The research questions originating this study are driven by the need to provide phenomenological understanding of CGs' experience of AHF toward the end of life. There is abundant evidence to document the difficulties in charting a disease trajectory based on symptom interpretation for individual patients with AHF. Similarly, uncertainty of the prognosis is the greatest obstacle identified by healthcare providers to initiating EOL planning or palliative care. Yet, little is known about how CGs experience the unpredictability of symptoms, or the silence surrounding the possibility of dying from AHF. There are no phenomenological descriptions to disentangle the emotional components experienced by CGs in planning for the end of life with AHF. To increase access to palliative or hospice care for patients with AHF, healthcare providers must gain a better understanding of the essential experience, or ethical intention which CGs bring to any conversation about the end of life with AHF.

Significance

Findings from this study contributes to our understanding of how CGs experience the symptoms of AHF and what type of communication they seek to construct meaning for their role in accompanying their care recipients toward death in the medical model of current AHF care. The CG perspective needs to be incorporated into evidence-based guidelines for communication to guide treatment choices including transition to palliative care in AHF. The general course of AHF can be anticipated in some detail. Nurses who are frequently the most constant presence in the wide array of healthcare providers encountered by AHF patients and their CGs, need to know how they can empower CGs to follow their ethical intention through the endstage of the disease. There are at this point no studies describing if or how CGs prepare or wish to prepare for their family member’s death with AHF, and what kind of care they intend to seek out for their family member.

Findings from this study describe CGs’ experience of symptom interpretation and communication in AHF, and provide a foundational understanding of CGs’ capacity to act within their ethical intention as they discern treatment options and advocate for their care recipients suffering and dying from AHF.

CHAPTER 2

BACKGROUND AND SIGNIFICANCE

Any review of the HF literature must be prefaced with the observation that large scale therapeutic trials and studies examining the HF experience tend to exclude the oldest old patients, those with severe disease and those at the end of life (J. Kirkpatrick & A. Kim, 2006). The literature review begins with a brief review of the epidemiology of HF among older Americans and describes its effects on patients. Next, it focuses on the family CG experience with special emphasis on symptom interpretation and communication in AHF. The background section ends with a description of the hermeneutic phenomenology as well as the philosophical framework of Paul Ricoeur used to link symptom interpretation and communication as possible determinants of CGs' ability to find self actualization in their role. Self actualization, or, using Ricoeurian language, *the ethical intention to aim for the good life with and for others in just institutions* depends on CGs' capacity to act on their own behalf and that of the patient. It was hypothesized for this study to play a role in how CGs engage in making treatment choices for their AHF patients at the end of the disease trajectory.

Epidemiology of Heart Failure

Heart failure is a chronic, life-limiting illness affecting approximately five million mostly older Americans. HF is the fastest-growing clinical cardiac disease entity in the United States, affecting 2% of the population and accounting for 34% of all cardiovascular deaths (Roger et al., 2011). It is considered to be a man-made disease of the elderly, because it is an inevitable consequence of successful treatment of prior hypertension and ischemic heart disease, as well as a natural progression of the cardiovascular aging process in an extended life span and as such it's prevalence is expected to continue to increase (Hunt et al., 2009).

The HF syndrome is characterized by progressive loss of cardiac contractility and failure to meet tissue oxygen requirements. Patients experience exertional dyspnea, orthopnea, lower extremity swelling, and impaired exercise tolerance; however, with increasing age, and a more sedentary lifestyle, exertional symptoms become less prominent. Older patients commonly present with more atypical symptoms, such as confusion, somnolence, irritability, fatigue, and anorexia (Rich, 2006), and with complex symptom burden due to comorbidities of lung disease, arthritis, diabetes, side effects of polypharmacy and psychosocial effects of chronic progressive illness (Opasich & Gualco, 2007). HF care and symptom management are generally provided in the outpatient setting but with advancing illness there are frequent hospitalizations for exacerbations. The HF illness trajectory is one of gradual decline punctuated by unpredictable events such as acute decompensation of HF or sudden cardiac death.

Advanced HF (AHF) for the purposes of this discussion is defined as Stage D HF designating patients with symptoms which are refractory to optimal medical management. These patients are eligible for specialized advanced treatment strategies, such as mechanical circulatory support, procedures to facilitate fluid removal, continuous inotropic infusions, cardiac transplantation or other innovative or experimental surgical procedures, or for EOL care, such as hospice. Evidence is lacking for the efficacy and safety of aggressive care for older AHF patients because large-scale clinical trials generally exclude the very old and seriously ill (Hunt et al., 2009).

Since 1994, mortality and hospital readmission rates have not improved for HF patients who are older (Kosiborod et al., 2006), and the rate of re-hospitalization or death for end-stage HF patients is 81% at one year (Hauptman & Havranek, 2005). Data from the Centers for Medicare and Medicaid Services show the likelihood of being admitted to an intensive care unit (ICU) or undergoing an intensive procedure during the terminal hospitalization continues to increase (Barnato, McClellan, Kagay, & Garber, 2004). HCPs unique readiness to provide aggressive care despite being at the end-stage of HF, associated with patient and families' unrealistic hope, is illustrated in a study by Cosgriff et al. (2007) which found that, if willing to undergo aggressive care, 58% of HF patients were given life-prolonging care as opposed to 11% of cancer, and 26% of patients with lung disease. HF patients were eight times more likely to seek invasive treatment despite a greater than fifty percent likelihood of death.

The Patient Experience

Reviewing eight research publications on symptom burden with AHF at any time from one year to the last three days before death in patients ranging from 67-83 years of age, Janssen and colleagues found a 40-85% prevalence of fatigue; 20-90% breathlessness; 15-75% pain from various causes; and 25-50% prevalence of reported insomnia (Janssen, Spruit, Wouters, & Schols, 2008). Their findings are similar to a comparison of symptom prevalence in advanced cancer, AIDS, and heart, chronic obstructive pulmonary and renal disease, where authors additionally found a 36% prevalence of depression, 49% prevalence of anxiety, up to 32% of confusion and up to 41% of anorexia for AHF patients (Solano, Gomes, & Higginson, 2006). The experience of these symptoms is described in the much-cited British mixed-methods study by Barnes and colleagues (2006b) using instruments and questionnaires sequentially over two years for 542 participants with NYHA stage III-IV patients, as well as conducting semistructured interviews with 40 patients, and 9 focus group discussions with primary care practitioners (n=79). Patients were not considered at the end of life, which is underscored by the authors' note that those who opted not to participate were generally sicker. Over half of patient participants reported being moderately to extremely bothered by breathlessness and fatigue. Symptoms impaired mobility and activities of daily living. Patients experienced uncertainty, frustration, panic and anxiety in association with symptoms. They did not know what the symptoms meant. HCPs acknowledged patients' symptom burden and the imperative to relieve breathlessness with better drugs or aggressive interventions when patients came to them in acute distress. However, they described feelings of helplessness and being at a loss when patients deteriorated despite optimal medical management. They found it difficult to support a patient in accepting functional limitations. HCPs felt patients' feelings of uselessness and confusion precipitated depression which further worsened symptom experience (Barnes, Gott, Payne, Seamark et al., 2006c). While symptom experience in AHF is similar to that in cancer, the authors noted that the patients in this community-based sample did not have access to hospice or palliative care (Barnes, Gott et al., 2006b).

Patients' unmet palliative care needs were also evident from a review of medical records of 80 patients hospitalized for AHF in their last six months of life which found documentation by physicians and nurses of 21 symptoms related to AHF, yet symptom relief was rarely provided or documented (L. Nordgren & Sorensen, 2003).

Despite the fact that physiologic symptoms lead to functional limitations (Masoudi et al., 2004), social isolation (Friedmann et al., 2006; Moser, 2002), depression (Junger et al., 2005; Konstam, Moser, & De Jong, 2005; Rumsfeld et al., 2003), malnutrition (Jacobsson, Pihl, Martensson, & Fridlund, 2004), and sleeplessness (Avlund, Damsgaard, Sakari-Rantala, Laukkanen, & Schroll, 2002; Brostroem, Straemberg, Dahlstraem, & Fridlund, 2001; Ebbeskog & Ekman, 2001; Trojano et al., 2003; von Haehling, Doehner, & Anker, 2006), HF patients may still experience a sense of well-being and harmony as they adjust and compensate for losses of function (Ekman, Ehnfors, & Norberg, 2000; Ekman, Lundman, & Norberg, 1999). Findings from the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) showed that despite significant symptom burden, even within 3 days of death nearly half of all patients reported good to excellent quality of life (Levenson, McCarthy, Lynn, Davis, & Phillips, 2000). It has been suggested that such discrepancy in the presence vs. experience of symptoms can be explained by the fact that overall quality of life with AHF may be associated with psychological well-being (Blinderman, Homel, Billings, Portenoy, & Tennstedt, 2008).

Similar to cancer patients, the end-stage HF experience was characterized by ‘can’t do’, ‘difficulties in walking’, and ‘relying on others’ (Horne & Payne, 2004). With advancing illness, HF patients’ capacity for self care described by Riegel et al. (2009) as “a cognitive and behavioral process aimed at maintaining hemodynamic stability and managing symptoms when they occur” became impaired. Factors identified as barriers to self care in HF specifically included patients’ inability to interpret typical and atypical symptoms, diminished functional status (Riegel & Carlson, 2002) and short-term memory loss, confusion, and fatigue (Rogers et al., 2000). HF-related ischemia, infarction and hypoxemia impaired the neural processes of executive function located in the pre-frontal cortex, affecting adherence to treatment, and decision making in 30-50% of the HF population (Dickson, Tkacs, & Riegel, 2007; Trojano et al., 2003). Patients were aware of their fluctuating levels of cognitive ability and how it affected self care and adherence (Ekman, Fagerberg, & Skoog, 2001). A Swedish phenomenography of the expression of autonomy within the care context found that while patients had confidence in and trusted their HCP, at the same time they felt excluded from decision making and reported a lack of treatment-related information. Patients wished to have the right of more self-determination but lacked the strength and knowledge to be able to influence their own care (S. Nordgren & Fridlund, 2001).

As patients’ ability for adherence decreased, involvement of family members in monitoring symptoms and communicating with HCPs improved symptom management (Riegel, Vaughan Dickson, Goldberg, & Deatrick, 2007). Building on work in self care, Sebern and Riegel coined the term *shared care* to operationalize supportive relationships as interpersonal processes which include communication, decision making, and reciprocity in close relationships within a system to exchange support. Communication referred to symptom interpretation, feelings and advice exchanged between patient and

CG constituting the meaning of the experience for the dyad. Decision making reflected either the patient's or CG's capacity to seek information and be involved in treatment choices. Reciprocity was a concept of partnership based on empathy and listening in providing as well as receiving assistance. In a study of 75 patient-CG dyads, Sebern and Riegel found that CG decision making contributed to self care maintenance; and CG decision making and reciprocity contributed to self care confidence (Sebern & Riegel, 2009). It was apparent that patients benefited from delegating aspects of symptom interpretation and decision making to their CGs, yet fluctuating levels of self care and control on the part of the patient required the CG to act in the spirit of reciprocity when taking over decision making to protect dignity, and prevent feelings of being a burden (Zambroski, 2008).

EOL Planning in AHF

It is estimated that only 20% of the general population have advance directives (DeLuca Havens, 2000; Hopp, 2000) and HF patients do not do any better. In a study measuring the prevalence of advance directives (AD) in cardiac critical care (CCU) versus cancer care, prevalence of AD in the CCU was low (26%) and many patients did not recall prior AD discussions. The CCU patients without AD, especially those with HF were more likely to want information about ADs than cancer patients (J. Kirkpatrick, Guger, Arnsdorf, & Fedson, 2007). In interviews, 31 end-stage HF patients revealed that they tended to think about death only during exacerbation of their illness (Willems, Hak, Visser, & Van der Wal, 2004). In a study of 415 subjects enrolled in cardiac rehabilitation, 96% would consider discussing EOL care with their physician but only 15% had done so, and only 10% were confident that their physician knew their EOL-care wishes (Heffner & Barbieri, 2000). Only 23% of HF patients in the SUPPORT study had Do Not Resuscitate (DNR) orders noted in their records prior to death, and only one in four patients had documented discussions regarding preferences for resuscitation (Krumholz et al., 1998).

Compared to patients with lung disease, patients with HF had less information and poorer understanding about their condition and prognosis and were less involved in decision making. They also received less health, social, and palliative care services, and care was often poorly coordinated (Murray et al., 2002). HCPs unwillingness to engage in HF prognosis and EOL conversations was explored in the UK (Harding et al., 2008): Semistructured interview data from 12 cardiology and palliative care staff, 20 patients, and 11 CGs at a tertiary hospital in London, England revealed disease-, patient-, specialism- and system-specific barriers. All patients and CGs in this sample lacked understanding of HF symptoms and treatment regimens, and none of them had discussed disease progression or future care needs with their HCPs. Patients and CGs said HCPs were too busy to invite questions and they did not know what questions to ask. CGs expected HCPs to initiate conversation and provide information that was needed. HCPs agreed that uncertainty of prognosis prevented them from addressing EOL issues. All participants pointed to AHF patients’ impaired cognition and memory as reasons why they did not remember discussions of future care even when they had taken place. Cardiologists brought up the fact that they generally either dealt with patients who improved, or those who died at any one hospitalization. They did not feel well prepared to address psychosocial needs of those patients who while not dying during the hospitalization, did not improve significantly and were likely going to continue to decline. There was reference to fragmented care and lack of continuity in communication. Both palliative and cardiology staff agreed that cardiologists did not have enough time to address palliative needs at the end of life.

Hospice and Palliative Care in Advanced Heart Failure

Median survival rate is less than 5 years for older patients and 30% die within one year of an index hospitalization for HF (Rich, 2006). Therefore the overall prognosis of older patients who have HF is worse than for most forms of cancer (Stewart, MacIntyre, Hole, Capewell, & McMurray, 2001). In a cohort of 1.2 million Medicare recipients, 253,093 were diagnosed with congestive HF in 1993; approximately 70% of these patients were deceased four years later, yet only 8% of those had utilized hospice. This compared to a 27% rate of hospice utilization among cancer diagnoses (Iwashyna, Zhang, & Christakis, 2002). In 2002, overall hospice use among Medicare decedents was 28%, with 68% of all cancer patients and only 12% of all HF patients receiving hospice care at the end of life (Connor, Elwert, Spence, & Christakis, 2007). Hospice enrollment has since increased to nearly 40% in a sample of Medicare beneficiaries who died with HF in 2007 and was associated with notably decreased hospital and ICU utilization in the last 6 months of life. However, there remained great regional variation in the use of hospice, and one third of all patients in this study were referred within less than week of dying (Blecker, Anderson, Herbert, Wang, & Brancati, 2011).

Continued low and delayed enrollment among AHF patients is due to lack of understanding of the role of hospice, difficulties recognizing the terminal phase, and provider concerns about reconciling hospice referral criteria with aggressive symptom management (Zambroski, 2004).

Questions have been raised about the usefulness of the hospice model for AHF care (Connor, Pyenson, Fitch, Spence, & Iwasaki, 2007; Lorenz et al., 2008; Stuart, 2007; Zambroski, Moser, Roser, Heo, & Chung, 2005): (1) Patients are either admitted too late (i.e. within days of death), and do not derive the intended benefits of hospice care; or they recover to the point where they have to be discharged from the service, causing more disruption and discontinuity for the family. (2) There is great variability in the quality of care and expertise to manage AHF symptoms among different hospices. For example, respiratory distress in AHF must be managed not only with morphine but also cardiac medications which require cardiologic supervision. (3) Patients suffer discontinuity of care in switching from cardiology services to hospice. (4) Few hospices cover the cost of palliative inotropic home infusions. (5) Many hospices require the patient to sign a DNR status which may preclude ultrafiltration, an invasive procedure to remove excess fluids not reimbursable in all hospices. A DNR status also technically requires deactivation of the implanted cardiac defibrillator, a step not all patients are willing to make.

Because most AHF patients die in the hospital (Olshansky et al., 2007), they should have access to palliative care (Hauptman & Havranek, 2005) as alternative to hospice care and defined as

> the holistic, multidisciplinary approach to the care of patients with life-threatening illnesses. The very nature of palliative care goes beyond symptom management to include enhancing the quality of life and decision making of patients and families, optimizing function, and providing opportunities for personal growth. Palliative care is comprehensive and patient centered in nature and yet includes the family as central to the process. It affirms life by supporting the goals of the patient and his or her family for the future, whether by offering hope of prolonging life or hope of preserving dignity and peace throughout the dying process. True palliative care entails input from multiple health professionals to meet the complex needs of seriously ill patients and their families (Zambroski, 2008).

Contrary to hospice, which is based on the patient’s terminal prognosis, palliative care is centered on patient and family needs in the setting of an uncertain prognosis and assures access to multidisciplinary pain and symptom management at the end of life with AHF. AHF palliative care may be transitioned to traditional hospice care when there is increasing frequency of hospitalizations, when patients and families express the wish or when treatment burden outweighs the benefits to the patient. In general, initiation of palliative care in the hospital has been shown to improve patient and family satisfaction with EOL care, reduce the number of invasive interventions and decrease cost of care without affecting survival time (Casarett et al., 2008; Finlay et al., 2002; Gade et al., 2008; Gries, Curtis, Wall, & Engelberg, 2008). Currently, the American College of

Cardiology and the American Heart Association support recommendations for palliative care in AHF with class 1c evidence (expert consensus, case studies and standards of care). Barriers to palliative care in AHF persist and are rooted (1) in the perception that HF is a treatable disease; (2) the simple availability of aggressive interventions without regard to the lack of evidence for their benefit in specific populations or at the end-stage of the disease; (3) insistence that prognostication is impossible on an individual basis despite our growing understanding of the course of AHF toward death; (4) the failure to communicate about patient goals of care and preferences for resuscitation and lay a foundation of shared decision making with healthcare proxies; and (5) failure to incorporate EOLC that extends into the community setting (Stuart, 2007). More research is needed to understand how patients and families make treatment choices at the end of life with AHF given these barriers.

Scientific Literature Review of the Family Caregiver Experience

Up until recently, HF caregiver research was mostly done in the UK and Europe. Early cardiac caregiver research focused on rehabilitation of the patient with myocardial infarction and addressing the needs of family members in the Intensive Care Unit. Since the mid-1990s, CG research responded to the emergence of the HF syndrome, at first in the context of discharge teaching to manage complex medical treatment regimens in the home. There is now a growing body of literature describing the CG experience using both quantitative and qualitative approaches, much of it originating in the UK and Scandinavia. With increasing awareness of the impact of home-based care on CGs, research is beginning to describe psychosocial needs of families living with a loved one who has this life-limiting illness. The challenges of symptom interpretation in AHF are well described from the perspective of HCPs. CG studies speak to their general lack of understanding of symptoms and symptom management, and fail to explain how CGs interpret the meaning and implications of symptoms for their own life and that of their patient's.

Most studies exploring communication issues in HF care come from the UK and North America. This review excludes studies from South America, Spain and France which operate a more patriarchal medical system and represent different communication challenges than the North American and Northern European systems with a more pronounced focus on patient autonomy and shared decision making.

Throughout the evolving field of HF CG research, the terms informal caregiver, close family member and surrogate decision maker (SDM) are used interchangeably with the understanding that close family members often act as informal caregivers and eventually assume the role of SDM. This review includes nursing research and research from other disciplines (1997-2011) which explore the HF CG psychosocial experience.

Search Strategy

A computerized search of MEDLINE and CINAHL was conducted using the following search words and combinations: HF AND caregiver OR family OR family member OR spouse, NOT review, NOT ICU, limited to 1997-2009, age >65, English, Human. This search was then updated in November 2011. The initial CINAHL search yielded 53 articles including qualitative descriptive work and intervention studies, MEDLINE yielded an additional 14 studies. The updated search yielded an additional 13 mostly quantitative descriptive articles.

The identification of studies involved several steps. (1) Exclusion criteria applied to reviews or articles describing instrument development, withholding/withdrawing of care, or the perspective of organizations, professionals or the patient only. Heart transplant, technologically dependent HF patients, and patients recovering from acute cardiac events and their CGs were also excluded. (2) Titles and abstracts were screened for the following inclusion criteria: empirical studies addressing HF CG situation and needs, with well-defined research questions, selection of participants, and adequate methodology and analysis. (3) Studies were separated into quantitative and qualitative categories. This search strategy yielded 26 quantitative and 19 qualitative studies describing the HF CG experience. Tables of the quantitative and qualitative studies can be found in Appendix A.

Results of Literature Review

Caregivers of patients with congestive HF experience high CG burden and depressive symptoms, which negatively impact both patient and CG health (Hooley, Butler, & Howlett, 2005; Martensson, Dracup, Canary, & Fridlund, 2003; Nieboer et al., 1998). Other variables identified in these 32 studies were social support, communication issues, perceived control and self-efficacy, emotional stress vs. physical strain, sleep disturbance and age and gender differences in reaction to caring.

Caregivers of older HF patients are typically older spouses, who suffer from chronic illnesses of their own. Being a spouse, older, depressed and caring for a sicker patient increased CG strain (Barnes, Gott et al., 2006a). Semi-structured interviews with 30 CGs of patients with mild-to-moderate disease in Canada described shared care, visible care as in assistance with ADLs and help-seeking, and invisible care as in symptom monitoring and energy management. They had poor understanding of the disease and its treatment regimen, but much experience with its effect on patients' lives. They tried to preserve autonomy and normalcy as was best and safest for the patient (Clark et al., 2008).

As with dementia or cancer, increasing complexity and number of caregiving tasks along with deteriorating patient health contribute to CG depression and/or burden, which in turn negatively impact HF CGs' health (Hooley, Butler, & Howlett, 2005; Martensson, Dracup, Canary, & Fridlund, 2003; Nieboer et al., 1998; Pressler et al., 2009; Saunders, 2008a). Frequent AHF hospitalizations increase CG stress and depression (Schwarz & Elman, 2003) and contribute to financial burden (Dracup et al., 2004; Pattenden, Roberts, & Lewin, 2007; Saunders, 2008a). Younger CGs are at higher risk for emotional stress and depression (Dracup et al., 2004), while older CGs are at greater risk for physical stress (Barnes, Gott et al., 2006a) and burden (Saunders, 2008a). With a sample of mostly adult children as CGs, Saunders found financial worries and impaired CG health were the most strongly associated factors for health-related quality of life (Saunders, 2009).

Having to be available to their patient around-the-clock was felt to be both a comfort and a strain (Brannstrom, Ekman, Boman, & Strandberg, 2007a). A study using the Critical Incident Technique explored CGs' sleep disturbance due to patients' sleep apnea or frequent night time awakenings. Participants described their anxiety, daytime fatigue and dissatisfaction with quality of sleep. They felt abandoned by HCPs who failed to acknowledge the magnitude of the problem (Brostrom, Stromberg, Dahlstrom, & Fridlund, 2003).

Lack of social support is commonly identified by HF patients (Falk, Swedberg, Gaston-Johansson, & Ekman, 2006; Luttik, Jaarsma, Moser, Sanderman, & van Veldhuisen, 2005; Murberg, Bru, Aarsland, & Svebak, 1998; Yu, Lee, Woo, & Thompson, 2004) as contributing to depression and decreased quality of life and seems to affect CGs similarly (Aldred, Gott, & Gariballa, 2005; Martensson, Dracup, & Fridlund, 2001; McIlfatrick, 2007). Social support did not moderate stress as a cause for depression (Schwarz & Dunphy, 2003). Social isolation and disassociation of self were named obstacles in the way of surviving the chaos of the HF roller coaster. Caregivers' grief was consistent with the concept of chronic sorrow and the inability to find recognition for their suffering (Weller Moore, 2002).

Caregivers struggle with isolation, hopelessness and loss of confidence. Murray and colleagues (2004) suggested that their sense of meaninglessness and lack of purpose could be seen as depressive symptomatology but could also be responsive to spiritual care. Caregivers' mental strength affected their perceived burden (Luttik et al., 2007) and CG emotional health was linked to better patient outcomes ((Evangelista et al., 2002; Rohrbaugh, Shoham, & Coyne, 2006; Rohrbaugh et al., 2004) and decreased healthcare utilization (Bull, Hansen, & Gross, 2000c; Christakis & Allison, 2006; Schwarz & Dunphy, 2003).

However, the mutual effect of emotional well-being among patients and CGs is inconclusive. A study by Evangelista (2002) showed a negative effect of CG depression on patient emotional health, but Martensson and colleagues (2003) were unable to reproduce this.

The positive effects of marital quality and spousal relationship as predictors for survival were measured (Coyne et al., 2001) and confirmed by a four and eight-year follow-up study (Rohrbaugh et al., 2002; Rohrbaugh, Shoham, & Coyne, 2006). Female HF patients with male CGs reported better relationship quality than male patients (Rohrbaugh et al., 2002). Following up on the effect of spousal distress in the spouse CG-patient dyad, Rohrbaugh et al found that the spouse CG's distress at baseline predicted an unfavorable course of patients' HF symptoms and general health over the next 6 months (Rohrbaugh, Shoham, Cleary, Berman, & Ewy, 2009). They recommend intervening with spousal distress to improve patient outcomes; however, one might also hypothesize that spouse CGs intuitively anticipate patients' deterioration.

Symptom Interpretation

Caregivers must observe their patients for various representations of angina, shortness of breath, lethargy and/or confusion or change in appetite (Clark et al., 2008). These symptoms may be due to medications, depression, other concurrent chronic illness or an unrelated acute process and may therefore be reversible, or they may signal further deterioration in health status and impending death (Molloy, Johnston, & Witham, 2005). Older patients themselves have been shown to do poorly in recognizing and interpreting symptoms of AHF. For example, Jurgens and colleagues (Jurgens, Hoke, Byrnes, & Riegel, 2009) found that AHF patients failed to sense somatic changes like worsening of dyspnea due to the gradual nature of the change and their ability to compensate and accommodate for loss in functional ability. They propose that AHF-related impaired cognitive function negatively affects AHF patients' ability to participate in symptom interpretation and may hinder CG interventions. Furthermore, symptom interpretation in AHF is challenging because objective signs often do not correlate with the patient's subjective illness experience (Shah et al., 2001). For example, patients may attribute increasing fatigue and functional losses to the natural aging process rather than an AHF exacerbation (Levenson, McCarthy, Lynn, Davis, & Phillips, 2000). Conversely, increasing depression may herald worsening AHF before there is evidence in cardiac function tests (Moser, 2002).

In a systematic review of the prognostic/EOL communication literature with adults suffering from chronic, life-limiting illness, Parker and colleagues found that patient/CGs in general had high levels of information need at all stages of the disease process regarding the illness itself, likely future symptoms and their management, and life expectancy and information about clinical treatment options (Parker et al., 2007). As patients' health deteriorated their information needs decreased while those of their CGs increased.

Uncertainty in symptom interpretation is an important variable in shaping the HF CG experience. The slow decline seen in the HF trajectory is punctuated by sudden exacerbations, when severe shortness of breath, activity intolerance and mental status changes require admission to acute care. Patients and their families experience 'disruption, incoherence and reconciling' as they struggle to make sense of, and live with this life-limiting yet unpredictable illness (J. S. Mahoney, 2001). While earlier in the disease trajectory, evidence-based aggressive medical management often reverses such symptoms in repeat-hospitalizations, these same symptoms ultimately also precede death with AHF. Uncertainty leads to psychological morbidity, inability to plan and unrealistic expectations for CGs (Barnes, Gott et al., 2006a). Caregivers find it difficult to recognize when their patient enters the final stage of the illness (Aldred, Gott, & Gariballa, 2005; Harding et al., 2008; Selman et al., 2007). The unrealistic expectation that HF is always treatable makes it difficult for patients and family members to incorporate in their thinking the fact that symptoms of exacerbations are also symptoms of dying with HF (Murray et al., 2002).

Even though clinicians have learned much about the end-stage of HF, it continues to be challenging to prognosticate for HF patients. The diagnosis of active dying leaves much room for clinical subjectivity: “Ultimately the decisions regarding when the end of life is nearing reflect a complex interaction between objective and subjective information, emotions and patient and family readiness.” (Hunt et al., 2005, p. e61).

Communication

Topics of communication in HF are unique because of the responsibility to manage complex medical regimens, the call for behavior and life style changes, an uncertain disease trajectory, the need for ongoing negotiation of goals and treatment choices between patients, families and HCPs, blending of aggressive and palliative care, and EOL planning (Fahlberg & Panke, 2005).

Few studies address HF CGs’ specific communication needs. Concerns about the future were common and, although few participants reported having been explicitly told about their prognosis, many made intuitive statements about limited life expectancy for the patient (Aldred, Gott, & Gariballa, 2005). A lack of agreement among CGs and HCPs about the communication of prognosis was evident (Imes, Dougherty, Pyper, & Sullivan, 2011): Although clinicians report that they are discussing prognosis, patients and CGs frequently do not corroborate these reports (Fried, Bradley, & O'Leary, 2003). Fried et al found 39.9% of their CG sample had unmet communication needs which were associated with higher CG burden scores (Fried, Bradley, O'Leary, & Byers, 2005). Caregivers often lack understanding of the HF syndrome, treatment regimen and prognosis and suffer from fragmented communication with their patient or HCPs (Aldred, Gott, & Gariballa, 2005; Barnes, Gott, Payne, Seamark et al., 2006c; Harding et al., 2008; Selman et al., 2007). Involvement in discharge planning increased CGs' sense of preparedness for their task (Bull, Hansen, & Gross, 2000a, 2000b). Caregivers' perceived control and self-efficacy contributed to emotional health and useful illness discussions (Rohrbaugh et al., 2002). While perceived conflict with providers is common (Abbott, Sago, Breen, Abernethy, & Tulsky, 2001; Burns et al., 2003; Kirchhoff, Song, & Kehl, 2004; Rodriguez & Young, 2006; Zaforteza, Gastaldo, de Pedro, Sanchez-Cuenca, & Lastra, 2005; Zickmund, Blasiole, Brase, & Arnold, 2006), establishing partnership with HCPs was an important component of reconciling with the disease (Martensson, Dracup, & Fridlund, 2001). Communication deficits specifically addressed were side effects of medications and formal support resources, especially for those with lower socioeconomic status or minorities (Pattenden, Roberts, & Lewin, 2007).

Communication research in AHF is assuming more urgency as most recent applications of technology such as the Implanted Cardiac Defibrillator (ICD) and Ventricular Assist Device (VAD) are being incorporated into treatment guidelines (Hunt et al., 2009). Such devices require shared decision making of patients and/or their CGs for discontinuation at the end of life. In addition, the VAD alters disease trajectory by introducing potential for device-related complications as cause of death (Rizzieri, Verheijde, Rady, & McGregor, 2008). Kirkpatrick & Kim (2006) present a thoughtful description of ethical issues raised in HF communication by new treatment modalities and research. One example are patients with an implanted cardiac defibrillator (ICD) who are in a position to determine their most likely manner of dying: turning off the ICD may allow sudden death from arrhythmia; continuing the ICD will lead to a prolonged end-stage with heavy symptom burden and potential for repeat painful firing of the ICD

(Lewis et al., 2006). It is recommended that discussion to de-activate their ICD is part of advance planning (Goldstein & Lynn, 2006), but there is evidence that physicians are not prepared to initiate and conduct EOL conversations (Hauptman, Swindle, Hussain, Biener, & Burroughs, 2008; Imes, Dougherty, Pyper, & Sullivan, 2011; Kelley, Mehta, & Reid, 2008). Such discussions occurred in only one-fourth of patients, for one in four of those only within hours or days of death (Goldstein, Lampert, Bradley, Lynn, & Krumholz, 2004).

Strengths of Current Research

Only eight of 45 studies were non-nursing initiated. Nurses have embraced the cause of HF CG research which is an indication of their professional insight and deep understanding of the challenges facing this population. It also indicates a commitment and willingness to engage in partnering, supportive relationships with CGs. Articles used strong qualitative techniques covering interviews, ethnography, participant observation and the Critical Incident Technique. Method and analysis sections are well described and transparent. Statistical analyses, while lacking power, were described in detail and appropriate for the various comparisons. Nurses have begun to investigate this new field of HF CG research with good intuitive hypotheses, sound research techniques and creative designs.

Limitations of Current Research

Out of 26 quantitative studies only two were prospective longitudinal studies (Hooley, Butler, & Howlett, 2005; Nieboer et al., 1998), all others were cross-sectional or retrospective. No RCT examining HF CG outcomes was found. Researchers have found it useful to remain vague in their definition of CG making it impossible to directly compare studies because of sampling variability. Most studies include white, female CGs which leaves many unanswered questions for male and/or ethnically diverse populations. Most CG-patient relationships described are between spouses, failing to differentiate the needs of current baby boomers caring for a parent with HF. Not all studies detail severity of illness of the patient population which has been shown to affect CG outcomes.

There is great variability in the instruments used to measure CG outcomes. For example, burden should be assessed with a scale that measures both positive and negative aspects of caregiving (Harkness & Arthur, 2006), which makes the frequently applied Zarit Burden Inventory less useful than the Caregiver Reaction Assessment. Some studies used scarcely validated scales or self-report questions. Only one study used a physiologic marker, salivary cortisol, and it correlated poorly with the accompanying stress scale (Schwarz & Dunphy, 2003). Studies measuring depression among CGs did not mention use of antidepressants. With the exception of two studies (Ãgren, Evangelista, & Stromberg, 2010; Saunders, 2008a), none had enough sample size for statistical power to test hypotheses. Some studies carefully traced significant attrition of their sample size due to sudden deterioration in patient health or even death. Caregivers of sicker or older patients also tended to refuse participation resulting in systematic sampling bias. Due to mostly volunteer participants, none of the studies specifically included informal CGs who reported dysfunctional relationships with their patients. As a final point it must be said that cross-sectional communication research does not capture adaptation in prognostication processing as is necessary with chronic life-limiting illness.

Directions for Future Research: Extant Literature Review Reveals Gaps in Knowledge

Future studies of anxiety, depression and stress need to include larger samples and more diverse CG populations with clearly delineated patient illness severity and measures of CG burden. Nurses should select and consistently use a few instruments that have been validated in this population. Additional outcome measures might include markers of immune function, healthcare utilization, number of infectious episodes, and salivary cortisol.

More studies exploring the process of communication and its relationship to outcomes in the US are needed, because findings may vary from those in the UK and Europe. One example would be to capture CGs' experience and meaning of decision making in the setting of uncertainty, and the essential experience of transitioning from curative to palliative care.

Findings confirm that HF patients and their families have a high level of unmet palliative care needs, and that lack of information has a negative impact on their quality of life. In terms of EOL communication, more studies are needed of the impact of prognostic disclosure on (a) patient and CG decision making and longterm satisfaction, (b) use of invasive treatments at the EOL, (c) bereavement outcomes in CGs, (d) preparation for death, and (e) achievement of preferred place of death (Hancock, Clayton et al., 2007b; NIH, 2004). An additional line of inquiry should be communication about EOL planning between CGs and care recipients. Fried et al. (2005) developed a survey instrument to measure satisfaction with CG-CR communication and found that CGs desired more communication about EOL planning, but care recipients did not. This conflict and its emotional context would benefit from more phenomenological exploration especially given the current push for advance directives and the need for CGs to assume surrogate decision maker roles.

Even when EOL discussions occur between HCPs and CGs, little is known about how CGs process the information and counseling received, or how such conversations support or even empower them in their caregiving role (Hancock, Clayton, Parker, Walder et al., 2007a). Research is needed to establish "what type and what level of information has the potential to improve physiological, cognitive, emotional and behavioral outcomes for [AHF] patients and their caregivers" (Molloy, Johnston, & Witham, 2005, p. 601).

Little is known regarding how patients and surrogates understand HF-related content in ongoing conversations throughout the course of the disease, and evidence-based recommendations concerning how to discuss dying, life expectancy, or likely future symptoms with patients and their families are lacking (Goodlin, Quill, & Arnold, 2008; Zapka, Moran, Goodlin, & Knott, 2007). One of the five research goals formulated in a consensus conference for HF EOL care therefore pertained to communication and stated: “More research is needed to identify content and technique of communicating prognosis and treatment options with patients with advanced HF; physicians caring for patients with advanced HF must develop skills to better integrate the patient's preferences into the goals of care” (Goodlin et al., 2004, p. 209).

Using phenomenology over time this study aims to describe how CGs integrate symptom interpretation and communication to negotiate frequent choices between curative and palliative symptom management unique to HF therapy, and how they transition with their patients from living with to dying from AHF.

Specific Focus for Phenomenological Inquiry in the AHF Caregiver Experience

Aside from a general lack of description of lived experience in AHF family caregiving, I see three distinct lines of inquiry that merit insight from the phenomenological perspective, specifically the concepts of perceived control, communication and decision making, and the process of incorporating family values.

Perceived Control

The HF caregiving experience has been described in terms of burden, stress and strain which affect biopsychosocial aspects of living (Molloy, Johnston, & Witham, 2005). More recently, there is description of the mediating effect of perceived control on CG emotional health and perceived burden (Bakas, Pressler, Johnson, Nauser, & Shaneyfelt, 2006; Bull, Hansen, & Gross, 2000a; Chubinski, 2007; Dracup et al., 2004; Molloy et al., 2008). In these studies, self-perceived control is roughly conceptualized as personal control over caregiving tasks, having authority over decisions related to caregiving and feeling equipped to use particular skills and knowledge. Findings from these small descriptive studies show that increased perceived control may improve CG mental health, satisfaction and engagement in caregiving. In an ethnography of clinic sessions at a tertiary academic health center Penrod et al. described the HF disease trajectory within that culture of care: AHF was actively treated up to days or hours before death when suddenly the responsibility for care shifted from the hands of experts into the hands of CGs. Throughout the course of the disease, the theme of informal caregiving was "to seek normal." "Normal" was found in the medical model, where all efforts were directed at maintaining medical stability through gradual decline and episodes of life-threatening exacerbations. Caregivers were "content to rest all control and responsibility with HCPs" (personal communication Penrod, November 21, 2009). However, it was difficult for CGs to find normal after the abrupt shift "when there was nothing more to do" (J Penrod et al., 2009). Previous studies described the concept of self-perceived control using surveys, questionnaires and instruments without actually eliciting CGs' description or lived experience in the course of caregiving. Phenomenological depth is needed to understand how minimal control or involvement in decision making prior to the last phase affects the CG experience, if and how CGs reclaim a sense of control and involvement, and how equipped they feel to use their own skills, knowledge or even intuition at the end of life with AHF.

Communication, Decision Making and Reciprocity

Building on a large body of literature in *self care*, defined for HF patients in medical terms as symptom interpretation and monitoring to maintain hemodynamic stability (Riegel et al., 2009), Sebern & Riegel describe how self care is gradually replaced by *shared care* as the patient's condition deteriorates. Shared care between patients and CGs involves communication, decision making and reciprocity (Sebern & Riegel, 2009) and may influence CG self care maintenance and confidence. Again, communication, decision making and reciprocity were measured using a psychometric instrument, leaving the internal process of experience and meaning of these concepts unexplored.

Zambroski (2008) suggests that self care management in AHF may shift from symptom interpretation with the goal of adherence to treatment plans to decision making about other matters that gain importance at the end of life. Little is known about what type of self care activities are needed among patients and their CGs when no more improvement in global or health-related quality of life can be expected. The question remains how CGs link symptom interpretation to maintain hemodynamic stability under the supervision of expert HCPs over the long course of the disease to the symptom interpretation and management they are required to engage in after the sudden shift to palliative care in the last phase of the disease. In other words, how do CGs make the transition in interpreting symptoms as those of living with HF to those of dying from HF? More research is needed to understand how CGs interpret symptoms, and negotiate treatment options in communication with patients, other family members and friends, and HCPs, in order to "develop the simplest, least burdensome self care illness management interventions that target the most meaningful outcomes for patients, their families, and the healthcare system" (Zambroski, 2008, p. 275).

Including Family Values into Decision Making

The high prevalence of depression and anxiety among CGs of AHF patients (Usher & Cammarata, 2009) merits an examination of the nature of their socioemotional suffering. Foster and McLellan (2002) point out that caregiving and decision making at the end of life must include family members' perspective and ethical consideration of fundamental questions about responsibility, guilt and commitment. Such factors may weigh heavily when a family member participates in decision making on whether to treat an AHF patient aggressively for acute pneumonia or a urinary tract infection, which may involve yet another prolonged hospitalization and prolonged recovery. There are no studies examining the role of moral obligation, virtues and values originating within the family context in the predominantly clinically and bioethically oriented world of HF symptom interpretation, communication and decision making. Phenomenological inquiry is needed to illuminate how family members incorporate family values into symptom interpretation and communication in order to construct meaning for their intentions and actions as CGs. Illuminating the shift from clinical and bioethical parameters such as hemodynamic stability and patient autonomy to family-centered values of responsibility and commitment, phenomenology gives voice to lived experience at the transition from curative to palliative care which is as of yet outside of survey instruments and measurement tools.

Why Phenomenology

Hermeneutic phenomenology explores lived experience and meaning of experience. It is a philosophy, a way of being and a method for qualitative research (Omery, 1983). Contrary to descriptive phenomenology, hermeneutic phenomenology is interpretive and a way of being in the social-historical world where the fundamental dimension of all human consciousness is expressed through language: “the belongingness to the world is the interpretive experience itself and [that] all understanding is mediated by interpretation” (Ricoeur, 1992, p. 101). According to Ray (1994), researchers must be well versed in the particular philosophy guiding the entire research process from phrasing the question to discussion of findings; and use the vocabulary of their school of thought. Both the author and interpreter of a text are limited by subjectivity, but presuppositions invite discourse and constitute the possibility of intelligibility or meaning. Meaning is derived through reflection and validation within a shared language and a common humanity. Understanding actualizes itself in appropriation which changes attitude, behavior or practice (Ricoeur, 1976).

The Hermeneutic Phenomenology of Paul Ricoeur

Paul Ricoeur was a post-structuralist philosopher who systematically distilled works from antiquity to the present to extract transcending thoughts of Aristotle, Socrates and Plato and contemporary critical and religious philosophers into his hermeneutic *Philosophy of ethics*. He concluded what makes us human is our ability and desire to seek self-understanding or meaning in reflection. Reflection is a function of language using an internalized process of explanation and understanding which he called the *hermeneutic arc*. The hermeneutic arc can be applied to any expression in speech, writing, art and action.

According to Ricoeur, the self is situated in a body which is anchored in time and space and understands itself through language and discourse to arrive at narrative identity, formulate guiding ethical intentions and to connect with others. Discourse as text, once released from the author, is autonomous and open to many interpretations. Both the author and interpreter of a text are limited by subjectivity. However, meaning is derived through reflection and validation within a shared language and a common humanity which lends a certain degree of objectivity to structural and empiric analysis of language in the text (Ricoeur, 1976).

Ricoeur suggested that human selfhood has two components: *character* and *self-constancy*. These two components arise out of a person’s split perception of the self, the intersection of (1) *idem*, which has a name, and distinguishes itself from other human beings in certain permanent personal characteristics, and (2) *ipse*, which is subject to constant change over the course of a life time. Selfhood strives for a life story which is the narrative of “being-toward-death”, it is framed by events and entangled in the life histories of others.

Narrative tells the who/what/why of actions which arise out of the determinate nature of practice in the space of experiences as described by Sartre, and align or misalign with the goal of the “good life” along the horizon of expectations, a concept borrowed from MacIntyre (Nussbaum, 1986). Actions arise out of human beings' internal and external limitations, making any narrator the character and agent, but only the co-author of his own life story. The fact that "every action has its agents and its patients" (Ricoeur, 1992, p. 157) gives equal weight to the active or passive voice in a story, makes the narrative a tool for acting and suffering narrators alike and introduces "the idea of justice, as the rule aiming at the equality of the patients and agents of action (Ricoeur, 1992, p. 157).

As human beings, we live out the dialectic between being objects of both the natural material world, and the world of action shaped by freedom of the will. In narrative, the individual tries to create coherence between such defining events as birth, aging and dying, facts of personal characteristics or being acted upon by others, and his experience of emotions and life knowledge which lead to action (or omission of action). Actions are compared against standards of excellence formulated by an individual, a profession or an organization through ethical, moral and practical reflections. According to Ricoeur, such a narrative of actions forms the basis to describe any human's ethical intention defined as "aiming at the good life with and for others, in just institutions" (Ricoeur, 1992, p. 172). The good life is "the nebulus of ideals and dreams of achievements with regard to which a life is held to be more or less fulfilled or unfulfilled (Ricoeur, 1992, p. 179)". Because ongoing ethical, moral and practical reflections are an integral part of being human, there can never be evaluative neutrality in our narratives (Ricoeur, 1992, p. 115), "in the exchange of experiences […] actions are always subject to approval or disapproval and agents to praise or blame" (Ricoeur, 1992, p. 164). This may be one mechanism to explain why CGs frequently examine their actions for causes for guilt, or the bereaved person feels the need to rewrite her story with a positive spin in order to make memories of her loved one's dying more tolerable.

Paul Ricoeur's Philosophy of Ethics

Ricoeur argued that in the dialectic between the individual idem and the other (which may be part of the self as ipse, or another human being) there is always potential for moral conflict. By looking at the self as already possessing an "other" quality, this conflict becomes internalized into human essence and cannot always be satisfactorily reconciled by moral or ethical norms. What is good for all is not always good for one. An agent of action may also be the patient, i.e. the one suffering from this action. Human life holds a certain element of tragedy because limitations of body, character and context pose threats to being oneself, to keeping one's promise and to living out the ethical intention in pursuit of the good life. To illustrate this dilemma one need only look at the common caregiving situation of having to place a loved one in the nursing home: Struggling to apply ethical intentions of a greater *lifeplan* for the good life ("I will never abandon you and make you go there against your will") against moral norms or limitations imposed by the world or the other ("but I am unable to care for you by myself anymore") the CG seeks to find resolution in practical wisdom ("I may feel guilty but we do not have a choice anymore") which is grounded in ethical principles ("I will continue to love you by visiting every day and making sure you are well-cared for") above moral norms (a good wife never puts her husband in a nursing home).

Given the fact that CGs are asked to engage in shared planning of EOL care for patients with AHF there is an emerging need for ethical frameworks that make possible conversations of withholding or withdrawing of treatment aimed at prolonging life, in order to switch focus towards palliation aimed at the end of life with AHF. It is important to elicit ethical ramifications and insight into the process of forming an ethical intention for caregiving and decision making not only within established medical bioethical foundations, but also from the CG perspective. The acknowledged lack of evidence-based practice for communication in HF calls for phenomenological inquiry to establish a moral, ethical or practical basis for EOL conversations with CGs of AHF patients. The addition of the CG perspective is an important piece in addressing barriers to EOL planning in HF. Fundamental understanding of CGs' ethical intentions for caregiving and decision making at the EOL within Ricoeur's *Philosophy of ethics* allows health scientists to develop interventions which reconcile aggressive and palliative symptom management in HF and prepare and support CGs in effective patient advocacy.

The following Figure 1 is an illustration of the development of the ethical intention within Ricoeur's philosophy of ethics. It depicts the larger relationship of the self (idem and ipse) with the other and just institutions. The self and other grant each other respect (solicitude) on the continuum of friendship. Based on respect, the self derives self esteem which furthers capacity to act toward the ethical intention to aim for the good life with and for others in just institutions.

This study of communication and symptom interpretation in AHF places itself within this framework from the researcher's preconceptions of communication as a tool, and symptom interpretation as the context for the family CG experience. It incorporates what is currently known in the literature of (1) perceived control in association with capacity to act, (2) communication, decision making and reciprocity as taking place on the continuum of friendship, and (3) the exploration and incorporation of values and beliefs to be taking place within idem and ipse, and the larger context with others and in just institutions.

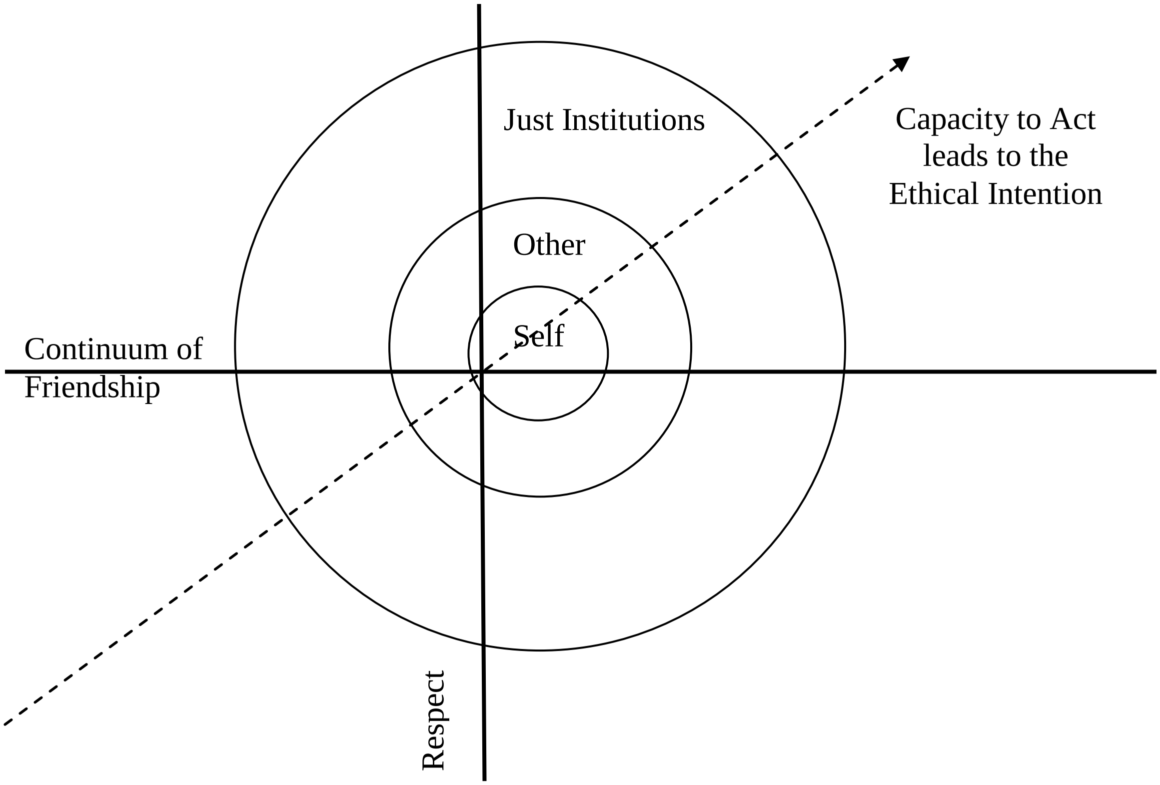


Figure 1. Paul Ricoeur’s philosophical framework.

Applications of the Ricoeur Method in Nursing Research

Arguing that the hermeneutic arc was an innately natural human process in any and all communication, Ricoeur himself deliberately never formulated a methodology within his theory of interpretation. It was Dr. Astrid Norberg, then a nurse researcher at Umeå University, Sweden and Dr. Anders Lindseth, then a philosopher teaching at Tromsø University, Norway who in the 1990s developed a method of interpretation grounded in Ricoeur’s philosophy of ethics. They adapted the four-part hermeneutic arc of naïve reading, structural analysis, critical reflection and appropriation to fit a scientific methodology for qualitative research with the four steps of naïve reading, structural analysis, comprehensive understanding and formulation of results. The method was readily adopted by Scandinavian health science researchers even though a publication detailing the method was not published until 2004. To gain a thorough understanding of the philosophical framework I studied with Dr. David Klemm, an international expert on Ricoeur at The University of Iowa. To learn about applications of the method based on his philosophy, and to extract methodological considerations, I conducted a literature review of studies using Ricoeurian hermeneutic phenomenology. Finally, to review my own application of the method, I travelled to Sweden to learn from Lindseth and Norberg directly and to visit with scholars who have used this method extensively, including Dr. Ingegerd Bergbom, editor-in-chief for the Scandinavian Journal of Caring Sciences and Dr. Inger Ekman who has mentored many students in application of the method at the at the Institute of Health and Care Sciences of Sahlgrenska Academy in Gothenburg.

A literature search of PubMed and CINAHL between the years 1998 and 2012 yielded several applications of Ricoeur's hermeneutic philosophy in nursing. Using his writings as philosophical framework for interpretation as well as following his steps in the interpretation of text, nurses were able to describe various themes in EOL care, suffering, communication, chronic illness, the CG experience, mental illness and heart disease. For example, living with chronic illness was described as *getting in harmony with oneself* and *existence of hope and spirit of life/life courage* (Delmar et al., 2005). Such an interpretation arose out of Ricoeur-mediated understanding that life is an ongoing narrative in which the self has to balance change with constancy to remain true to the self. "The self is aimed at rather than experienced" Ricoeur states. "The person is still a projected synthesis that seizes itself in the representation of a task, of an ideal of what the person should be"(Ricoeur, 1986, p. 69). Hope and courage are constituents of the demand for happiness. "Reason demands totality, but the instinct for happiness, insofar as it is a feeling that anticipates its realization more than it provides it, assures me that I am directed toward the very thing that reason demands" (Ricoeur, 1986, p. 68).

A selective review of studies using Ricoeur's hermeneutic phenomenology can be found in Appendix A. The following discussion focuses on methodological considerations extracted from existing studies which used hermeneutic phenomenology based on any method grounded in Ricoeur.

Most studies used the method developed by Lindseth and Norberg (2004) and were performed in Scandinavia. Sample sizes ranged from 4-27. Researchers generally claimed purposive sampling, although it was not always clearly described how it was purposeful. Subjects were called "informants" or "participants" and as with any phenomenology were always volunteers. Participants were usually referred by associated staff from clinical areas which introduced bias but may have improved the quality of information elicited. Referrals can also be considered a strategy for purposeful sampling.

Later studies agreed on the need to achieve saturation, either within the entire sample (Delmar et al., 2005; Eldh, Ehnfors, & Ekman, 2006) or within each interview (Horwitz, Theorell, & Anderberg, 2003). Interviews usually followed either Mishler (1986) or Kvale (1996) methods. Some authors noted that informants tended to recall facts and events rather than reflect (Fagerberg & Kihlgren, 2001; Forsgarde, Westman, & Jansson, 2002). This illustrated the importance of allowing informants to dwell with the questions, perhaps for some time before the interview, and to seek out thoughtful individuals.

Most designs were retrospective, cross-sectional. Some had the intent to describe an evolution of the phenomenon over time (Fagerberg & Kihlgren, 2001; Horwitz, Theorell, & Anderberg, 2003; Lohne, 2008; Svedlund & Danielson, 2004). I found the request to describe hope in past/present/future especially creative and consistent with Ricoeur philosophy to let the informant create a coherent story over time (Lohne, 2008). There were detailed consenting procedures for some of the more ethically informative studies (Eldh, Ehnfors, & Ekman, 2004; Haggerstrom, Skovdahl, Flackman, Kihlgren, & Kihlgren, 2004; Talseth, Jacobsson, & Norberg, 2001).

Australian researchers included a theoretical framework and inclusive literature review into the introduction for the study as opposed to into the discussion. They argued that it was part of their pre-conceptions and therefore stated out front (Donnelly & Wiechula, 2006). This is congruent with the premise of interpretive phenomenology.

While the research questions were generally consistent with Ricoeur's philosophical framework, the actual interview questions were rarely mentioned and may not have been phrased in Ricoeurian terms. Some studies felt it necessary to add a layer of structural interpretation by explicitly asking Ricoeurian questions to the text: Who does the informant see himself to be? What is his ethical intention for self and others? How does it affect him over time? (Fagerberg, 2004; Fagerberg & Kihlgren, 2001; Hellzen & Asplund, 2006a) One would expect participants to address these themes as part of the naturally occurring hermeneutic arc and storytelling in any reflection about a phenomenon, however if such reflection is not immediately apparent from the line of questioning, it is entirely within Ricoeur's theory of interpretation to pose these questions to the text itself.

Illustrating what they called "stages of sophistication" in interpretive hermeneutics was performed by Donnelly and Wiechula (2006) in following interview data through three layers of analysis. First, they applied the very pragmatic 14 step method for text interpretation articulated by Burnard (1991). This was followed by more reflective interpretive analysis within a pedagogical framework designed by van Manen to lead to deeper understanding of the human relationship experience. The third layer added abstraction achieved within Ricoeur's hermeneutic philosophy which considers the written text to be autonomous discourse, free from the nuances of speech or context of dialogue by which it was created. By stripping the text of any unwritten intentions of the one who created it at the proximal end of the hermeneutic arc, the text itself becomes partner in dialogue with the researcher at the distal end. Rather than the speaker using text to speak about him or herself, the text now speaks about the human experience itself. Freely floating, contextually unbound text invites interpretation from all angles. However, Ricoeur frames explanation along the hermeneutic arc at the distal end, where new understanding can be found, with the assertion that many explanations are possible for parts of the text, but only one is most probable for the whole of the text (Ricoeur, 1976).

Another example of interaction with the text rather than informants themselves is a follow-up study performed by Delmar et al. (2005). In their original study, the researchers interviewed 18 participants to illuminate the experience and meaning of living with a chronic illness. They found the essential phenomenon of striving to live in harmony with oneself (acceptance). Delmar et al. (2006) then re-analyzed the same text to investigate what it said about the interaction of acceptance and dependence. It became apparent that there were two definitions for dependence, one relational which allowed to be dependent without losing dignity, and the other based on a liberalist view which led to self-blame, guilt and feelings of inadequacy.

Describing the mechanics of the research procedure, most researchers did line-by-line coding by hand. Only one study used software for coding (Edvardsson, Sandman, & Rasmussen, 2003). Eldh et al. color-coded themes and compared the coloring patterns between three different coders. In this particular study investigators also experimented with counting most frequently occurring themes and words but did not draw conclusions from these findings. This may be a line of inquiry to be pursued using capabilities of NVIVO software. Using Ricoeur themes, one could query the text for expressions of capacity to act, for example participant statements including “I can/can’t”, “I did/didn’t” etc.; or look for phrases indicating ethical intention, e.g. “I wanted to/had to”, “I wish/was afraid that”, “I promised/ always thought/ really should have” etc. to get a quantitative measure of the predominance of some themes as expressed in percent of text in addressing a certain way of feeling. However, the qualitative researcher most likely sees no need for such numerical verification in texts where the words themselves convey meaning much more clearly.

Usually there was more than one coder and findings were reflected upon with team members, researchers from other disciplines, or trusted informants. Some studies validated findings with their informants in (example Horwitz, Theorell, & Anderberg, 2003; Wiklund, Lindholm, & Lindstroem, 2002), and interestingly enough this feedback had therapeutic effects. Ricoeur himself did not see the need for member checking, because once the text is released by the speaker, the speaker has no more influence on how it is processed by the listener (Ricoeur, 1991). This is an important consideration when the speaker and listener do not share the same context, for example due to historical disconnect or cultural distance, as with interpretation of bible text. Here, the new meaning created for the present or future may be different than meaning in the past. In current health science research, member checking is certainly acceptable because the speaker and listener operate within the same context, and understanding is grounded in looking backwards to the speaker with experience of the past, to create meaning that shapes being and doing in the present and future.

The fact that new meaning created may be therapeutic for participants is particular to the method which is so clearly linked to a philosophical framework describing what it means to be human. Building on this characteristic, the “caring conversation” as nursing intervention was first described by Frederiksson, analyzing the effect of touch and presence in ICU patients (Fredriksson, 1999). The therapeutic effects of the hermeneutic arc and Ricoeurian questioning were also found in studies of suicidal and psychiatric patients (Fredriksson & Lindstroem, 2002; Talseth, Jacobsson, & Norberg, 2001), patients suffering from fibromyalgia (Horwitz, Theorell, & Anderberg, 2003) and patients in hospice care (Olthuis, Dekkers, Leget, & Vogelaar, 2006). Frederiksson and Eriksson (2003) went on to describe the role of the nurse in such conversations, linking the ethical dimension of communication with the nursing code of ethics within the hermeneutic arc.

I have personally applied Ricoeur’s method to an analysis of CG journals of patients with Alzheimer’s disease. Caregivers spontaneously reflected on four themes: (1) Feeling connected or disconnected in friendship, (2) Trying to find authenticity for self and patient, (3) Struggling for self esteem, and (4) Impaired capacity to act. Integration of the four themes within Ricoeur’s philosophy of ethics revealed the main theme or essence described by CGs in their journaling: *trying to stay real while the patient is disappearing.* Lack of friendship, authenticity, self-esteem or capacity to act negatively affected their ability to formulate an ethical intention for happiness and self-actualization in their own lives. Feeling disconnected from self and others, or unable to protect their own autonomy against the needs of the patient, they had difficulties envisioning happiness and self-actualization, because it was inextricably tied to nursing home placement or death of their patient. Implications for HCPs from the findings of the analysis pointed to the need to empower CGs’ ethical intention by providing a safe and just space for their voice to address not only the patient’s personality retreat, but also the caregiver’s (Bursch & Butcher, 2009).

CHAPTER 3

METHODOLOGY

Nursing as Human Science

Nursing is the science of art and human caring directed at the health and well-being of individual clients, and clients as local and global communities. Underpinning nursing as a human science with the Theory of Human Becoming, Parse stipulated that "humans in mutual process with the universe structure meaning multidimensionally, coauthor health, freely choose ways of becoming, and move beyond each moment with hopes and dreams" (Parse, 1998, pp. x-xi). Nursing science uncovers the meaning of living and dying health in continuous relationship with the environment and requires methodologies which describe phenomena as experienced and participated in by humans. Beyond man's biological, psychological or spiritual parts, Parse emphasized the simultaneity of human experience, not delimited by terms of disease or pathology (Parse, 1998). Other nurse scientists have embraced the concept of evolution in each individual human's being on to death: there was Newman's theory of Health as Expanding Consciousness (Newman, 1994) or Watson's Theory of Human Caring which join others in the transdisciplinary field of caring sciences and draw from a pool of research methods appropriate not only to studies in medicine and nursing but also in the humanities and social sciences. Patterson & Zderad introduced phenomenology to nursing in 1976 when they described *presence* as the process of being available with the whole of oneself and open to the experience of another through a reciprocal interpersonal encounter (Paterson & Zderad, 1988). It was a research method that either described or interpreted the subjective, lived experience of human beings in an effort to grasp the meaning associated with such experience (Benner, 1994a). Phenomenology in nursing science is grounded in the idea of *verstehen*, meaning that human experience can be understood based on the shared humanity between subject and researcher (Patton, 1980).

Watson constructed the *descriptive-empirical phenomenological research method* which presupposes and examines “essence that is the common intersubjective meaning of the human experience of a certain aspect of reality. Anything that can be said about how people perceive, experience, and conceptualize a given human phenomenon” includes data analysis, whereby “the researcher interrogates each meaning unit for its psychological-nursing-human care relevance” (Fawcett, 2005, p. 568).

The two schools of phenomenology distinguish themselves as being either descriptive or interpretive. Descriptive phenomenology grounded in Husserlian philosophy requires the researcher to shed him or herself of all preconceived knowledge of the phenomenon, a practice known as bracketing. There should be no preconceived questions and no review of what is known, if anything in the literature, about a phenomenon. Interpretive phenomenology on the other hand is based on the Heideggerian assumption that the researcher is part of and cannot abstract him or herself from the *life world*. This requires the researcher to be aware of what is known about a phenomenon and to recognize the new insights a participant brings to the description of a phenomenon (Lopez & Willis, 2004).

For example, Watson’s theories preclude bracketing, because, recognizing themselves as being intertwined with their subjects in human, intrinsically caring relationships or energy fields, nurse researchers are open to healing or re-patterning not only for the subject but also themselves. Interpretive phenomenology aims to offer insights into how a given person, in a given context, makes sense of a given phenomenon of some personal significance – in this case witnessing a loved-one suffer from AHF.

My examination of the experience of family CGs of patients with advanced HF is grounded in Watson’s theory of nursing in which professional caring of the nurse is a natural and integral act arising out of essential human interrelatedness. However, in order to understand the essence of human experience in being a CG for the AHF patient, I am placing my informants against the broad, non-nursing related, philosophical canvas of Paul Ricoeur.

Methodology Choice and Rationale

As outlined in Chapter 1, and described in detail in Chapter 2, Riceour offers a model to combine both a philosophy of the phenomenology of ever becoming human (ontology) and the integral role of language and hermeneutics (epistemology) in this process. In this manner, hermeneutics (text interpretation) provides a philosophical underpinning for phenomenology, which describes the meaning of lived experience and serves to externalize beliefs, values and commitments. Ricoeur describes the work of hermeneutics as

> …to seek in the text itself, on the one hand, the internal dynamic that governs the structuring of the work and on the other hand, the power that the work possesses to project itself outside itself and to give birth to a world that would truly be the 'thing' referred to by the text. This internal dynamic and external projection constitute what I call the work of the text. It is the task of hermeneutics to reconstruct this twofold work (Ricoeur, 1991, pp. 17-18).

Ricoeur recognizes text to represent the sense of what it meant to the one who created the text as well as the new and different sense it may assume in the one who reads the text. Understanding and explanation in the hermeneutic arc "combat on two separate fronts against a reduction of understanding to empathy and a reduction of explanation to an abstract combinatory system" (Ricoeur, 1991, p. 19). Hermeneutics does not try to find understanding from hidden intention and meaning of the writer "behind the text" instead it seeks understanding and explanation "*in front of it*, as that which the work unfolds, discovers, reveals. Henceforth, to understand is *to understand oneself in front of the text*" (Ricoeur, 1991, p. 88). Given the fact that there is an unseverable connection (*belongingness*) between the writer and the text on the one hand, and reader of a text on the other hand, Ricoeur acknowledges that the reader can never grasp the actual experience of the writer, only it's meaning. Appropriation, or new meaning within the intersubjective context, can only take place when the reader places *in suspense* his own belongingness, that is his relationship and preunderstanding with the sense of a text. The upcoming section on data analysis presents an in-depth discussion of the various occasions for *distanciation*, which Riceour terms the attitude to affect such a state of suspense within the hermeneutic arc.

There is considerable precedent for the use of Ricoeurian hermeneutics in health science research and specifically in nursing as shown in Chapter 2. By combining philosophy, method and methodology for this study I hope to seamlessly integrate the ontology of being a CG to a person suffering from AHF with epistemology of (1) explaining and understanding symptoms and (2) using communication to make meaning for the ethical intention in caregiving. In other words, the philosophical lens applied to the inquiry and methodology provides the framework to support both the subject's as well as the researcher's beliefs and perceptions and explains the process of finding new meaning and implications for nursing.

Research procedures

The following description of research procedures will detail sampling considerations and the process of recruitment including important thoughts about informed consent and ethical concerns for conducting interviews that inquire about death and dying. The strategy for the interviewing process was taken from Kvale's *InterViews: An introduction to qualitative research interviewing* (1996). Data analysis methods are synthesized from Ricoeur's *From text to action: Essays in hermeneutics* (1991) and corroborated by writings from Lindseth and Norberg (2004), and Wicklund et al. (Wiklund, Lindholm, & Lindström, 2002). The chapter ends with a discussion of rigor in phenomenology, a data safety monitoring plan and procedures for protection of human subjects.

Sampling

Sampling Strategy

Sampling strategy in phenomenological inquiry is a matter of debate: Sandelowski (1995) argues for greatest variety in the data set, whereas Patton (2002) promotes homogeneity in small samples. Convenience sampling is acceptable because the investigator is interested not in the greatest variability of an experience but its commonalities. This study used a combination of consecutive and purposive sampling to recruit CGs of AHF patients. The criteria for purposive sampling were developed after the literature review as performed in Chapter 2.

Well aware that I was sacrificing breadth of the experience by eliminating certain groups of participants I sought homogeneity for greatest depth of the experience. I limited sampling criteria to spouses and partners to the exclusion of adult child CGs; Caucasians to the exclusion of other ethnicities who might have culturally different experiences of health care, caregiving and death and dying; care recipients who were covered by Medicare to the exclusion of those who have different financial coverage of healthcare and perhaps fewer co-existent illnesses. I also sought to include CGs whose care recipients were treated in acute cardiology as well as palliative care or hospice.

Sample Size

According to Spiegelberg (1976) there are no requirements for sample size in phenomenology. Benner (1994b) and others argue for a sample size that is defined by saturation of the data, Creswell (1998) promotes anywhere from 5-25 informants, Ray suggests “usually a small number of 8-12” (1994, p. 127). Kvale states the number of interviews in common interview studies to be 15+/-10 and, in concordance with Sandelowski (1995), strongly cautions against quantity of participants over quality and depth of analysis: “A general impression from current interview studies is that many would have profited from having had fewer interviews in the study, and instead having taken more time to prepare the interviews and to analyze them” (Kvale, 1996, p. 113).

Given the anecdotal evidence that it is difficult to recruit CGs of endstage HF patients, the limited time frame for dissertation work, and the longitudinal aspect (three interviews over 2 months) of my research question I initially set sample size between 5 and 15. I found saturation of themes after five participants but included another two participants to verify saturation and add more depth to my description. The final sample size of seven participants was well within usual and acceptable phenomenological sample sizes in the literature as described above.

Setting

The Heart Care Center at a large regional hospital in the Midwest serves as referral center for 70 physicians caring for HF patients in urban and rural settings in surrounding counties. It includes inpatient HF services for 12-16 advanced HF patients each month with nurse-managed outpatient follow-up care and telehealth contact. Most interviews took place at participants’ homes. Two interviews occurred in a private room at the hospital. One participant preferred to meet at a diner for all three interviews.

Recruitment of Participants

All recruitment procedures were approved by the University of Iowa Institutional Review Board (IRB-02) and the regional hospital’s Institutional Review Committees (IRC) prior to initiating recruitment for this phenomenological study. The required forms for the IRB/IRC and the letter of acceptance from the regional hospital can be found in Appendix B.

Eligibility criteria were the following

Spouses or partners living with the care recipient, who identified themselves as primary providers of practical and emotional support for their care recipient.

Caucasian.

Care recipients 65 and older.

Care recipients were diagnosed with NYHA class III or IV AHF, or stage D refractory HF and the referring ARNP would not be surprised if the care recipient were to die within the next year. This is a commonly accepted screening criterion for referral to palliative care in AHF (Goodlin et al., 2004).

Caregivers accompanied care recipients to clinic visits and considered themselves involved in making health care decisions with or for the care recipient.

Caregivers needed to be willing to reflect and share their deepest feelings about the meaning of symptoms and their experience of communication as well as their own role as CGs.

Caregivers spoke English well enough to engage in sufficiently rich and detailed interviews.

Caregivers were willing and able to give informed consent.

Caregivers had access to a telephone for weekly check-in phone calls between visits and to contact the investigator when needed.

The only exclusion criterion for participation was a current diagnosis of psychiatric illness or major depression. The criteria can be found in the Initial Contact Worksheet in Appendix B. The purpose of the study was discussed in detail at the outset of the study with the Director of Heart Care at the regional hospital, and the ARNP in the program. They gave feedback and helped develop the fact sheet for eligible CGs, and the introductory script for the ARNP to present the study to eligible CGs (see Appendix B). I maintained intermittent telephone and e-mail contact with the ARNP throughout data collection to clarify eligibility criteria and guide purposive sampling.

The initial estimate projected approximately 12-16 CGs per month who would meet eligibility criteria at the Heart Care Center, however this turned out not to be true and recruitment was very slow. After only three participants were recruited over a period of five months it was suggested that the age criterion for care recipients were set too high and an IRB modification was done to include care recipients 50 and older. This led to the inclusion of a CG-CR couple who were both still working full-time and added clearly defining and limiting qualities of the CG experience to the findings. Throughout recruitment, the ARNP volunteered evidence to support how care recipients were at the endstage of the disease which was helpful, because CG participants did not clearly share this perspective. Upon my request to include recipients of palliative or hospice care, I was referred one CG whose care recipient had had a palliative care consultation, and one care recipient with DNR status. Of the eight CGs approached about participation only one declined when I followed up on the ARNP's referral with a phone call. This CG stated that she felt quite overwhelmed at the time and did not want to engage with yet another member of the healthcare community. I declined to include one participant who lived on the West Coast because telephone interviews may have been significantly different from the protocol set for this study.

Procedures for Participant Recruitment and Obtaining Informed Consent

Recruitment took place at the hospital's Heart Care through the ARNP who made the initial determination of eligibility based on care recipient (CR) diagnosis. She also made a decision as to whether the CG would be a thoughtful person to reflect about caregiving issues. She then approached the eligible participant guided by the recruitment script:

> A doctoral student from the College of Nursing at the University of Iowa in Iowa City is currently conducting a research study to learn more about the experience of family members who care for a heart failure patient, like you are. We are assisting in the study by identifying caregivers who may be eligible for her study and providing them with information about the study. The study goes over 2 months and involves in-person and phone interviews with the researcher. Would you like to read about this study to see if you are interested in becoming a participant?

If the CG responded positively, she handed them the fact sheet and the consent form (Appendix C), explaining:

> This is information about the study and the consent form you would be asked to review and sign if you agree to be in the study. I would encourage you to read it carefully and maybe talk it over with other family members or friends. There is a contact number for you to call the researcher. We ask that you contact her within one week, if you decide that this is something you would like to be a part of. She will go over everything in detail with you and answer any questions you might have. If you wish, you may let me know that you are interested in the study and I can give your name and contact information to the researcher who will then give you a call. You should know that the researcher is not connected to your healthcare team here at CRST, and whether you decide to participate or not will not in any way affect the care (name of the patient) receives here. Thank you for considering this. We want to support caregivers in their experience, and with this study we will learn more about what they need.

All CGs preferred that I contact them directly, and the ARNP communicated their contact information via phone call or confidential e-mail. During our first telephone contact I used the Initial Contact worksheet (see Appendix B) to confirm participants eligibility and willingness, answer initial questions about the consent form of which there were never any, and set the time and location for our first interview.

The consent form was reviewed during the first interview by reading through it together. I was conscious of ethical considerations in palliative research as described by Casarett (2005), specifically, maximizing value for study participants, benefits to participants, need to minimize risk and burden, and protecting voluntariness of participation. I emphasized the value of the study to produce knowledge for CGs in the future. While the sample was going to be small, the in-depth nature of the study would give a good preliminary description about the previously uninvestigated experience of AHF CGs. The study would be valuable to the participant because it invited their voice and perspective and explored outcomes of care that are of importance to CGs who are often marginalized in management of HF. Caregivers uniformly expressed appreciation of the opportunity to talk about difficult issues with someone who understood their circumstances as AHF CGs. This line of reasoning has been shown to be a reason for participation in studies of palliative care and bereavement (Cook & Bosley, 1995; Emanuel, Fairclough, Wolfe, & Emanuel, 2004).

As researcher investigating ethically sensitive issues of suffering and dying, I had to establish trust and rapport. It was neither the intent of the phenomenological interview nor did I have the qualifications of a psychotherapist to delve into sensitive issues without invitation and provoke an emotional crisis. Self-reported distress in qualitative studies is less related to the topic of inquiry and more a result of participant characteristics (Takesaka, Crowley, & Casarett, 2004) and therefore was unpredictable for this study. In order to minimize the risk of emotional distress beyond the everyday experience of someone who reviewed the effects of a loved-one’s suffering I made myself available for telephone consultation. I also requested the contact information of a trusted family member or friend who would be able to support them through an emotional crisis. Finally, they were given the phone number of the ARNP at the Heart Care Center and of the chaplain from the hospital’s Palliative Care Service. They were referred to Dr. Butcher, my co-chair in case they had concerns about the study itself.

If at any time a participant became too emotionally distraught to focus on the purpose of the interview, I was prepared to end the interview, turn off recording devises as well as my researcher role and switch into the role of the nurse who needs to support a client through a crisis (Martin et al., 2007). This may have simply involved use of empathy and staying with the participant until he or she was more composed and then resuming or re-scheduling the interview; it may have necessitated a phone call to the participant’s support person, or it may have ended the research relationship to protect the participant from harm. In the event of any ethical problem I was ready to consult with members of my research community at the College of Nursing and School of Social Work. Formal ways to minimize risk and burden as well as protecting voluntariness of participation are detailed in the consent form in Appendix B.

The Interview Procedure

The first interview was scheduled at CG convenience either during the first meeting at the hospital or via telephone soon after. The time frame of 2 months for the interviewing of each CAREGIVER was chosen in consideration of the fact that the diagnosis of AHF is associated with a very unpredictable disease trajectory and high risk for sudden death (Goodlin et al., 2004). In the event that a patient died before the second or third interview occurred, the last interview would be a bereavement interview, scheduled whenever the CG was ready. Research procedures included gathering minimal demographic information such as contact information, age, gender, ethnicity, relationship to patient, living situation and whether the CG was included in the advance directive or living will (see demographic information sheet in Appendix B). I also noted how often the CG accompanied the patient to clinic visits or hospitalizations in the preceding 24 months. Participants were asked to select a pseudonym to protect their anonymity in all written documentation for the study. They invariably selected names that held deep personal meaning and value which they explained to me. Save one, all participants consented to supplying me with a contact phone number of a close person, which I could involve to provide emotional support to them if needed. One participant preferred to contact me directly if she felt in need of additional support because she did not want to burden family or friends with her own distress.

Recruitment and data collection occurred between August 2010 until July 2011. There were three phenomenological interviews in approximately one-month intervals for six of the seven participants. One CR died after the first interview and a bereavement interview took place 5 days after the death. Interviews lasted from 34-96 minutes each which was consistent with length of interviews in similar studies, for example see the exploration of dignity and respect in living with chronic illness (Delmar et al., 2006; Öhman & Söderberg, 2004). Interviews were recorded with a digital recording devise as well as a cassette recorder for back-up.

Interviews were loosely scripted with the interview guide in Appendix B. Questions were adapted to and co-created for the needs of each participant and built on knowledge attained in previous interviews and telephone check-ups. My questions were funnel-shaped in that they began each interview with a description of the caregiving experience or summary from the previous interview but then focused on symptom interpretation and changes in symptom interpretation in the first and second interview, and communication and expectations for the CG role in the first and third interview.

The conversations served both the thematic purpose of responding to the research question as well as the dynamic aspect of creating a trusting relationship and facilitating deep reflection. Kvale lists different types of interview questions for the phenomenological interview to elicit descriptive, behavioral, experiential, emotional, cognitive or evaluative content (Kvale, 1996). For example, my introductory question "Today I would like you to please tell me what it is like to care for (name of patient)" was followed by the structuring question "You could start by talking about how you got to be (name's) caregiver" and aimed to elicit a spontaneous description of *what* was happening. The direct questions "What are some of the symptoms of heart failure that (name) is experiencing?" and "Who do you talk to about (name)'s (symptom)?" later on in the first interview served to push forward thematically. This encouraged participants to respond reflectively to all three questions by offering descriptive, emotional, cognitive and evaluative responses. If needed, follow-up questions to guide reflection were used, such as "What is easy or difficult for you about (this symptom)?" I also used probing questions "could you say something more about that", interpreting questions "is it correct to say that you feel…", as well as silence or affirmative nodding.

While the first two participant interviews were in progress, I recognized additional questions to stimulate deep reflection:

> Can you give me a metaphor or image or comparison for what it is like to care for (your spouse)?

If you were to explain it to another person, how would you describe heart failure?

What advice would you give a person who was new to the caregiver role in AHF?

Finally, I co-created with them a drawing of the disease trajectory for AHF and asked participants to reflect on their role at various points throughout the course of the illness.

I ended each session by thanking participants for sharing specific highlights from our conversation, followed by a couple of debriefing questions which I had learned in conducting interviews for Dr. Carolyn Turvey on patients' feelings about their implanted cardiac defibrillators. The questions "Before we end our session, I wonder if you have any questions or concerns for me?" and "How do you feel about our conversation today?" allowed the participant to comment on their experience of the interview itself. I kept track of their responses in a special file in NVivo8, along with my own brief assessment after each interview, to monitor each participant burden.

I offered to conduct weekly 5-minute telephone check-ups with participants, scheduled at their convenience, in order to keep track of experiences related to symptom interpretation and communication which they might have had in the previous week. I planned to use this information to trigger participants' memory for reflection in the next interview, and also to maintain an empathetic relationship between interviews. This strategy was most important for one participant who was diagnosed with onset of Alzheimer's disease after the first interview. Three participants opted out, preferring to keep a journal of events instead. One participant preferred not to have phone calls because her life was too busy and she trusted to be able to keep track of events herself. One participant seemed to enjoy the social aspects of the call in addition to the fact that she had much to tell about weekly events in her husband's rehabilitation in skilled care. The last participant did not reveal much regarding symptoms or communication events but appeared to want to reassure me that all was going well instead.

At the conclusion of all interviews two pieces of apparently missing information became apparent. First, only one of the CRs reported angina as a symptom observed in the CR. Presence or absence of chest pain is a disputed fact in descriptions of the patient experience and I wished to verify that this was not simply an error of omission in this study. Second, in reviewing transcripts for changes in symptoms over time there was also little change observed within the two-month observation window of the study design. These two issues compelled me to request an additional IRB modification to contact all participants one last time to specifically inquire about any manifestation of cardiac discomfort, and to glean more about changes over time through the extended time window which ranged anywhere from nine to three months since respective participants' last interview. Participants were again consented for this final follow-up phone call, and all of them agreed to participate. The IRB modification, consent letter and telephone script can be found in Appendix B.

Throughout the study I reflected in my research journal about relationships with individual participants, specifically to examine (1) development of potential bias threatening my research perspective, and (2) development of dependence and over-involvement on the part of the participant. Kvale recommends to "investigate with the final report in mind" (Kvale, 1996, p. 274). Such an attitude removes the researcher from the immediate situation and allows her to guide both herself and the participant towards the story which needs to be appropriated and communicated to the world as a result of the study. Such focus on the future helped preserve both my own, as well as the participants' integrity.

> Recognizing bias: I found it initially difficult to reconcile my participants' experience with the experience of family CGs in the ICU, my own frame of reference. On the surface, there was less existential suffering than I had expected. Yet, learning about their home lives with AHF was like an adventure with new insights and revelations, many of which explained attitudes, beliefs and behaviors which I had

observed in the ICU. I recognized within myself a deep reluctance to invade their home experience with any sort of preparation for the ICU experience, and fortunately this was not the intent of my study to begin with. However, it allowed me to experience deep within myself the profound hesitation barring HCPs from bringing up bad news. I had never felt hesitation in the clinical context, where the situation was ruled by physiological signs and symptoms which were logical and irrefutable, and all too often reduced both my own as well as the patient and family member's ethical intentions to simply surviving the next hour. Using Kvale's advice to elicit the story that must be told, I surrendered myself to capturing participants' narratives of lives lived as described in their metaphors.

Development of dependence or over-involvement: One male participant struggled with grief and sadness during our interviews. I caught myself trying to "cheer him up" by appealing to his masculinity and his sense of humor. Fortunately this was successful only because it allowed me to lead him back to these feelings from a stronger emotional vantage point as the interview continued.

One participant, whose husband was near death felt a great deal of anger towards the medical establishment and not all her stories were "rational". I found myself wanting to explain "misperceptions" and defend the medical system that tried to provide good care to her husband but obviously failed miserably to do so. Again, I had to fall back on Kvale and simply listened to her story honoring her perceptions without trying to "explain them away" to myself.

Another participant gave thoughtful descriptions of her feelings but openly asked for my judgment calls on whether her feelings were normal, good or bad. In this case the story that needed to be told was about feeling unsure in the CG experience, so I chose not to engage in such dialogue but kept re-directing to her story. I only encouraged her to find a CG support group, a suggestion which she followed up before the next interview. At the conclusion of all our interviews I spent some time reviewing her doubts and self questioning, sharing what is known in the literature about such feelings.

All participants had questions about the pathophysiology of AHF, medications and health concerns not related to AHF, or related to their own health. Sometimes it made sense to incorporate teaching into the interview situation to invite reflection about new-found understanding for example, when they asked about the natural progression of the disease or advance care planning. Other times I requested to talk about their questions after the interview was concluded.

I expected there to be moments of tension between my scientific and ethical responsibilities in the interviews, for example, when participants asked for information about their patient, or for my opinion in certain situations. They did not seem to fear to speak freely in case I share information with the healthcare team and I was able to balance my role of researcher against that of clinician by emphasizing that I was not connected with their healthcare team in any way, and anything they shared with me would be kept confidential. They seemed to perceive me as their conduit, as if in dialogue with HCPs or imaginary other CGs and in the heat of the moment occasionally charged me with something akin to “you tell them that!” They seemed to understand that I was unable to discuss with them anything related to the care of their patient but on several occasions I helped them identify issues that might benefit from intervention and make a plan to communicate questions or concerns to their healthcare team for clarification.

While it could not be predicted if or how CGs’ reflections in our conversations would affect their self-perception, there were some therapeutic effects. Kvale lists such changes in self-understanding resulting from reflective interviews among *fields of* *uncertainty*, that is “problem areas that should continually be addressed and reflected upon throughout an interview inquiry” (Kvale, 1996, p. 69). One example was processing work done between interviews, for example when they realized that they had managed a symptom or conversation with their CR differently after their reflections in the interview situation. Therapeutic effects were made explicit especially with the debriefing questions.

Ricoeur method

By developing a method from Ricoeur’s theory of interpretation, nurse researchers can achieve congruence between philosophy, methodology and method. Distinct steps of interpretation of text (hermeneutics) are premised by distanciation and include naïve reading, structural analysis, critical reflection and appropriation. These steps have been used primarily by Scandinavian health sciences researchers to interpret journals, audiotaped and transcribed interviews and narratives. Grounded in the interrelationship between epistemology (interpretation) and ontology (interpreter) Ricoeur’s hermeneutic arc moves the interpreter from naïve understanding limited by distinct world views of interpreter and author, to deeper understanding in which the text is seen in relation to the author, interpreter and the world (Geanellos, 2000). “To understand a text is to follow its movement from sense to reference: from what it says, to what it talks about” (Ricoeur, 1976, p. 80). He describes the process of explanation and understanding within the hermeneutic circle in his publication *From text to action: Essays in hermeneutics, II* (Ricoeur, 1991).

Creating a text

Text is discourse fixed by writing. It may be transcribed speech or dialogue, as in an interview. Or it may be a journal entry as discourse that could be said, “but that is written precisely because it is not said” (Ricoeur, 1991, p. 106). Needless to say, in order for there to be interpretation, there has to be meaning which differentiates the text of a journal entry or narrative from a grocery list or the description of how to tie a shoe. Text inserts itself between the writer and reader, any communication between the two sides is only possible through the text. Text intercepts the referential function of speech, that of which the writer speaks. By suspending its referential function the text can then engage any other text or reference, in the world.

The text for this study was created from interviews with participants, a final follow-up phone call, research journal, telephone check-ups, participants' written notes, my reflective journal, and discussions with other experts such as members of the dissertation committee. All sources of text were captured in a project in NVivo 8 software. Interviews were digitally recorded and transcribed verbatim including laughter, crying, sighs, pauses and non-lexical sounds. Observational notes written directly after the interviews, notes from telephone check-ups, participants' written notes and my reflective journal were kept in a securely locked file cabinet at the College of Nursing.

Distanciation: a basic premise for interpretation

In order to retain both the richness of subjective experience and objectivity and rigor of scientific analysis in interpretation of discourse, any method must have a way to deal with the interpreter's subjectivity. Ricoeur addresses this through the process of distanciation as an attitude inherent in the author, the text and the interpreter.

Human discourse is a fleeting event in time, where something is communicated by someone within a unique irreproducible context. By its very nature, discourse already separates the event which is temporary, from its meaning which may endure. This first act of distanciation, speech itself, separates the preconceived worlds of speaker and listener. Ricoeur argues that further distanciation is inherent in the very act of writing which fixates discourse and renders it autonomous from the speaker's context and intentions. Discourse as text, instead, becomes re-contextualized in the reader's context. For example, by transcribing an interview we collapse the space and time of shared context between interviewer and interviewee into a new projection given by the text itself. Any interpretation of the text as a description of being in the world now must happen *in front of the text*, which distances experience of *being as a given* to *being with the power to be open to* alternative interpretations (Ricoeur, 1991, p. 86). Distanciation, which allows objective interpretation and explanation of text therefore is not a matter of method, but inherent in the very nature of discourse. Distanciation is addressed again in the first step of the arc of interpretation or hermeneutic circle, naïve reading.

Naïve reading

The first step in the methodological application of the theory of interpretation involved placing the text on a platform of shared language and human experience, the reader undertakes the first naïve reading. : "To read is … to conjoin a new discourse to the discourse of the text" (Ricoeur, 1991, p. 118). It is the task of reading and interpretation to restore reference to the text and to find the author within the text. "Understanding seeks to coincide with the inner life of the author, to liken itself to him (gleichsetzen), to reproduce (nachbilden) the creative process that engendered the work" (Ricoeur, 1991, p. 106). A preliminary understanding will arise clearly, framed by the reader's pre-understandings. The aim of the naïve reading is not to evaluate for truth or state as facts, but to be able to re-tell the experience as stated in the text. The reader engages with the writer by re-phrasing without judgment in an act of respect and solicitude. In re-telling the reader allows himself to be moved by the text and registers his own essential response based on his own pre-understandings. As he formulates questions to the text the reader becomes aware of his pre-understandings and recognizes where the text fits or does not fit. While suspending judgment is essential, complete bracketing of pre-understandings in the Husserlian sense is not required and would, in fact, take away from the meaning and essence of the text as it generates a response in the reader.

In order to capture my naïve understanding of the text created in the interviews and telephone check-ups I listened to the digital recordings and created a summary transcription for each first interview. I grouped the text into preliminary categories which were apparent from the line of questioning and the direction of the participant's train of thought. I noted my personal responses and questions that arose out of pre-understandings in the reflective journal immediately following each interview. These reactions helped formulate questions for the next interview, externalized my bias and were retained for critical analysis later on. New information from the second and third interviews were added to the summary from the first interview in different colors, using the "track changes" function in Microsoft Word. This yielded a summary document describing the participant's experience by speaking to all the categories addressed in this particular discourse over time.

Structural analysis

Discourse as work mediates between the irrationality of an event and the rationality of meaning. In assigning meaning, the speaker consents to the reality of the event (Ricoeur, 1991, p. 79). This work is individual and never alike for any two people. However, by fixing discourse into writing, discursive meaning becomes objectified and susceptible to structural analysis and explanatory methods. "Hermeneutics… remains the art of discerning the discourse in the work; but this discourse is only given in and through the structures of the work. Thus interpretation is the reply to the fundamental distanciation constituted by the objectification of man in works of discourse, an objectification comparable to that expressed in the products of his labor and his art" (Ricoeur, 1991, p. 83). Structural analysis occurs within that space where referential function is suspended and is aimed at elements constituting the sense of the text: what is said (as opposed to what is talked about, which references to the meaning held by the writer). "The sense of the narrative consists in the very arrangements of the elements, in the power of the whole to integrate the subunits; and conversely, the sense of an element is its capacity to enter in relation with other elements and with the whole of the work" (Ricoeur, 1991, p. 116). The task of structural analysis is to segment horizontally into *elements, dramatic units* or *action kernels,* and to discover the hierarchy of these parts in the vertical integration of the whole of the text. These parts constitute the essential and limiting elements of an experience: elements, which cannot be substituted or omitted in the experience ("I have to stay with him all the time"), and elements which describe what the experience is not ("I am not free to do my own things anymore.").

Structural analysis asks "who" and "what." Who speaks? This question identifies the characters in the story who are acting (agents) or being acted upon/suffering (patients). How are these characters connected to themselves, the other or the world? How are they connected to past, present and future? In structural analysis, "we understand the characters not at all as psychological subjects endowed with their own existences but rather as the roles correlated with formalized actions" (Ricoeur, 1991, p. 117).

What happens? This question identifies action kernels that together constitute the structural continuity of the narrative. Again, no psychological or behavioral analysis is required, but simply the sequencing of action nodes, "each closing off an alternative opened up by the preceding one" (Ricoeur, 1991, p. 117) and each being essential and limiting to the whole of the action sequence.

Structural analysis proceeded through line-by-line coding for meaning units with special attention to who acted and what was his/her role; what was being done; and what was being felt. When meaning units could be double coded for either action kernel or dramatic unit, I found it helpful to perform vertical integration to assign a primary code: i.e. was the speaker primarily talking about action causing a feeling, or vice versa, was a feeling leading to action. Meaning units were condensed using original language of the participant. Structural analysis maintains text on the non-referential platform, it explains what is happening with whom, but it does not interpret why. This suspense of the referential function is lifted in critical reflection which fulfills the text in present speech and moves it toward meaning. It is the action kernels and dramatic units together which compose the meaning units to be retained for critical reflection.

Table 1. Example of structural analysis and critical reflection yielding subthemes and themes.

meaning unit	condensed	action and drama kernels
Interviewer: Do you ever talk to CR about what <u>you</u> need? Oma: Yeah sometimes, but if I say too much, there again, he misinterprets and thinks that he's a burden, so I have to be real careful. And I've told him different times, I've said you know when you want to go some places, it's not always real convenient, could you wait? Well I tell him he has "this much patience and there's room in between" [shows index finger and thumb pinched together]. Because, he's not a patient man, he never has been. But you know, he tries to understand, but the next time it's the same	It's difficult to talk to the CR about your own needs, because it makes him feel like he's a burden	action: trying to talk about your own feelings or needs drama: having to be careful, experiencing the same problem over and over again CG-as-agent becomes CG-the-patient
Subtheme: Negotiating dignity and respect between the CR and CG		
Theme: Striving to restore dignity and respect to the dispossessed CR and CG		

Critical reflection

In critical reflection the reader tries the fit of exposed meaning units with his own context, theoretical frameworks in the literature, discussion with other experts in the field and any perception of the senses which shine light on the phenomenon, each from a different perspective. As meaning units are returned to context, the phenomenon as a whole emerges. Structural elements and meaning units are compared to the preliminary understandings derived from naïve reading. If they corroborate pre-understanding they can be taken as validation of existing knowledge and theory. If they do not fit, they must be explored in critical discourse with alternative interpretations and theoretical frameworks to lead the interpreter to new understanding, an expansion of his horizon. Many interpretations are possible but in critical reflection the reader arrives at the one interpretation which explains the most meaning units in the best way. Like the strands of the double helix essential for Creation, the intertwining acts of understanding and explanation are the necessary elements to create production and communication of new shared meaning.

In this step, I used action and drama units, combined them with the actor/patient role and identified preliminary sub-themes to which I subordinated all coded meaning units so far. Sub-themes were grouped according to similarities and according to their limiting and defining characteristics, to find themes, which yielded one larger over-arching meta-theme describing the essence of the experience. I looked for patterns in themes across sequential interviews for each participant as well as between participants.

Interpretation of the interviews in a process of dwelling with the data may be a solitary process in hermeneutic phenomenology and I found several studies published by only one coder (Allen, 1989; Fagerberg, 2004; Lohne, 2008a, 2008b; Pedersen & Saltin, 2006; SmithBattle, 2008; Spidsberg, 2007) as well as unpublished dissertations (Lassig, 2008; Miner, 1996; J. Palmer, 2009; Robley, 1998; Rozea, 1995; Stetson, 1998). However, team involvement may add depth and richness (Crist & Tanner, 2003). I discussed initial and final findings with an expert in phenomenology (Butcher), who reviewed one interview for consistency in coding and deliberated with a strategy for naming of themes and subthemes for all four research questions. In that process my more abstract Ricoeurian themes of, for example “accepting the role of caregiver on the continuum of friendship” became more descriptive in popular vocabulary: “becoming a caregiver in the spirit of human affinity”. The actual interpretive process is iterative, simultaneous with data collection, and follows the sequence of naïve reading, structural analysis, critical interpretation and appropriation as outlined by Ricoeur (1976) and formatted for nursing research by Lindseth and Norberg (2004).

It is acceptable but not essential in hermeneutic phenomenology, to validate findings with participants. Doing so had therapeutic effects for participants in studies by Horwitz and Wiklund (Horwitz, Theorell, & Anderberg, 2003; Wiklund, Lindholm, & Lindstrom, 2002). All scientists using the method in studies involving more than one meeting took the opportunity of repeated contact with participants to verify findings, and to adjust their interview questions to probe for emerging themes (Atsalos, O'Brien, & Jackson, 2007; Farnell & Dawson, 2006; J. Palmer, 2009; SmithBattle, 2008; SmithBattle & Leonard, 1998). This is the practice I was able to follow by retelling summaries to participants at the beginning of the second and third interviews and incorporating their clarifications or elaborations. For example, I began the second interview with TC by recalling his feelings of sometimes just wanting to walk away from it all, his occasional anger and depressed mood. This gave him an opportunity to tell of a hunting trip with his son-in-law where he was able to express his emotions, and led him to further elaborate on his desire to plan ahead somehow and to prepare himself for her to be here one day and gone the next.

Appropriation

Interpretation based on critical reflection leads to *appropriation* where the interpretation of a text "culminates in the self-interpretation of a subject who thenceforth understands himself better, understands himself differently, or simply begins to understand himself" (Ricoeur, 1991, p. 118). Final appropriation is equally based on the explanation of cultural signs (scientific and lay literature, movies etc.) and elements of action and drama derived from structural analysis, and on the critical reflection which constitutes meaning. The act of interpretation, as opposed to explanation, bridges cultural distance between the writer and reader, it “brings together, equalizes, renders contemporary and similar, thus genuinely making one’s own what was initially alien” (Ricoeur, 1991, p. 119). Interpretation brings the text into the present, like the performance of a Beethoven symphony brings to life a historic musical score. After mediation through structural analysis, the text becomes actualized in the reader’s referential world defined by what is already known about the phenomenon from scientific and possibly popular literature, music and art. Objective structural analysis remains meaningless without the reader’s personal and qualified commitment to restore reference to the text. For example, in order for a construction worker to benefit from nitroglycerin therapy he must not only understand the causation of angina, he must also appropriate the interpretation in his own frame of reference, namely that his usual strategy of simply being tough and working through any pain will not relieve an acute blockage in his coronary artery and that this pain is not a sign of weakness but of acute cardiac ischemia.

Moving appropriation beyond understanding and interpretation of an individual, which, according to Ricoeur would be only “the romanticist ideal of coinciding with a foreign psyche” he says:

> What is indeed to be understood- and consequently appropriated in a text? Not the intention of the author, which is supposed to be hidden behind the text; not the historical situation common to the author and his original readers; not the expectations or feelings of these original readers; not even their understanding of themselves as historical and cultural phenomena. What has to be appropriated is the meaning of the text itself, conceived in a dynamic way as the direction of thought opened up by the text (Ricoeur, 1976, p. 92).

This leads to the disclosure of all possible ways of looking at the text. By focusing on the world as projected by the text, interpreted in the dialectic of explanation and understanding, the reader sheds self-centered and dogmatic pre-understandings, frees himself from psychoanalytic dialogue and historical distance and initiates a new self-understanding. Appropriation opens up the reader’s ego to find a new self in a world of expanded meaning and possible action. Hermeneutics thus provides the epistemological bridge of critical reflection to the ontologic condition of human beings who appropriate through explanation and understanding and who are transformed to act differently by ongoing engagement in the hermeneutic circle. This process led to discussion of all findings as well as implications for nursing and further research in Chapter 5 of this dissertation.

Scientific Rigor

Phenomenological rigor conveys quality in craftsmanship (Sandelowski, 2006) in describing truth as it emerges in a world unfolding (Ray, 1994). Rigor determines how well the reader can appropriate new meaning created and how transferable the findings might be. Sandelowski (2006) initially named four criteria of rigor: credibility, fittingness, auditability and confirmability.

Credibility

According to van Manen as cited by Ray (1994, p. 131), “Credibility, […] is a validating circle of inquiry, […] where the description and interpretation of experience are something we can nod to and recognize as experiences that we had or could have had.” Distanciation inherent in Ricoeur’s method is productive in that it allows understanding beyond the historical context which explains meaning for the individual, to an understanding that transcends into existential dialectic and human experience in general. An *attitude of suspicion* moves the reader/interpreter between limits of dogmatism and skepticism towards appropriation which goes deeper than recognition, whereby behavior change in the reader may happen in the future, long after the study was read (de Witt & Ploeg, 2006). Credibility as a nod of recognition may also refer to the curious therapeutic effect of an interview where continuing reflection in the participant may shape communication in the meantime, which in the case of this study became apparent in subsequent interviews. Methodologically, the overall credibility of a hermeneutic phenomenological study rests in the concepts of fittingness, confirmability and auditability.

Fittingness

Hermeneutic phenomenology is descriptive in that it lets the phenomenon under investigation speak for itself, and it is interpretive in that it assumes that all phenomena are already meaningfully interpreted by the one who experiences and/or observes the phenomenon (Ricoeur, 1976). Appropriation arises out of a fusion of lenses of participant and researcher. In order to answer the research question about lived experience, both participants and researcher must fit with the phenomenon. Participants must be willing and able to reflect on the personal experience under investigation. Sampling is purposive and directly influences transferability of findings. It is the researcher's task to drill down to the essence of personal experience presented in text that is most descriptive of not only the sample but all people, based on a shared humanity and language.

Given the importance of the phrasing of the research question, I would add to the category of fittingness my own qualifications to explore the phenomenon of ethical intention in HF CGs. The fact that I have clinical experience with the patient presentation of end-stage HF and my practical knowledge of Ricoeur's philosophy of interpretation make me a good fit for conducting this phenomenological inquiry.

Confirmability

Phenomenological confirmability has to be qualified: Understanding as arrived at from guessing and validation through interpretation within the hermeneutic circle does not claim to find the only truth. Rather than to attempt empirical verification of a phenomenon, the method uses logic of qualitative probability: "To show that an interpretation is more probable in light of what we know is something other than showing that a conclusion is true" (Ricoeur, 1976, p. 78). Ricoeur likens hermeneutics to "an argumentative discipline comparable to the juridical procedures used in legal interpretation" where converging indices, much like triangulation of data in the natural sciences, provide "a firm basis for the science of the individual" (Ricoeur, 1976, p. 79), specifically as the individual expresses himself in discourse. Phenomenological validity is therefore not value-neutral or free of bias, but values and preconceptions are accounted for much as variables in multiple correlation studies.

In an iterative process throughout the study, transcripts were read and re-read numerous times to search for meanings and varied patterns. Caregiver responses that needed clarification or follow-up were noted and addressed in the next interview or in future interviews with other CGs in on-going verification. I discussed interpretations with Dr. Butcher, other members of the dissertation committee, the HF ARNP and a trusted AHF caregiver to achieve confirmability.

Auditability

This is a process by which readers can follow every step of the research process and reach the same or similar conclusions. In a review of phenomenological methodologies, de Witt and Ploeg (2006) found techniques commonly used such as the decision trail, reflexive journaling, systematic data analysis and explication of decisions to use any certain phenomenological method. In addition to verbatim transcription of interviews, I kept a research log holding the audit trail from phrasing of the question, through all iterations of interviewing and analysis including discussions with other members of the research team, to presentation of findings as they were returned to the hermeneutic circle for future reflection by the reader. Using systematic data analysis as described in the hermeneutic arc of interpretation by Ricoeur, I present the evolution of CG quotes to meaning units, sub-themes and themes in table form. The reflexive journal served to keep track of ongoing connection-making as I dwelled with the data. All sources of materials were kept in a file in NVivo 8 software on the H Drive, accessible to me only. In these ways, I conducted the study in a way that another could reproduce or adapt it to arrive at complimentary findings (Crist & Tanner, 2003; de Witt & Ploeg, 2006; Sandelowski, 2006).

Data and Safety Monitoring Plan//Protection of Human Subjects

Participants were protected under rules and regulations of the University of Iowa IRB and the Mercy and St/ Luke's IRC. Requirements of participation and information for informed consent were explained in detail prior to the first interview. The consent documents provided study participants with information about the use of the digitally recorded voice recordings, and transcripts. Furthermore, the study participants were informed that: (a) their real names and voice recordings would not be used in research presentations and publication; (b) study findings likely would be published in poster and journal format; (c) no direct benefit to them from participating in the study was anticipated; (d) possible risks and discomforts of study participation included experiencing negative feelings such as sadness, grief, or anger; (f) they always retained the right to refuse to answer any questions and either the participant him/herself or the researcher could end an interview session if it was felt to be harmful to continue; and (g) participants could discontinue their participation in the study at any time.

Finally, participants were informed at the time of consent that in the event of an emergency situation (for example a heart attack or verbalized intention to harm themselves or others), emergency services or their primary physician (depending on the circumstances) would be notified. Participants would be given the previously mentioned phone numbers to contact for support in case they were experiencing feelings of grief, sadness or anger beyond what they could cope with. Participants also gave the name of a trusted family member or friend who I could contact with their consent, in case they needed emotional support in relation to the study. They were informed that if abuse or neglect of an individual was observed or discussed in the interview, Iowa law required me to report such information to the Department of Human Services for investigation, or to give them resources to file such a report themselves. There was ongoing monitoring of participant burden using debriefing questions at the end of each interview and a brief written assessment in the researcher's reflective journal.

Participants' names and contact information was not entered into the NVivo 8 program files but securely stored separately from study documents of audio recordings, transcribed interviews and the researcher's reflective journal and research log. Participants were assigned a pseudonym to de-identify study documents. Identifying information and hard copies of transcribed interviews were stored separately in two locked file cabinets in the investigators office at the CON. Electronic versions of de-identified aggregate demographic information, transcribed interviews, research log and reflective journal were stored in the NVivo 8 program file on a secure site on the school's H-Drive which is password protected and allows access to the data for the primary investigator only. Digital voice recordings of interviews were transcribed by a transcriptionist who CITI certification for confidentiality requirements and was approved by the IRB. As soon as possible after each interview, digital recordings were downloaded on the secure H drive, and erased from the recording device after transport. The cassette recording was erased as soon as the digital recording was determined to be intact immediately after the interview. To avoid risks to data safety inherent in e-mail, transcriptions will be transported via secured electronic communication to and from the professional transcription service. Transcriptions were directly loaded from the secure server into the NVivo 8 project by the researcher. Participants retained their written notes or journals which some had created between interviews. All observations noted after the interviews were entered into a journal which the researcher kept in a locked file cabinet either at her house or office.

CHAPTER 4

FINDINGS

The research questions to be answered with this study were: (1) How do CGs experience themselves in the daily acts of caring for their spouse with advanced heart failure? More specifically, (2) how do caregivers explain and understand symptoms of advanced heart failure and (3) how do caregivers use communication to explain and understand the caregiving situation? The final question built upon the previous three by asking (4) how do symptom interpretation and communication shape caregivers' ethical intention for advocacy and making treatment choices over time? The data for the study were collected in three consecutive phenomenological interviews with seven participants, each over a two-month time span, and finalized with a follow-up phone call at the conclusion of data collection as described in Chapter 3.

Findings are introduced with a description of the demographics of this intimate group of CGs. Information about CRs was not intentionally collected; however, I organized what information was volunteered by CGs in the course of our conversations to convey aggregate information. This information is entirely based on CG stories and not verified by medical records or supplemental information from the ARNP at the referring hospital. To further protect CRs' anonymity, they are summarily referred to as "CR", rather than their first initials.

The actual findings extracted from line-by-line coding of transcribed interviews are presented as themes and subthemes within the philosophical framework of Ricoeur and assigned to the four research questions. Themes and subthemes are described in detail and supported with quotes. Findings-over-time for Question 4 are presented in terms of development of recurrent themes across participant stories regarding symptom interpretation and communication particularly as they applied to their needs for ACP.

Vignettes about each participant are presented in Appendix C. These summary descriptions of participants are based on interviews, phone calls and my observations during visits as recorded in the research journal. The vignettes add a limited personal profile for each participant, show development over time within cases and hold the metaphors assigned by most participants to their overall experience as CG to the CR with AHF.

Participant Demographics and Care Recipient Aggregate Information

Minimal demographic information was elicited using the demographic data work sheet found in Appendix B and is displayed summarily in Table 2. There were two male and five female participants ranging in age from 58 to 87 years old. Their educational preparation ranged from 11-18 years, with a median of 13 years. Only one of them was still employed, all others were retired. The question of how long each one had thought of themselves as being CGs elicited interesting responses. The two male participants said that they had been CGs for the entire duration of their marriages of 52 and 41 years respectively, because there had been health problems all along. One female CG emphatically denied being a CG at this point, thinking of herself as a spouse and partner above all else. One female participant had cared for her current partner for 5.5 years, but had been CG to a previous spouse for four years as well. Two female participants had been AHF CGs for 1.5 years; and finally, one participant, in answering this question, realized with wonder, that she had put in 18 years of caregiving for her husband so far.

All participants felt that they were involved in making healthcare decisions with their CRs. Five participants had standard American Bar Association (ABA) Advance Directives (ADs) and Living Wills (LW) for their CRs and also themselves. One did not know what it said because she was not included as Health Care Agent (HCA) due to the fact that she was not legally married to her partner. One spouse did not know if there was an AD; and one spouse initiated but never completed the process during the study. Three CGs had actually discussed ADs with their CRs, four had not. Three of the remaining CGs with ADs stated that their ADs requested no CPR or “heroic efforts”. One CR did not have an AD.

On average, CRs had taken their CGs to 24 HF-related clinic visits in the last two years although there was a wide range from 3-130. Participants stated that there were additional visits for other equally chronic conditions such as diabetes mellitus (DM), chronic obstructive pulmonary disease (COPD) or cancer. CGs had been hospitalized for AHF between one and seven times over the last two years with additional short-stay emergency department (ED) admissions.

Table 2. Caregiver demographics.

Pseudonym	**Oma (O)**	**Elmer (E)**	**The Count (TC)**	**Chewey (C)**	**Lee (L)**	**Librarian (Lib)**	**Smiley (S)**	**(median) range**
Age	75	74	62	58	87	81	73	(74) 58-87
Gender	f	m	m	f	f	f	f	
Years/education	12	13	12	18	11	17	14	(13.86)
Years of being CG	18	52	41	0	1.5	1.5	5.5	0-52
Presence of AD	yes	yes	no	don’t know	yes	yes	yes	
Discussion about AD with CR	no	yes	yes	no	yes	no	no	
# of clinic visits in 2 years	ca. 130	24	>24	3	>24	>24	>10	(24) 3-130
# of hospital stays in 2 years	4	6-8	3	3-4	2	1	4-5	mean (3.5) 1-7

All CRs had at least one coexisting medical condition. Two CRs had a combination of pacemaker (PM) and implanted cardiac defibrillator (ICD), one had a pacemaker only. Some CRs used home oxygen, and some were prescribed a continuous positive airway pressure (CPAP) device, which is non-invasive ventilator support most commonly used for sleep apnea. One CR was hospitalized at the onset of the study, one was re-hospitalized during the study period. One CR received Do-Not-Resuscitate status (DNR) prior to discharge to a nursing home (NH), and another prior to moving to an assisted living facility (ALF). One CR received hospice care and three CRs died in the course of the study.

Table 3. Aggregate CR demographics.

Chronic Conditions	**pacermaker /ICD**	**pacermaker only**	**home oxygen**	**CPAP**	**hospitalized**	**DNR status**	**Hospice**	**deceased**
COPD (3) DM (5) Cancer (1) Arthritis (3) Dementia (1) Fibromyalgia (1)	2	1	3	3	2	2	1	3

Structural Analysis: Findings

Line-by-line coding of all interviews as a whole (the text) created subthemes which were eventually grouped into themes to answer the four research questions as laid out in Tables 4-7. The themes are linked to the philosophical lens Figure 1 (p. 45) which illustrates the centrality of the relationship of the self with the other both within and without, as well as how interactions with just institutions shape capacity to act towards the ethical intention of caregiving. As articulated in Chapter 2, symptom interpretation and communication were singled out as being of particular interest in this exploration of the context of AHF caregiving. Findings from symptom interpretation and communication are discussed separately under Questions 2 and 3 respectively, presented in summary form in Question 1 and then integrated into the final Question 4 to answer how they contribute to shaping the ethical intention in caregiving.

Question 1: How do caregivers experience themselves in the daily acts of caring for their spouse with advanced heart failure?

This question explores how CGs experience the self in the role of CG and how they derive self esteem to perform in the role. The first theme, *Becoming a caregiver in the spirit of human affinity* shows the reasons for becoming a CG to be grounded in the human experience. The second theme, *Striving to restore dignity and respect to the dispossessed caregiver and care recipient*, incorporates the various sources of self esteem, or denial of self esteem for the CG and allowed participants to describe how they derived capacity to act for both themselves as well as their CRs in the role of CG. The third theme, *Gathering your resources within civil society to shoulder the responsibilities of AHF caregiving* illuminates the various burdens identified by CGs, the need for social connections and negotiating the healthcare system. Incorporating CG metaphors into these three themes led up to the essence of being an AHF CG as *being fearfully vigilant, at the mercy of the disease and its treatment and worrying about that which remains unspoken*.

Table 4. How do caregivers experience themselves in the daily acts of caring for their spouse with AHF?

meaning unit	subtheme
Theme 1: Becoming a caregiver in the spirit of human affinity	
"I think that's life in general. We take care of each other." "I love our life together, and I love him, he is a golden soul." "When I had a knee replaced, he did have to take care of me." "If something happens to him, I don't know what I'll do, because my only income is the social security check."	Accepting caregiving as a human obligation
"We help each other with the meds-, we get our month or two week box out and she does hers and I do mine." "I never thought that we would get to this point, where he would have to have somebody looking after him."	Viewing caregiving as a natural evolution of aging vs. unexpected or intrusive
"If he needed a caregiver, he should have married a nurse. I am his partner. We do the best we can with and for each other. That's how I see it."	Setting boundaries around the CG role
Theme 2: Striving to restore dignity and respect to the dispossessed caregiver and care recipient	
"But I do get angry at myself for being angry. I do. 'Why did you do that?' I question myself." "I had not driven, so at 84 I had to start and got my license. 'You go, girl!' That's what everybody said." "I am good now but a year from now, or 6 weeks from now, something could happen, I could take a turn for the worst. We have to start thinking about things like that."	Examining your own strengths and weaknesses while being challenged and transformed
"It irritates me to see him doing it [be incontinent], and then I have to take care of it. I say to CR, 'try to go to the bathroom'. 'I don't have to'. So I'm not going to make him."	Negotiating dignity and respect between CG and CR
"It's funny though, he really sucks it up and keeps marching on and is at work every morning at 7, but there are times when he is very dependent too. Can you get me this or that, you know." If he can't do it, I don't mind helping him, but there's a lot of things he can do. You have to get a little hard sometimes to make him do things for himself." "She likes to help me do dishes. I wash and she will sit and dry them."	Aligning self-determination with the CR's waxing and waning capacity and competence
"Well, I feel bad that he has to have cancer, I'm thankful that its one of them that can be treated."	Holding one's own by reframing or reclaiming sovereignty

Table 4. Continued

Theme 3: Gathering you resources within civil society to shoulder the responsibilities of AHF caregiving	
"Coming to the hospital is a big chore, all those clinic visits. Daily, coming to the hospital, and sitting down here is worse than working, than being home and working," "I'd like the dietitian to show us if there is anything in the supermarket that we can eat!" "The amount of pills she takes before she gets to the donut hole, in a year's time its $7000, plus the [insurance] premium. But after we make it through the first 5-6 months of the year [Medicare] pays for everything."	Feeling burdened
"When other people are good to CR it kind of takes the load off." "Sometimes I feel kind of lonely, especially since we aren't involved in the things we used to do."	Staying connected to the web of society and rallying practical support vs. feeling alone and set aside
"The nurse said: 'You caught it in time and that's the biggest thing, is timing for something like this." "The thing that bothered me was in the hospital, I feel like they should be asking me too. But the doctor comes in and most often they don't even acknowledge me in there."	Being a partner in the healthcare network vs. feeling disallowed and discounted
The essence of being a caregiver to a care recipient with AHF	
Metaphors: Being on edge all the time, peaks and valleys, a prisoner of the disease, roller coaster (O). Walking a narrow path, fine-tuned like the space shuttle, going off into outer space, intruding vs being an intruder (C) looking out for stormy weather (S) being like a ball on a rubber band, between a rock and a hard place, it's a war (TC)	
Being fearfully vigilant, at the mercy of the disease and its treatment and worrying about that which remains unspoken.	

Theme 1: Becoming a caregiver in the spirit of human affinity

The first theme is comprised of three subthemes which give insight into why CGs accepted the caregiving role, how it was part of the maturing spousal relationship and the fact that some of them chose to set boundaries around their CG role.

Accepting caregiving as a human obligation

Caregivers accepted the role out of feelings of love, reciprocity and, perhaps in one case, with a touch of utilitarianism. “I think that’s life in general. We take care of each other. It doesn’t always happen, but it’s supposed to. I think it’s what people want to do. Of course there are always exceptions and you can hear some grumbling.”(S) Oma thought maybe sentiments were changing about this human obligation: “I was brought up in an age where you took care of the person, not like it is now.” And Lee elaborated on abdication of the CG duty: “A lot of people, they’ll take their family to a nursing home and they never come back and see them.” They spoke about their CRs uniqueness and deservingness of caregiving as an expression of love. TC was short but emphatic: “It’s just the way I feel. She’s my whole life.” Most gave longer stories of why their CR deserved their care and commitment:

> He is a wonderful person, warm, caring, loving to his family. [] I love our life together, and I love him, he is a golden soul. He brings a lot to my life; we aren’t at all alike. Through him, my world becomes bigger. It opens up a whole bunch of things! Butterfly collecting, football, tailgating, basketball, theater, those are all things in my life now. (C)

Caregiving was strengthened by feeling a sense of reciprocity: “When I had a knee replaced, he did have to take care of me”(S), and Elmer said: “She is so much part of the organization: I think we both feel the same about that. I will take care of her as long as I can, that is my job.” Chewey pointed out that while she was concerned about CR on a daily basis “we help each other in many different ways. He is a wonderful emotional support.” For Smiley, in addition to being committed to her partner, there may have been a utilitarian aspect to her caregiving: “I’m getting social security, and I probably wouldn’t get a full check if we were married. It takes the two checks to live. If something happens to him, I don’t know what I’ll do, because my only income is the social security check.”

Viewing caregiving as a natural evolution of aging vs. unexpected or intrusive

Caregiving was seen as natural evolution of aging together in a committed relationship by the six retired CGs. Both male participants saw themselves in the role of CG ever since they were married: “Soon after we were married she had things start going haywire. This is over 50 years though, not just yesterday. The issues are just there and they have to be taken care of and handled.”(E) There was a sense of team work in the role as both partners were developing various health issues as a part of aging: “we help each other with the meds, we get our month or two week box out and she does hers and I do mine.”(TC)

While she had been his CG for heart disease for many years, Librarian called CR’s complete dependence on her due to his dementia an unexpected development: “I guess I never thought that we would get to this point, where he would have to have somebody looking after him.” She articulated the grief that came with accepting their mutual decline:

> There are some days that I kind of feel down. Our life as we knew it is over. This is the new life, I guess. I know you can’t live forever, although some people think they can try. We have had a good life, and I don’t regret that. I guess I hate to see it end. I’m sure most people do when they get to be this age when they’re close to it.

Chewey felt like she had to make time for the disease, as it was intruding into her busy schedule: “I have spring break coming up I am trying to divvy up the days; where I am going to be and with whom. So we’ll have four days together, to sort things through. We haven’t had that for awhile.”

Setting boundaries around the CG role

The two couples who had been together for the shortest time, and for whom this was the second or third relationship, set boundaries around their engagement in caregiving. Chewey said: “You keep calling me “caregiver”, that is not me. If he needed a caregiver, he should have married a nurse. I am his partner. We do the best we can with and for each other. That's how I see it." Smiley, who had cardiac issues of her own and whose CR did not accept caregiving of any form easily, sometimes needed to remove herself from a conflicted caregiving situation: "So I just left him. If he's going to get sick, you're going to get sick, but at least you're not going to make me sick."

Theme 2: Striving to restore dignity and respect to the dispossessed caregiver and care recipient

The four subthemes of this second theme describe CGs critically examining their performance in the CG role, their awareness of the need to balance dignity and respect between themselves and the CR, their constant reassessment of CRs' ability to function independently, and their coping strategies depending on whether they felt themselves to be passive or active in the role of caregiving.

<u>Examining your own strengths and weaknesses while being challenged and transformed.</u>

CGs tried to maintain a sense of self esteem while listening to the call for caregiving and they questioned themselves when they felt to have done less well in a caregiving situation. They derived pride from learning skills needed to become better CGs, and they worried about their own health and how it might be limiting their capacity to act as CGs.

Maintaining a sense of self was important. Librarian prided herself on her appearance and continued sharp intellect at age 82: "I don't know what 82 looks like, or how an 82-year-old is supposed to act, I don't feel like I can be that old, you know? As long as I'm able to do whatever I like to do..." Oma felt in continued demand for her baking: "My grandson did call me the other day, he said 'Grandma, I'm going deer hunting, can you make this for me? And this? And this? To take?" Because it's a bunch of guys, they always take stuff!"

Learning new skills increased self esteem. Lee's CR lost his driver's license after one of his syncopal episodes, and she had to get her own license: "I had not driven, so at 84, I had to start and got my license. 'You go, girl!" that's what everybody said." TC was trying to describe how improved symptom interpretation on his part increased his esteem for himself and others: "I guess I would call it trust or maybe faith and trust together. Trust in my judgment and, well, with all the doctors. I think the faith is that I did the right thing at the right time. I can handle it more. When it first happened, it scared me." Oma was proud of being able to adapt her cooking: "Oh yeah, you learn more. I knew the diabetic way to cook. But with the heart you have to be careful too. And yet I try to fix some of the things he likes." She added:"We had an accomplishment last week, I gave him a shower; I mean I got him in, onto this bench that he uses."

All CGs felt that the stress of caregiving affected their health, and therefore their capacity to act, negatively. Oma admitted to experiencing depression, loss of confidence and hope at times: "I think that as a caregiver sometimes, the downs become too many." Chewey reported stress-related weight gain: "I just feel that sometimes mental and emotional turmoil takes more tolls on us than anything we can do physically. I've probably gained 80 pounds since I have known him." She felt anxious a lot of times especially when CR had uncontrollable vomiting or lacked the energy to pick up after himself: "I get anxious when bad things happen to the house. It's kind of your sanctuary."

Librarian felt tense from having to take over for her CR. Whenever she had one of her small bursts of anger it was followed by "sadness or, I don't know, guilt. And I find myself having to take those pills for heartburn and stuff more than I usually do so I figure my stomach is getting disturbed." She elaborated: "Sometimes I get so tense my teeth hurt, I grit my teeth but then I remember to do breathing exercise and it helps. It just seems like some days I wake up and I'm really nervous." She felt possessed by restlessness: "I'm always doing something, cleaning up the kitchen or doing one thing or another just to keep moving." She had put off a doctor's visit for vertigo and a skin condition and so she added: "Another concern I have is if something would happen to me, if I would become ill, what's going to happen to him?" This prompted her plans to move to an ALF.

Lee was involved in a small car accident during the acute stress of CR's transfer from the NH to home the day before he died. The next day, after CR was pronounced dead she was admitted to the hospital for observation to rule out a blood clot in her leg.

Smiley had two episodes of uncontrolled atrial fibrillation requiring cardioversion since being a CG to CR. She has noticed her blood pressure creeping up on her home monitoring device: "This morning it was 152 over 86 or something. The little warning sign the other day it said stage one hypertension. So I've to call [physician] and let him know and see if I should do something different." She anticipated benefiting for herself by learning about HF: "So I think this is going to help me to look out for myself a little better, also."

Even though his blood sugars were running too high TC said: "I am pretty healthy." In view of significant heart and lung disease he qualified his statement: "I am good now but a year from now, or six weeks from now, something could happen, I could take a turn for the worst. We have to start thinking about things like that." He did admit that it was probably stress-related when he got very sick with 'flu after CR returned from the hospital after Christmas. Interestingly, TC shared how his own physical fitness improved as he participated in CRs rehabilitation program: "All the muscles that I knew I had, they finally get built back up. It does make me more confident about myself."

Elmer had hypertension and some neuropathies and was newly diagnosed with diabetes but he hoped it would not affect his caregiving: "So that should all behave itself! I hope!" He said the only negative effect of caregiving on his health was that he "was tired a lot". On the other hand, he had to accept his own diagnosis of dementia which was sure to change his role as CG in the future, requiring reciprocal augmentation of his capacity to act from his CR.

Participants denied themselves esteem when they felt to have failed in their caregiving task. Elmer couldn't help but let it be known how upset he was about his recent diagnosis of Alzheimer's disease, but he regretted: "I've got to learn to quit it because it upsets her. It upsets her bad. And then her BP goes wacky, and I know darn well it's me doing it." Librarian felt guilty for moments of anger: "I get angry at him, yes. Then I just leave the room and do something else. Pretty soon, it's gone. But I do get angry at myself for being angry. I do. 'Why did you do that?' I question myself."(Lib)

Negotiating dignity and respect between caregiver and care recipient

CGs expected a certain degree of friendship or respect from their CRs. Oma describes CR's typical non-verbal behavior after they had a little disagreement where she felt disrespected: "and then he regrets it. You can tell, he'll get real quiet, and the next day he'll try to be good." Chewey bemoaned: "CR expects you to wait on him. He throws his t-shirts in the laundry, wrong side out, expects me to turn them right side out. Now I just fold them wrong side out. I'm getting a little stubborn, too." They did receive praise from their CRs on occasion, e.g. Smiley after her CR's exacerbation:

> When he was bad and needed to go to the hospital, I had to help him get dressed. I drove the car right up to the door, and helped him out, and put him in the car, and took him to the hospital. The day I brought him home from the hospital, he said 'you did a good job. You took care of me well,' he said. He's not one to give out compliments easy.

Librarian's CR who was also undergoing personality changes due to Alzheimer's disease was becoming unusually complimentary of her which made her a little suspicious that he was having utilitarian reasons: "He says I'm beautiful and all this stuff, but before this happened, he never said anything like that to me. I wonder if somewhere he's thinking ‘I have to be really nice to her so she’ll stay’.” Participants understood that the give and take of respect and esteem in any relationship was complicated but that the disease had added an edge to it. Oma described it like this:

> I think it’s just you’re the person that’s there. You have a really bad day; you take it out on the person that’s there. He used to get mad once and awhile, but not as hurtful as he is now, since the heart disease thing. So you try to understand, but some days it hurts worse.

There were many moments when CGs were denied esteem from the CR, for example when their efforts to support the CR were disregarded. Smiley described being disrespected, having to take the blame and feeling excluded from her CR’s care:

> Whenever I try to talk to him, like he has an appointment, maybe he forgot, or the time’s different, then he gets upset. Well, he likes to use swear words. So, it’s my fault that he forgot an appointment or whatever. I get frustrated because I’d go to doctor appointments with him, and I sit there and listen so I know what’s going on. Then I have a question, and he looks at me like, keep your mouth shut or you’re not coming back, this kind of thing. Sometimes it is frustrating.

Struggling with an hourly toileting schedule for her CR, Librarian recognized the competing states of respect for herself and her CR: “It irritates me to see him doing it [be incontinent], and then I have to take care of it. I say to CR, ‘try to go to the bathroom’. ‘I don’t have to’. So I’m not gonna make him.” Elmer described another situation that required sensitive balancing of CG vs. CR dignity and respect: “Now with that bladder infection, I get to apply the salve in the most disagreeable places. And she can’t reach it. So it’s me.” Weight control was also an issue that tested mutual respect:

> [CR weight] is a terrible subject. If I even hint that she needs to lose some, its war. She is very conscious of it but she can’t get rid of it. She weighs every morning, and I’m not allowed to look at the scale but I know what it is. It’s in the 350 area. And that is way too heavy.

Chewey felt that the type of personal care she had to perform for her CR was in some way robbing her of respect: “I am just angry that I am having to do that when I’d like to be doing something else and not cleaning up that sort of thing.” Librarian recognized her

CR’s gradual loss of a sense of dignity and self esteem which in turn impacted her own self esteem: “Now, if I don't say, ‘You need to take a shower’, he'll just not, and he won't shave. By having to make him do things, that makes me uptight. When I have to act like his mother, that's not a natural role.”

Aligning self-determination with the care recipient’s waxing and waning capacity and competence

For all CGs, AHF caregiving required careful balancing of the CR’s waxing and waning activity tolerance and cognitive functioning, depending on how symptomatic they were at any given time. Participants described caregiving to be a life-long task (E and TC), something not to be questioned but accepted as a duty and consuming their entire days by providing assistance with ADLs(O, E, TC,) and even IADLs (L and Lib). Lee was supervising her CR’s care at the NH from 9 am in the morning until 9 pm at night. Chewey and Smiley’s CRs were still independent in daily life and needed actual caregiving behaviors only in times of crisis.

CGs were constantly discerning whether their CR needed help, or should act independently. Sometimes they were worried about being overprotective and sometimes they had to take over decisively. Oma stated her sudden insight: “I had an awakening the other day: he had open heart surgery 18 years ago, so this has been going on for that long, but there were times in between where he recuperated enough that he could still do things.” Smiley compared the constant caregiving she provided to her second husband who died from cancer, to her role with her current partner who was suffering from AHF: “I don’t really feel like a caregiver as much as when my husband had cancer. It’s not really like a caregiver in my feeling, anyway, because right now he’s doing well and does whatever he wants to do.” Chewey described it this way: “As ill as he is, he is just one tough cookie.” He went to work every morning at seven am, yet it was funny, she said, because “there are times when he is very dependent too. Can you get me this or that, you know." With the same fluctuating activity tolerance Smiley found it difficult not to feel used at times: "Well, it's been going on for so long. So, I'm just getting a little bit frustrated, I guess, at times. He's well enough physically that he can certainly do quite a bit." Librarian described constant discernments: "I think I'm doing a good job. There are times I think maybe I'm overprotecting, or doing too much. Yet, it bothers me to see him struggling to get up, or struggling to do something." As a CR's capacity to act grew less, the CG had to take over completely to protect and ensure care. Lee recalls the last five nights sitting in a chair at CR's bedside in the NH: "He never, ever pushed a [call] button for any care the whole time. That's why I tried to spend as much time with him."

Participants infused negotiation of care and respect for the CR's autonomy into various activities and choices. They tried to preserve CRs' ability to be active, productive and have a sense of purpose to the best of their best ability. All felt an obligation to encourage: "But, we'll get him through it, I told him. You have to encourage them, no matter what you know, you have to encourage them."(O) They worried to be their CR's last asset: "I think he feels like he's losing everything, therefore as a caregiver, you're it. He gets better when I'm there."(O) Smiley saw CR's need for her constant presence differently: "It's like he needs me there. If he can't do it, I don't mind helping him, but there's a lot of things he can do. You have to get a little hard sometimes to make him do things for himself."(S)

CGs invited CRs into shared activities and team work: "You have to work very hard to find something he can do. He'd gotten so bad, as I told him; he was even doing the dishes. I try to find things."(O) Mowing the lawn on a riding mower seemed to be a favorite activity for Oma and Smiley's CRs: "We've got a big garden. We go down there and we mow about three acres, and he gets on the lawn mower."(O) Smiley did the tricky spots around the railroad ties "So when he got on the riding mower, he didn't have to stop for that. I think he appreciates when I do things like that."(S) The female CRs missed being able to do the cooking, TC told: "She used to really like to cook and she can’t do that anymore because she can’t stand.” Now, he says “she likes to help me do dishes, I will wash them and she will sit and dry them.” Elmer and his CR also share food preparation: “The other day we cooked some food, and she said, ‘Get me some cups, and some macaroni, and some cheese’. I said, ‘how much do we need’? ‘I will figure that out, you just keep bringing me the raw materials.’” Elmer said he didn’t mind her “acting like a drill sergeant” at those times.

Throughout the interviews, CGs pointed out valuable contributions their CRs made in their life together: “She is very talented in setting up decorations, you can see some of them around here,” Elmer said pointing to objects in their living room. Oma was glad to have CR as a communication partner: “He knows what’s going on. Yesterday, I’d changed our insurance all around and we were discussing how to take care of it. That I would really miss, because even though he’s sick, he still knows what’s going on.”

All CGs experienced role change, having to assume some of their CRs’ old responsibilities and having to give up some of their own favorite activities. Librarian described how the pattern of their marriage had changed: “We've been married 58 years. Our lives were so different and yet, we've had a good marriage. He would play golf and be gone all day and I would go volunteer. We do spend the whole day together now.” Caregivers commented on other role changes brought about by AHF: “The set back’s hard with the depression. When he was younger, he was always my rock. And now, the roles are reversed.”(O) Librarian talked about the fact that she had to manage CR’s diet: “He cannot do that at all. I said to him the other day, ‘Yeah, I'm your mother and your wife, too’." Female CGs had to learn how to care for the car: “I have to do it all. Well, it doesn't feel good. I'm worrying a lot.”(Lib) Oma missed having CR’s advice: “At times I certainly miss that joint decision. We got the oil changed in the car and they told us we needed new tires. I don't know anything about that.” Librarian told: “We used to decide things together. We're going to buy new carpet. Now it's me. ‘You're the boss, [Librarian]. If you think we need it, you can do it’, which is very different.” There was more yard work as well: “I have to get his lawn tractor out of the shed now. I learned how to do it without running into anything. I have more of the outside work to do, reaching things, and helping with things in the garage.”(O) TC needed to assume paying the bills: “That was CR’s job. That was a big thing, how to take care of all these bills. It makes you realize, what if she wasn’t here? And it makes you stop and think; it sure did me.” CGs had to give up some of their customary housework chores and it affected their self esteem: “I can’t do any of that anymore. That bothers me, it’s a loss of what I do.”(O)

Holding one’s own by reframing or reclaiming sovereignty

CGs developed coping strategies for situations where they saw themselves as the ones being acted upon, as in a patient role. Because they had no control over the situation they reframed their attitudes instead. At other times, when they felt as agents in charge of caregiving, they readily reclaimed their capacity to act in various ways.

Participants coped by reframing their caregiving in the context of normal aging. They mourned for an altered retirement: “In the back of your mind you do. But you know you can’t change it, so it’s not something I dwell on. Things that I thought were really important when I was younger, I found out aren’t so important.”(O) There was also reframing in changing personal patterns of behavior. Chewey viewed it as a compromise when she had to give up open windows in her house for the sake of CR’s respiratory issues: “We have things that we enjoy together. It’s not just all him or all me.” Regarding her strict standards for neatness she said: “I guess I have to balance my life. I can’t be constantly cleaning, sorting, doing the laundry while he does absolutely nothing here.”

They wanted to keep life as normal as possible, to plan for alternate settings of care, or a decline in their own health. They wanted to continue some of their own favorite activities: “So far, I’m still able to do everything that I have to. And I still do crossword puzzles and all that stuff. I'm not walking like I should, but I'm still going to [volunteer work], and do dieting."(Lib) Elmer tried to keep a positive attitude about newly imposed driving restrictions and his own aging: "I can still get to all the farms, the pharmacy and the grocery store. But my life seems shorter. Seventy-five kind of snuck up on me. I don't want to be 75. It helps to go see your grandkids."

Providing a sense of lightness was an important habit for Elmer and Oma: "If you aren't laughing, you are crying and there is enough of that going on. We try to keep things happy."(E) Oma demonstrated one of her positive spins after CRs cancer diagnosis: "Well, I feel bad that he has to have it, I'm thankful that its one of them that can be treated." Trying to reframe the frequent doctors' visits, Elmer said "You've got to make fun out of it somehow, or you'll just sit around and bawl your eyes out."

There were instances when CGs struggled to actually reclaim capacity to act, specifically in the managing sodium-restricted diet, getting to appointments with their CR, dealing with medication regimens and their side effects and taking care of their own needs. There was always relief when they found a safe food for their CR: "we finally can, because of the low sodium thing, do the meals you cook in the microwave for two or three minutes." Other barriers in public life related to disability and access were more difficult to negotiate: "they don't make it easy for the caregivers. And when you have enough on your plate, sometimes that's a bad thing too."(O)

Sometimes they took medication management into their own hands, weighing the inconvenience and embarrassment of incontinence against potential fluid retention: "He's supposed to take the diuretic. When I give it to him, he just has a really serious problem of being able to get to the bathroom on time. So I really have not given it to him every day." Elmer and his CR were exploring alternative medicine in search of pain relief: "There's a place that makes potions out of cactus flowers. It's supposed to help with pain. And it does. And we don't even tell our doctors that; I don't know, we might get thrown out of the office or something."

CGs were aware of the need to care for themselves. They reclaimed self care by getting away occasionally and seeking emotional release. “Yeah, I spent almost three weeks deer hunting with my son-in-law. We both got our deer this year!”(TC) They needed to understand their own anger or sadness: “you can’t be with someone every day 24 hours a day without getting angry sometime. There just isn’t anybody that can do that, unless they are perfect.”(O) It helped to talk to friends or have a good cry sometimes: “You have to brighten up a little bit, and let yourself down a little bit. There are times when there is nobody in the house and you can have a good cry and get it over with.”(O)

Theme 3: Gathering you resources within civil society to shoulder the responsibilities of AHF caregiving

This third and final theme identifies the biggest burdens articulated by this group of CGs as sources for the support needed from friends and family, as well as public institutions ranging from the food industry to healthcare providers, health insurance and Medicare.

Feeling burdened

Participants identified six burdens that defined the AHF caregiving experience: (1) Enduring frequent clinical encounters and being at the beck and call of the CR while trying to negotiate time for yourself, (2) Struggling to find safe foods, (3) Bearing the financial impact of AHF healthcare expenses, (4) Constantly trying to cheer up the patient, (5) Symptom interpretation and (6) Communication. Burdens (4) and (5), and burden (6) are summarized here and examined in more detail in Question 2 and Question 3 respectively.

Enduring frequent clinical encounters and being at the beck and call of the CR while trying to negotiate time for yourself.

CGs were tied into frequent clinical encounters and their CRs’ needs, and found it difficult to negotiate time to accomplish tasks unrelated to caregiving. “Coming to the hospital is a big chore, all those clinic visits. Daily, coming to the hospital, and sitting down here is worse than working, than being home and working,” Oma said, before she added “I wouldn’t not do it, I can’t do that.” Librarian agreed: “It seems like we have so many doctor's appointments and things like that. I don't have time to volunteer anymore.” She gave an example of their schedule:

> He saw [physician] right after we got out. Then he sees him again in June and then we see [physician] again this Wednesday. He had prostate problems, too, so we see [physician], who's the urologist, next week also. Having to have that blood level checked every two weeks, it seems like we're stopping there to get that done. And his [blood thinner] thing was not good and so I have to take him again to have blood work done this Thursday, to have it rechecked.

All CGs spoke to the fact that they felt tied to and dependent on their HCPs in their attempts to maintain continuity of care. When Librarian was weighing her options for relocation to Florida or to be with her daughters, one of CR’s doctors told her: "Think about changing doctors and all that before you make that decision to leave." She said: “that swung me to staying here [because] CR has been seeing [physician] for 25 years now. To change and go to a different one, I just wouldn’t have the same feeling of trust, I guess.”

CGs’ days were spent meeting the CRs needs: “most of the time it’s ok, it’s just sometimes you have your day planned. You know, that I need to do the laundry, I need to do this, and that’s the day he picks [to want to go for a ride].” Oma tried to negotiate time with her CR in the past, mostly unsuccessfully: “If I say too much, there again, he misinterprets and thinks that he’s a burden, so I have to be real careful.” Chewey found she had to schedule vacation time to accompany her CR on his impromptu butterfly excursions, and yet she was unable to get him to consent to a dietary consult or advance care planning session.

Finding safe foods

It appeared that, on a daily basis, participants' greatest burden was related to finding safe foods for their CR. Chewey was most eloquent about this issue:

> A low sugar diet is not so tough, but a low salt diet is tough. There is sodium in everything. Even the milk he is drinking right now. So you try to cut back on your fat and your sugar intake and you end up with more salt. And if you try to limit the sodium, really there isn't anything that doesn't have sodium in it. Maybe celery, but I doubt it.

She had done a lot of label-reading and decided: "there is an awful lot of misleading marketing." In general, CGs found healthy food to be more expensive and less accessible. Elmer, talking about a weight loss program: "What's bad about that program is that the food is expensive. But it is nourishing food, its good food. I can't complain about that, it's just a little expensive." Elmer experienced another barrier to getting healthy foods: due to his progressive dementia he had difficulties in unfamiliar places: "We have one [grocery store] downtown. Everything is reasonably priced; they recently remodeled. I walked in there and all I see is boxes! There are so many choices it just bewilders me." Therefore, although the convenience store is more expensive and limited in its food choices "it's sometimes the only choice I have", Elmer concluded.

There were multiple diet restrictions for all CRs and for some also a fluid restriction. While all CGs professed their CRs to be adherent to the sodium restrictions "most of the time", their stories showed just how difficult it was. TC told: "She has been doing really well staying away from salt. They told her that is poison to her with congestive heart failure. We make our meals pretty salt free." He added that they don't go out to eat much anymore "because most of the stuff they make is salty." Then he admitted: "We have this little restaurant right downtown there, we'll go there every once and awhile. She likes their biscuits and gravy. When they make it, sometimes it's so salty you can't hardly eat it. But it's always good!"

Chewey and her CR were both professionals with long days. Because they were often too tired to cook at the end of the day they were used to eating out. "Now, when we go out to eat we go to [restaurant] because the people there know him and make sure to serve him things that are very low in sodium." Procuring safe food was challenging when traveling. Chewey tried to bring a cooler of "safe foods" but CR said "I'm getting to the point where I can hardly eat what I eat every day. I'm getting sick of it."

CRs missed their "forbidden foods". Smiley described CR's struggles: "Ham, it's his favorite meat, can't have that." When they were invited at a relative's house: "it was a nice, thick slice of really nice ham. He ate it, but then the rest of the day he kind of watched it. So I don't think it hurt him any." This CR did frequent compromises, eating salty food for one meal, and no added salt for the rest of the day, or taking additional diuretic medication. After eating fried cat fish one evening: "next morning he got on his scales and he had gained two pounds." After our interview one day, Smiley was bringing him a [restaurant] sandwich: "He was good this morning. He didn't have much breakfast with salt. I think he kind of adjusts that way."

Elmer's CR was restricted in sugar, sodium, fats and calories as well as fluids. She had tried weight reduction all her life and experienced a great deal of emotional pain surrounding food. Elmer explained: "it's a terrible subject. If I even hint that she needs to lose some, its war. She is very conscious of it but she can't get rid of it." He goes on to tell their story of frustration and little hope:

> She's talked to a dietician again after this many years of having diabetes. She's heard every story, heard of every product, got the same recommendations, so you don't gain much by going to [dietitians] anymore. They are trying to put three menus into one and that is hard to do. Her potassium is always low from losing all the water. We've been trying closely to watch salt content. She watches what she eats, that is something she didn't do before. But I don't know if she is going to lose any weight. She weighs three times a day, and takes her blood sugar at least

> three if not four times a day. They cut her back to a liter and a half of water. But every pill says take with plenty of water. It's hard to do. So I think we probably make more slip ups than we should.

One example of a slip-up Elmer gave was the fact that the alternative medicine they were using without their physician's knowledge required four ounces of medicine to be diluted in eight ounces of juice which constituted one fourth of her daily fluid allowance.

Participants wanted to learn about the salt and sugar content of foods, and looked for professional advice. For various reasons, Chewey had to cancel two appointments with the nutritionist at [grocery store] "so three months later we are still trying to get together. I'd like both of us to go, and I'd like her to show us if there is anything in the supermarket that we can eat!" Smiley felt better informed: "We met with a dietician the other day. I got an idea what's allowed. You don't have to go totally without it, but 2,000 milligrams a day sounds like a lot until you figure up what's in everything."

There were some creative solutions and changes in cooking habits. Chewey's CR liked a low sodium soup that he could spice up with [non-sodium spice]. Oma's CR liked tomato juice so she canned their own tomatoes without salt and "just put in chili powder and onion powder and jazz it up a little bit, he likes it". An added bonus was that "he helped me all summer with things like that. I've got that down pat. We can all his fruit and everything so there's no sugar in it, no salt, or nothing."

Lee's story illustrated the emotional and life-giving nature of being able to feed your CR. When she witnessed his loss of appetite towards the end, she fed him some soup "He was lying down, and I couldn't stand it to see him not eat, and so I was feeding him." This unfortunately resulted in aspiration pneumonia, was labeled non-compliant behavior by the HCP staff and caused some conflict in association with his transfer from the hospital to the NH.

Bearing the financial impact of AHF healthcare expenses

Participants were asked about any financial impact AHF might have on their daily lives or planning care. Expenses related to health insurance and medical treatment affected the working couple, Chewey and her CR, the most. “He has a very good health care policy. But we pay over $2000 per month in health insurance. If he can’t work, that is going to take more than half of my paycheck.” However, CR just turned 65, “So there may have been a change in what he pays because of Medicare. But I know that he has a supplement and he pays quite a bit for it. His medications are $1200 or $1300 a month.” Chewey stated repeatedly that “CR is driven to get things paid off and squared away. I don’t think he will be satisfied until he does. Now if his health takes a turn for the worst, I don’t know what happens to all of that.” She didn’t think finances were going to limit his choices for treatment: “His medical bills have all been pretty much taken care of. But he takes 11-13 different medications a day so he said that the $1500 [of supplemental insurance] a month about covers his medications.”

All retired participants reported high medication expenses but felt otherwise sufficiently covered by Medicare. Only Lee recognized that home healthcare would be unaffordable and therefore felt that finances limited her choices for care until CR became a hospice patient. Elmer reported that since they were switched to Medicare financial management of the disease has become easier. Before Medicare, their insurance cost $17,000/year. Now, they spend $7,000 in the first five or six months each year for medications and the insurance premium “before she gets through the donut hole”, then “Medicare pays for everything”. Healthy food choices also affected Elmer’s pocket book: “But, do you want to lose weight? Or do you want to argue over a dollar bill?” He concluded: “We just try and survive. We are more surprised that we are not broke. We aren’t rich either.”

Oma did not feel in financial duress: “We live pretty simply anyway. We have insurance, because I worked at [factory]. He is also a member of the VA. We planned that all ahead before he got sick.” They make use of a drug plan through Medicare and have supplemental insurance. “We have to pay the first five days, $150.00 a day, when he goes into the hospital. That's $750.00, everything else is covered. We pay $15 when we go to the doctor, for what they charge us, that is nothing really."

Librarian and her CR had sufficient insurance and resources from financial planning throughout their professional careers, whereas TC and his CR were covered by Medicare and Medicaid.

Smiley at first didn't see much financial impact other than "We maybe don't go out to eat as much as we used to." After thinking about it more deeply, she revised her opinion. Medications remained an additional expense, as does each hospitalization "that few days he spent in the hospital, he got a bill from the hospital for $1,000. He hadn't gotten the second one yet. That's what didn't get paid between Medicare and the insurance. So money is an issue."

Fighting depression

Summarizing from Question 2 Symptom interpretation (SI), participants sought logical explanations for their CRs' low moods in feeling like a burden, lacking energy, and inexorably losing function. Witnessing this sadness in their CRs was a constant drain on CGs' energy. CGs would have preferred their CRs to be angry instead because it would have better mirrored their own response to feeling helpless and being tied down in the CG role.

Symptom interpretation

As summarized from Question 2 SI as a burden is described in Theme 2 *Being afflicted with the task of symptom interpretation* where CGs found this responsibility to be overwhelming and burdensome, they felt forlorn at the frontier of symptom interpretation because their CR did not participate, and they felt caught in the mechanics of medical management of the disease which gave them little choice or perceived control as CGs.

Communication

Again, summarizing from findings in Question 3, communication as a burden was apparent in three themes. In *Learning about the meaning of AHF in your life*, CGs encountered barriers to communication with their CRs and HCPs and struggled with conflicting or missing information. The theme *Using your words to get things done* described challenging communication techniques in conversations with their CRs and troubled communication techniques with HCPs. In *Putting all the pieces together to be the best caregiver to the end*, CGs had to stand up for their own ethical intention for happiness, sustain the CR in his own quest for happiness, and anticipate interruption of communication through NH placement or death.

Staying connected to the web of society and rallying practical support vs. becoming socially isolated

All participants acknowledged that there was a loss of social activities for both the CG and CR. Chewey reported that she had to give up biking and camping and “we don’t get to do as many things together, we don’t go dancing, we don’t travel the world. We’ve stopped doing lots of those things. He won’t go for walks.” Librarian agreed: “I’m sad because CR’s got this problem and he can’t do anything that we used to enjoy together, like going to plays, or concerts.” She is sad for herself, too: “The other day we had some friends over and they were telling us [what] they were doing as couples, going on this bike trip [etc.]. I thought, ‘Well, we just are left out of all that stuff anymore’.” Librarian was looking forward to moving to ALF because she expected more social interactions and even a bit of exercise for her CR: “There's somebody there all the time. And from the elevator down to the apartment is a long hallway that’s carpeted, and it has railings on both sides. That walk down there won’t hurt him. It might help.” Elmer pointed to the need for family presence: “Her grandchildren and great grandchildren are just the most important things, I think that she has.”

Going on outings for any reason was a welcome diversion: “He likes to go gambling so once and awhile we’ll do that. When he’s well enough, I try to take him, a lot of times we’ll go where there’s not smoking. Just to see him enjoy it...” Smiley’s CR was getting bored: “He can’t do anything and he’s just sitting around doing nothing. He’s wanting to go do something.” But it was difficult for them to find a moment in time when neither they nor one of their friends was having a health crisis, to go on a long-planned two-day trip. Chewey’s excursions to go butterfly collecting with her CR were quite anxiety-provoking for her, as described before. Librarian told how CR’s incontinence curtailed their social life: “He’s having trouble with incontinence at times. So that’s why, partly, I guess, I felt it was easier to stay home than go someplace.” There were issues of dignity (a diaper) and pride (having to ask for help) whenever they planned to leave the house: “That’s a practical consideration. I could always have him wear a diaper but I don’t think he’d like that. I’m sure one of our friends would go along if I asked. So I’m gonna try it and see what happens.” Frequent doctor visits required significant physical effort; as a matter of fact, Oma’s CR died on one of their trips to the doctor.

Participants relied heavily on family and friends to maintain self esteem on the friendship continuum for both themselves and their CRs. Friendship support meant anything from opportunity for socializing, therapeutic conversations or humor breaks.

Families were supportive when they showed love: by visiting, writing cards, reminiscing, and empathizing with the CG experience. TC speaking about his family’s involvement in caregiving: “Oh, they have to be there for her. No ifs, ands or buts. I know they can’t be here every day when she is sick but just even calling her helps.” Lee recalled the recent Easter holiday: “He was there in the hospital. All my family took turns coming two or three at a time kissing him and hugging him, all my nieces and nephews. They love him dearly.” She appreciated how her granddaughter decorated CR’s room at the NH with personal information and pictures: “She did these signs here and left all those pictures, so the staff would know who he was talking about if he called me ‘babe’. And that he was very deaf.” Oma put it simply: “When other people are good to CR it kind of takes the load off.”

Respite care provided by family members was especially affirming: “This week has been real bad. Then my daughters will take a day off their vacation to take dad so that I can go to luncheon with my friends. So that pulls you up, something to look forward to.”(O) It was affirming to hear family members value CGs’ health and agree to NH placement sometime in the future if it were necessary to protect the CGs health; Oma quoting her daughter: “Mom, if he gets too much, he will go somewhere else to live, because we’re not willing to trade you for him”. Family approval of important decisions about the future was important; Librarian in making decisions about settings of care: “Our daughter was here Easter and we went to [ALF] and she said, ‘Yeah, I think I can see why you like it there, Mom’.”

By continuing to support and respect the CR, friends supplemented care and provided relief to the CG. “He used to be a very good card player, but now he's not, of course. So our good friend said, ‘Okay, CR. You're down to my level now.’ It's very good of her to say things like that.”(Lib) Friends offered understanding and opportunities for emotional release. “I have been talking to our friend in D. She has really been a good support.” When he failed to notify them of a previous hospitalization: “I got my butt chewed out for it. They said, ‘we told you we’d be there for you’.”(TC)

CGs employed formal and informal practical supports to allow for as much independence as possible: “I should just let him shower on his own. I did have a grab bar installed in our shower, and he said, ‘oh, this is really a big help’.” TC mentioned: “She’s been trying to get out more. She has a walker with a rollator, and an electric chair that helps her get out.” Some received practical help with household chores from family or paid providers, which was sometimes associated with awkwardness in requesting help, or allowing a stranger into your home. “We have a girl that cleans once a month, which was a big step. Letting someone new come into the home and clean up your mess."(E) Living in an isolated, rural setting, Elmer also hired family: "Our son lives a mile and half away. When it snows he comes over here with his tractor and blows the snow into the yard, I don't have to do that. We've got everything in place, a lot of practical help." However, asking for help was not easy, and CGs were very concerned not to overburden family and friends with their own problems because they felt that these others had lives to live and problems of their own. Librarian decided not to move closer to her daughters to find more help in her caregiving: "At the present time our children are too far away to do anything. They want us to move, which is a big thing. Both daughters work full time. I'm certainly not going to go live with one of them." Elmer: "I talk to [granddaughter] sometimes I guess, but not much. She isn't living here to be our private nurse. So I hate to tie her down with all this." CGs wanted the same sensitivity in negotiating help and respect from their family members: "they say you can't be doing this or that. Well it's something I've always been doing and I can still do that. I know they're trying to help but all they're doing is making me feel my age."(O) Oma called her daughter's behavior helpful but overprotective and said: "Just sometimes you kind of have to sneak off!"

Formal practical help came from various directions: an adult daycare, and home healthcare providers who would shoulder some of the burden of physical rehabilitation. They supported the CG role in setting goals, enabling adherence, and offering encouragement. This relieved CG burden. "They were so good to him, made him laugh." Oma described the intense relief that came from even temporary NH placement:

> I could run to the store if I needed something, I could go down in the basement do some things if I was cleaning and I could do some things that I started. He was the kind that I think he's scared, with every right to be, about things, you know if something doesn't feel right. He was always yelling at me and I was always running back upstairs. It was kind of a relief to be able to sleep in, till I wanted to get up, or had to. Umm, to not have to worry about meals, he's diabetic you know, I just ate when I wanted to. I had a little more freedom for awhile.

All participants described the loss of friendship relationships and isolation due to caregiving responsibilities. It was difficult to maintain old friendship patterns outside the couple relationship. “I used to have a lot of friends I used to socialize with, couples and close girlfriends. And I don’t think I’ve seen any of them, or gone out with them in several years.”(C) Librarian, caring for her CR with dementia in addition to the AHF mentioned isolation and loneliness more than the other participants: “Sometimes I feel kind of lonely, especially since we aren't involved in the things we used to do. We aren’t active in church anymore, because he just likes to sit. He'll go and he'll just sit. That's not good either.”

Being a partner in the healthcare network vs. feeling disallowed and discounted

Home healthcare providers boosted self esteem when they provided humor, and a personal connection. Oma enjoyed the home healthcare team which came into the house for a few weeks: “She was a nurse. Him and her just hit it off. She was always calling him dad, he’d say ‘you look tired be careful driving home,’ so she’d say ‘yes dad’. That helped, they were so good to him.” Being treated as persons and having their emotions acknowledged by HCPs was supportive: “[Physician] called me. Every day almost he calls me to see how I am, and he feels so bad.”(L) TC felt rewarded when he brought CR in for an exacerbation: “They told me that with the way she responded this time, she’s going to come out of it quicker and easier. The nurse said: ‘You caught it in time and that’s the biggest thing, is timing for something like this.” Positive feedback from visiting nurses was empowering for Oma, Librarian and Smiley. Oma: “After he came home from the hospital, the visiting nurse stopped to see him. That was good. Everything was well. She does that to be sure he’s doing okay and getting the proper care.” Being validated made Smiley feel more confident:

> I listened to everything the visiting nurse said, and added little comments to it, and she said yeah, that’s right. CR asked her

> what Cardizem was, and I told him that that’s for irregular heart. She gets out her little book and reads about it. And I was right.

Librarian wished she was getting more affirmation from HCPs: “because I think I’m an insecure person and have been. I like to be told that I’m doing well.”(Lib)

In general, formal care providers, such as physicians, nurses and clergy were felt to be inaccessible for day-to-day friendship support. “[Physician] was our family doctor, worked in the big “cement building” as I called it. He doesn't accept calls after 5, and the heart doctor that has taken over, no they don’t take calls.” He added emphatically: “They are too important. Put that down in your notes: doctors are too important.”

However, professional HCPs relieved the CGs’ emotional burden by offering support, presence and competence in caring for the patient in times of crisis. This is what Oma needed and received from the ICU nurses: “[They] are so kind. ‘We’re going to do everything we can to get him better; you just leave him in our care. We’re going to make sure he gets well’, so it takes some of that burden off of you.” Oma found friendship support in the most unlikely places at the hospital, as examples of what makes a “just institution”: once, when she was feeling particularly discouraged the valet at the hospital “comes up to me and puts his arm around me and says ‘I’m praying for CR’. When you can get people in the hospital encouraging you, then you have a big network of people to care.”

There were various examples when CGs felt disrespected within healthcare institutions. Lee and Librarian highlighted issues with dignity and respect associated with formal care providers. Lee decried the lack of male carers in home healthcare:

> In eight weeks they came three times a week. That’s 24 times and never got him anywhere near that bathtub. No woman was ever going to see him take a bath. It was $135 for her to be here each time she came. I said, ‘I don’t want you to come back. I can’t stand it to hear him beg you and plead with you. It’s his modesty, not yours’. They had no man that they could send to help with it.

Librarian felt guilty about sending CR to adult daycare because he was offended by people's lack of table manners: "he really hasn't liked [adult daycare] that well. Couple days, he's refused to go. He realized a lot of people there are worse off than he is."

Some felt excluded by physicians during conversations at the office or in the hospital, Chewey said: "From my experience, the thing that bothered me was in the hospital, I feel like they should be asking me too. But the doctor comes in and most often they don't even acknowledge me in there." Elmer gave an illustration of the loss of recognition and dignity implied in having to see the many specialists for CR's various chronic illnesses:

> You go in with a sore finger, and you get a doctor that fixes sore fingers. Well what about the other finger? 'oh no, I don't deal with that finger'. That is so disgusting. To think that that's what you have to do. Before you can get a pill prescribed from a doc, you have to call him and he no doubt charges for an office visit even if it's over the phone. It's so irritating. But oh well, that's how the game is played. If you want to feel better, you have to play the game.

Elmer realized that due to fractured care nobody ever paid respect to their entire story.

> They give her [medicine] one or three or seven days and in a week's time she is almost over the infection part, but never quite gets over it. And at the end of the month, she has it again. So we call the doctor, he calls the pharmacy, pharmacy calls me and says CR has some pills. I go in and get the pills: same darn pills that didn't work before. So what are we doing here? So, that's what irritates me. I'm not the doctor, but I sure know what the symptoms are, and I know what the history is. And it seems to me that that is something the doctor should know too.

Elmer's helplessness in being able to successfully support CR in her incontinence was a profound reflection on the loss of dignity and respect experienced when HCPs' ignored the impact the problem had on their lives:

> It seems to me that someone could get a handle on this. We've seen all sorts of specialists and they've tried different medicines, and they don't seem to be working the best. And they say "ok, we'll see you in three months". Three months, we'll have the floor washed out by then. It's just aggravating. That makes it sound like its anger, and it's not, but she gets so upset with herself; I find her crying after she's had one of these episodes and has to call me; because she's dribbled on everything from the door to

> clear to the back of the bathroom where the stool is. And she doesn't want to get up from the stool, for fear of dragging it all through the room. So I get called on."

The typical progressive losses associated with chronic illness which define aging in American society left these CGs feeling inadequate, angry and then resigned. They found it hard to fight the CRs low mood which resulted from the loss of dignity and respect: "When it [depression] first started I kind of resented it. Because it took my time, and I thought, we retired to do fun things, and it's not. But as the years go by I guess it's just something you do." After 18 years of caregiving, Oma was most articulate about why her CR should feel like a burden at times despite her best efforts: "It makes me feel like 'what did I say' or 'what did I do' to make him feel like that. But you don't do anything, it's just them because they can't do it and they are frustrated and your there." So you have to take the blame for things that can't be changed: "Like the other night when we brought him to the hospital. He didn't want to come down here. Everyone walked out of the room and he said '[Oma], why did you put me here?'"

After years of aggressive cardiac interventions came the sudden loss of choices for medical support and treatment. Lee recalled the conversation where she was told that her CR would have to be placed in a NH: "She wasn't mean about it or anything, but it was just an absolute 'this is the way it is'. Well, I just couldn't buy that. It's like you don't own yourself." She went on to describe a sense of abandonment: "Once they saw that they couldn't help him he was out on the street. They didn't really care where he went. In fact, we had three more days [in the hospital] that we didn't see anybody except an occasional nurse."

Metaphors

Metaphors were helpful to illustrate the CG experience, how it made them feel and what it made them want to do. Oma felt that "you have to be prepared for everything that happens. Because one day he can be fine, and the next day he can be in the hospital. So you live kind of on an edge all the time. You never know if this is going to be the last time, because it very easily could be." Smiley described not finding CR home upon her return from a trip: "He was in the emergency room. You never know when you leave what's going to happen."(S) Chewey called being a partner to her CR "very challenging. It's very scary. I feel anxious," because "he is like the space shuttle, so fine-tuned. If anything gets out of order the whole thing goes out of whack."(C) She gave a metaphor:

> So I worry about keeping him in that narrow path that he can travel between the diabetes and the sugar, and now the salt. I'm not real sure about my role. Right now, I think we are on this narrow path because he can't veer one way or the other. He has to be very careful of what he eats. It is treacherous. I just see myself as walking behind him holding onto his belt and hoping that he doesn't fall.

Oma echoed the constant weighing of benefits and burdens of treatment: "So you walk a fine line wondering, shouldn't he have a life? Shouldn't he be allowed to go out? And yet if he gets sick, then they act like you should have kept him home. So I'm torn." TC's metaphor spoke to the relentlessness and unpredictability of AHF:

> Being a caregiver for CR from day to day is just like those balls on the paddle that are attached by a rubber band. They bounce back and forth, long and short or whatever. And you have to keep catching them with the paddle. It seems to me that the heart failure is always there and it will come back to you, you just don't know how or when.

He incorporated his feelings of helplessness and also his willingness to fight in the next image: "We're trying to fight the good and the evil at the same time. It's a tight war, actually. It's a damned-if-I-do, damned-if-I-don't situation. A rock and a hard place. We don't know what to do." Smiley's description referred not only to the nature of AHF but also to her CR's temperament: "with him it's like going from a sunny day into a storm, I guess. Yeah, because he gets angry, too, and so then there's all that turbulence, and you don't know how bad a storm it is."

Participants described a number of feelings. "I just feel sad that he's that way."(Lib). With time, they experienced exhaustion and depression, Oma said: "Eventually you do get tired. When you're getting up in the night, and trying to get your sleep, and trying to do the work of two people, you do get tired. And then sometimes things don't look too bright." She was continuously set up for disappointments: "I think that as a caregiver sometimes, the downs become too many. Because one week with the myeloma, the next week was this [exacerbation], and now, it's been a week with depression and its downhill again." TC was resigned about a future of intermittent crises: "they said it's one of them things that's going to irk her every so often. It's going to be part of life and I guess I've just got to get used to it. I'm not going to like it." Elmer put it like this: "Well, my first reaction was 'what in the world have I gotten myself into?' but then you just take care of whatever it is. Go to the doctor, get more pills." And yet, there were moments of anger at the caregiving situation itself:

> Like this morning, I overfilled our washing machine, and thought that it broke. I got so mad that I wanted to put my fist through the wall, then realized that wouldn't fix anything, just make me more miserable with a broken hand, and I'd have to fix the wall. So I walked away for about ten minutes. Just calmed down, started all over again. All of a sudden it hit me and I was like 'what am I doing here'. I wanted to walk out and say 'to hell with it'. (TC)

On the other hand, they appreciated hard-won recoveries: "Things have really changed in the last month because she has been able to do so much more for herself."(TC) Elmer summed up the bright sides of being a CG which included gratefulness for what was left "So far she is mobile and able to use her walker to get out to the car, and she sits in the passenger side which means that she can get her feet and legs in that have no feeling," and the ability to balance a sense of separateness and togetherness: "As long as she is happy I can watch television. She has hers and I have mine. She watches love stories and I watch shoot-em-up movies." Elmer enjoyed helping CR get dressed after she picked out her clothes, he said: "The togetherness is kind of nice."

Question 2: How do caregivers explain and understand symptoms of advanced heart failure?

Symptom interpretation (SI) constitutes a major part of the context for caregiving in AHF (see Chapter 2). Participants articulated three themes in this category, beginning with their ongoing attempts to understand the HF disease as part of their CRs' entire illness experience, the heavy burden of feeling responsible for symptom interpretation, and ending with their hopes and fears regarding progression of the disease in the context of very little information.

Table 5. How do caregivers explain and understand symptoms of advanced heart failure?

meaning units	sub-themes
Theme 1: Figuring out what makes up this new shape in the illness landscape	
“Heart failure- that sounds just terrible. If your heart fails, you’re dead.”	Feeling threatened by the term “heart failure”
“You think he can do more but he’s got no ambition, no get up and go. I guess maybe that’s when you don’t have the energy, you can’t breathe. You’re just there, and you don’t feel like doing anything.”	Defining the meaning of HF
“The shortness of breath makes me worry. I can get her oxygen but that is really about all that I can do. Sometimes I feel helpless.”	Being affected by the symptoms of AHF
“Well, that changes their personality, I’m sorry to say it but it does. I think he has a strong will to live, but I think he sees things coming and he’s more concerned about taking care of himself and feeling like he can’t do enough.”	It’s disturbing to see how AHF has changed the care recipient
“Occasionally he’s incontinent when he doesn’t have the diuretic, but with the diuretic, it just seems like a constant thing.” “She is just a mess. She’s got everything: the fibromyalgia, the arthritis, she is in pain constantly. Neuropathy!”	Multi-tasking to manage the many manifestations of the entire illness experience
Theme 2: Being afflicted with the task of symptom interpretation	
“I had to learn to do all that. Sometimes the responsibility gets a little overwhelming.” “I had to report every day for two years to [doctors]. That was a lot for me to do, to weigh him and tell them this every day, every day.”	Being responsible for SI is burdensome and overwhelming
“It’s really hard to tell with him, because he never tells you. ‘I’m fine’, and then all of a sudden, he’ll just not be fine anymore. That makes it really difficult.”	Feeling forlorn at the frontier of symptom interpretation
“Well, don’t they feel like they have to? His heart is working good so they said it’s not his heart. But they want to do a stress test to make sure.”	Feeling caught in the mechanics of medical management
Theme 3: Trying to add color to a grey future	
“[ARNP] was very informative, and we had literature on it. She had a folder and kind of went through that, but nothing was said about the future, about what could happen.” “You never know what to expect. She could be here one day and gone the next; you have to prepare yourself mentally for it.”	Being in the dark about symptom progression and trying to light up a path of preparation, knowledge and acceptance
“If only the medications would level off and keep everything under control and we could just keep him where he's at now.”	Trying to find freedom from worries in hopes for the future

Theme 1: Trying to figure out what makes up this new shape in the illness landscape

The first theme in SI sets the stage with five subthemes for what CGs understand about AHF. First, CGs felt threatened by the term “heart failure” itself; next, they defined AHF in terms of what it meant to them and their CRs; third, they shared the symptoms they observed, how they made them feel and what it made them want to do; fourth, they found it disturbing to see how the disease had changed their CR; and last, they reintegrated how they needed to manage not only AHF but all the other symptoms experienced by their CRs as part of their entire illness experience.

Feeling threatened by the term “heart failure”

CGs and CRs did not like the term HF: “He hates that word, heart failure, because he says sounds like I had a heart attack.”(S) Elmer pleaded: “To me it’s very confusing, that word. Heart failure- that sounds just terrible. If your heart fails, you’re dead. Why can’t we call it heart bruising or something. Let’s just call it something else, not heart failure.” Smiley’s CR kept telling people: “I had trouble breathing. He doesn’t tell them congestive heart failure. He doesn’t like to use that word. He said his heart was okay. Well, his heart wasn’t working properly or it wouldn’t have done that.” Perhaps their aversion to the term “heart failure” explains why most of their definitions of HF focused on issues related to fluid balance rather than actual heart muscle failure.

Defining the meaning of heart failure

Chewey admitted to not knowing much about the disease: “I still don’t have a clear picture of what it is technically. I know what the symptoms are, what he goes through in that.” In general, AHF was defined by being short of breath and swelling of the body, not being able to do the things you want to do and walking slowly and with effort. “You think he can do more but he’s got no ambition, no get up and go. I guess maybe that's when you don't have the energy, you can't breathe. You're just there, and you don't feel like doing anything."(S)

Caregivers made the connection between fluid retention, weight gain and shortness of breath. Smiley understood HF to be "like the fluid around the heart, but it gets in your whole system. It stops you from breathing right. He only has 46 percent capacity in the first place, so you have a problem to force that fluid out." Lee defined HF with the appearance of edema: "Mostly the swelling of his body. His body swells up, right here [pointing to trunk and abdomen] and then there's water in the lungs too." TC asked his doctor for the definition of HF and heard that the problem was with fluid surrounding the heart: "The fluid gets in the lungs and the chest cavity and squeezes the heart. I never knew that, thought it had to do with the heart itself. They said no, it's just the fluid around the heart." He was listening to and observing CR's doctors carefully:

> When she was retaining fluid her legs would swell. I know that her belly really swelled the last time. The doctor said that was the most dangerous part. They said that now what you have to watch is that fluid going into the tissue. That would be the hardest for the kidney to get rid of; and you might not notice it right away because it can take awhile. And he watches it, and he takes his finger and pokes like that to watch how long it takes for the dent to go away. And she has been really good, it pops out right away. So she isn't holding fluid back. Her oxygen has been up to 94, 95. That's without her being on oxygen. Her heart rate's good. At least it isn't her heart that's damaged. It just gets fluid around it and that's it.

Being affected by the symptoms of AHF

Caregivers observed CRs being short of breath or coughing; Chewey described: "I know that when he starts coughing, where you cough and cough and cough and can't get a breath in, and there have been times where he will pass out because he can't get a breath in." She worries with each cough whether it is simply a little cold, or related to fluid retention: " because I don't know where it is coming from. And then I feel like I've not been doing enough to make sure he isn't eating [too much salt]." TC talked about his response to CR's shortness of breath: "[It] makes me worry. I want to help her as much as I can, but I don’t really know how. I can get her oxygen but that is really about all that I can do. Sometimes I feel helpless.”

Being too tired to do the things CR wanted to do, Elmer said : “She wants to sleep all the time.” Librarian wondered: “He sleeps a lot, but I don't know whether that's medication or what it is that makes him sleep a lot.” Chewey told of her hard-working CR: “He comes home just exhausted. Last night, he didn’t eat dinner. He was in bed when I got home, and said he would eat later [] but he never got up to eat it.”

While CGs observed a lot of daytime sleeping they commented on trouble sleeping at night for both the CR and the CG, some of it either due to having to wear CPAP, or relieved by wearing CPAP. Chewey tells:

> He has sleep apnea; he has trouble breathing at night. He won’t wear a CPAP. I don’t know what I do in my sleep, but I know what he does in his sleep and that worries me, because he will stop breathing for long periods of time; that scares me. If I touch him I hear him go “ahhh” and take a deep breath. So I stay awake a lot of the time just to make sure he keeps breathing.

Elmer resorted to sleeping on the couch because CR had such restless nights “She needs her rest and anytime I would move she would wake up. So now I concentrate on keeping her sleeping.” A month later, CR was on CPAP as well and experienced better sleep except that

> as soon as she gets into bed she has to go to the bathroom and has to take the whole thing off and then gets back to sleep, and then has to go to the bathroom. So she wears it for as long as she can, and then she wakes up and by then we’ve had the mess. (E)

Participants made the connection between decompensation in HF and increasing confusion in their CR: “He doesn’t seem to have anxiety. Except when he gets that swelling up like where he don’t know what he’s saying and it takes his mind—because not enough oxygen is getting to the brain.”(L) Oma showed how she coped with it: “He’s a little more confused: he’ll say ‘well you didn’t tell me that’. I just say, ‘Well I thought I did’ because I don’t want to make him feel worse.” Chewey was especially aware of impaired recall at the doctor’s visit: “They will ask him what he did this morning, etc. but often he does get confused and will say he is fine. Even though he's been sick in the last couple of weeks, or even that very morning." Smiley observed: "I think that this lack of oxygen or something, affects his thinking. He forgets a lot of things. It's not just the medicine. He's more forgetful and probably less patient." She believed it affected his ability to remember instructions for taking his medications: "Well, sometimes he forgets to take his medicines. "He gets home and then he thinks, well I should be taking this one. Well, he shouldn't. He's got 'em all mixed up, what medicines he should take, and which ones he's not supposed to take anymore."

Speaking about depression, participants tried to find logical explanations for it, mostly linking it to CRs feeling of being a burden and lacking energy. Lee said: "He just thinks it's a hard thing for me. He said I'd be better off gone, and I always say well, I don't want to be without you, so that ends that conversation." Librarian recalls: "One time, shortly after we got back from Florida, he did say he didn't really like being this way and maybe it'd be better if he wasn't around anymore. Of course, I said that wasn't what I wanted." Finding him continue to withdraw she wondered: "I'm not sure if it's depression or whether the pills make him sleepy." Oma battled depression in her CR on a continuous basis: "He has a feeling of hopelessness; you have to work very hard to find him something he can do." But she too, tried to normalize it: "There are times that I'll see a little bit of depression, but when it's cloudy and icky out, I get depressed too! I don't think you feel as good when it's cloudy and nasty weather." Elmer sees his CR crying at times, it makes him feel: "Terrible. It could be easier if she was angry… but she doesn't get that way." When TC sees his CR helpless and sad it makes him want to: "scream! It makes me depressed, because I can't get out and do what I want to do and stuff like that." He understood that he was not only grieving her inability to do things but also his own.

Interestingly enough, six of the seven CGs did not observe pain related to HF or heart disease in their CRs a finding that was verified again in the final follow-up phone call. "He's never had pain."(L), "He's never really complained of pain in all these years that we've had this problem."(Lib) Only TC was able to observe angina: “She couldn’t tell me exactly what was the matter, she just didn’t feel well. Finally I got it out of her that it felt like an elephant was sitting on her chest, and that her arms hurt.” Again, TC was scared: “To this day I worry about her for that.”

It’s disturbing to see how AHF has changed the care recipient

Oma saw a different defining side of HF, perhaps alluding to CRs’ awareness of limited time left:

> Well, that changes their personality, I’m sorry to say it but it does. Before he was always very concerned about the family first, and he still is in a way but not like he was. It sounds like he's selfish, but he’s really not. I think he has a strong will to live, but I think he sees things coming and he’s more concerned about taking care of himself and feeling like he can’t do enough. Because he can’t, you know. He can’t paint, he can’t go out and work, he was a great one to take something and build something out of it. And he can’t do that. And that really bothers him. And I think, so therefore he’s gotten a little more maybe self centered? And I don’t mean that nasty, because he’s not a bad man.

Chewey noticed a similar change: “He suddenly became very focused on what he wanted to do in his life. Up until that point he really had no desires for hobbies or anything. And he works like crazy to overcome his financial problems.” Her CR was being medicated for anxiety and depression which she attributed to life circumstances but she saw anxiety permeate his entire physical being: “I think his anxiety comes from a multitude of places. He has restless leg syndrome, sleep apnea; he is troubled in those departments, breathing at night.” Smiley, too, noticed new restlessness in her CR: “He can’t sit still. Always has to be doing or going, even if it’s just for a ride. It’s good and bad. Sometimes I’d just like to stay home and relax. But there’s a restlessness in there.” TC was relieved when his CR finally received a medication for her life-long anxiety disorder. He was pleased to report that: ”it really works for her, she likes it. I can tell it’s good stuff, because I took one the other day myself!” Participants saw their CRs change in other subtle ways, Elmer: “She is happy 99 percent of the time, making jokes with people. I think that’s probably what led me to her when we were dating. But from time to time there is a little bit of weakness there.” Smiley observed her CR struggle with the sick role: “So many things that he shouldn’t get upset about, he does. He’s an old man that’s used to doing everything his way. Now he’s got to do it the doctor’s way and he doesn’t like that. To adjust and accept.”

Multi-tasking to manage the many manifestations of the entire illness experience

CGs very much viewed AHF in context with its treatment requirements and all the other symptoms their CRs experienced from coexisting diseases. They talked about medication–related problems. For Chewey’s CR in particular, there was nausea and vomiting, and diarrhea: “He kind of blames it on all the pills he takes, because he takes between 11-13 pills and it always seems to happen when he is right in the middle of taking them all. It all just comes right back up.” Nausea and vomiting was seriously affecting his capacity for medication adherence:

> When he throws up it is very violent. You swear his insides are going to come out. There are some nights where he says he’s only taken half of [his pills] but he can’t take anymore and that he’ll lose them all anyway. That would be a waste.

Other side effects were bleeding related to anti-coagulation; and fatigue from antihypertensives, beta-blockers and supposedly anti-depressants. Librarian reported some success after the physician changed the timing of medication administration upon her request: “He takes so many pills so I asked [physician] to change his blood pressure pills from morning to bedtime. This morning he went to coffee and one of the ladies said, ‘Gee, [CR] is participating more in the conversation’.” Incontinence which they named to be a side effect of diuretics, was the most difficult to cope with. “Occasionally he does it when he doesn’t have the diuretic, but with the diuretic, it just seems like a constant thing.” Recommended regular toileting schedules were ineffective for Elmer and Librarian’s CR: “Somebody said, just have him go to the bathroom every two hours. Well, I’ve tried that and he just says ‘I don’t have to go’.”(Lib) All CGs reported to scheduling the administration of diuretics according to activities planned for the day, to make space for incontinence and urgency. “When we have doctor visits I would make sure I don’t give it to him until we’re home for the day.”(Lib) Sometimes their strategy backfired: “Fluid build-up was a problem after our drive back from Florida. He didn't like taking that diuretic, so we did spend four days in the hospital.”(Lib)

CRs also suffered from symptoms related to one or more of the following coexisting conditions: diabetes, obesity, sleep apnea, lung disease, dementia, arthritis and residual effects from cancer and cancer treatments. Elmer described CR’s daily experience: “She is just a mess. I don’t know what to say about it. She’s got everything: the fibromyalgia, the arthritis, she is in pain constantly.” CR’s pain usually was worst at night, yet she was reluctant to take the prescribed narcotic: “she’d rather save it for when she really needs it with severe pain.” So, he said “I can’t do anything about it. Occasionally we sit on the edge of the bed at 2 am and both of us are crying. And I can’t do a damn thing about it.”

Oma mentioned the main source of CR’s shortness of breath: “That’s the COPD, that usually is it; he’s on oxygen full time.” However, she emphasized that what affected his being most was the worsening of his eye sight due to diabetic changes. Smiley commented on her CR’s gutted insides: “He has had cancer, and he’s had a kidney removed, and two lobes of his lung and he’s diabetic on top of that. “ Morbid obesity was an issue for both Elmer’s and TC’s CRs. TC tried to explain it away “she is a little over weight; the overweight came from when she was in the hospital one time. She started gaining weight and couldn’t stop and they said it was mostly because of her thyroids; because she doesn’t eat much…”

It was difficult for participants to tease out the symptoms of AHF from those of other comorbidities or what they considered to be normal aging. TC explained the activity intolerance to arthritis: “I would say that her movement is a little slower; I’ve noticed that. A lot of that has to do with her knees, she had the total knee replacement on one, and she needs a new knee on the other.” Librarian did not perceive activity intolerance to be a problem for her CR: “He walks very slowly. If he does anything it seems like he's exerting himself. Even walking from the bedroom to the kitchen, he gets short of breath, but he sits down and recovers very quickly. It's not a problem.”

The symptoms most affecting quality of life were not necessarily directly related to AHF. Librarian said: “It’s true; it’s really the dementia symptoms that bother me more than the HF symptoms. I think the physical problems, I feel like I can handle them better than his memory thing, or the fact that he can’t remember.” Which matches Oma’s perspective: “it could be worse; it would be terribly hard for me to deal with Alzheimer’s like my dad had.” For others it was loss of vision, side effects of medication management, and anxiety or depression.

Theme 2: Being afflicted with the task of symptom interpretation

Participants described in three subthemes how burdensome their watchful task of SI was to them. First, what it meant to be responsible for SI; second, how they wished their CRs would be more articulate about their own experience and that they as CGs needed reassurance with SI; and finally, how lonely and uncertain it was to stand by their CR through tests and interventions.

CGs embraced their responsibility for SI with some reservations. Chewey and Smiley still relied heavily on their CRs ability to recognize symptoms and respond appropriately. Smiley: “Well, when you know a person, you know about what you can get by with, and what he can take and do. He knows. He can do it himself.” Chewey: “He is pretty much in charge of [SI]. He has gotten better about realizing just how serious this is. So if he says to me, “I think you’d better call an ambulance,” I’ve got the phone, calling, right away." Elmer, with the beginnings of dementia, was extremely vigilant and observant, but left decisions for action up to his CR. The other four CGs felt entirely responsible for SI and taking necessary action for their CRs.

Being responsible for symptom interpretation is burdensome and overwhelming

Caregivers were ever watchful of their CRs: "I always check her, like when she's taking a bath. I don't leave until she's done. I want to be there in case something would happen. She says, 'You're like an old doddering fool!' But I'm not, I just care."(TC) Smiley always kept an eye on her CR when he was outside doing yard work:

> I heard the push mower start up. I saw him out there. Then all of a sudden the mower quit. I didn't see him. Well, he was behind the garage, so I went out to see how he was doing. He was just hanging on the clothesline. He couldn't breathe, and he was trying to catch his breath with the heat and humidity and everything.

Chewey explained: "I can't be with him all day long." She worried about what he ate when she was not watching. Smiley told how her vigilant behavior was more pronounced after he was released from another hospital stay: "I guess he hasn't been out that long, so I'm really not sure what's going on, but we're just watching for signs." Lee continued her vigilance into the NH: "I stayed until 9:30 at night until he'd been asleep for two hours. I was scared he'd wake up because the medicine was getting less effective. I wanted to make sure he's not going to wake up and want me." All of them had to constantly learn additional information as their CRs condition changed.

> I had to learn to do all that. First, he was getting cut all the time, and he bleeds a lot. You had to learn to watch that closely. Then you had to watch and make sure the fluid isn't there, and check the bottom of his feet which I didn't know before. Sometimes the responsibility gets a little overwhelming. And he doesn't see well enough I have to draw his insulin for him. And I do his pills, he knows how many he takes, and he's fairly certain what he takes, but with his eye sight not being real good I don't want him to make a mistake so it's just easier for me to do it. It's a lot of things going on plus trying to keep up my own work.(O)

CGs felt it was their role to prevent exacerbations or hospitalization, or at least ensure timely action: “When she was in the hospital, it made me feel helpless. Like I should have prevented it. I know that that isn’t my job. I am not a doctor or a nurse, but I make sure she takes her pills.”(TC) Oma struggled: “He’s one that can be fine and talking to you and then a half hour later be in the hospital. It’s really difficult because I feel guilty, should I have brought him sooner?” Librarian had to take into consideration her CR’s cognitive changes related to Alzheimer’s disease: “I'm not sure that he understood what I was trying to say. I think he did, but I'm not sure. I'm not sure of anything anymore.”

SI got more intense and involved home monitoring devices and telemetry health monitoring as the CR’s condition deteriorated, described by Lee:

> I had to report every day for two years to [doctors]. Now, that was a lot for me to do, to weigh him and tell them this every day, every day. Then the nurse would come and send more information. I also had to do his heart check on the phone. The last year they put that machine [arrhythmia monitor] on him, and that was at 10:00 every morning that I had to do that.

SI was not limited to symptoms of AHF, but included blood sugar monitoring as well. Chewey, speaking about CR’s sudden hypoglycemic events: “We’re traveling along and I think we are doing fine and all of a sudden he is very, very low. And that worries me at times.” Elmer had to plan ahead for CR’s hypoglycemia-related collapses: “What really scares me is the diabetes thing, and sometimes she gets so low its best that she get on the floor in a place where my son and I can get her up again.”

Feeling forlorn at the frontier of symptom interpretation

CGs wished that their CRs were more aware and assertive about symptoms and the care they needed: “It’s really hard to tell with him, because number one he never tells you. I mean, it’s ‘what’s the matter’, ‘nothing I’m fine’, and then all of a sudden, he’ll just not be fine anymore. That makes it really difficult.”(O) TC was exasperated when his CR did not wake him to tell him of her fear to go to sleep: “Why didn’t you wake me up? She says" Because I didn't want you to lose your sleep'. Silly girl!" Another time, TC's CR articulated why she did not tell him about the elephant on her chest: "I didn't want you to be worried or bothered." Oma wished "that CR would shoulder more of the responsibility. I try to explain to him that that would be a big help; that I don't like making all the decisions, or making decisions about nursing homes, and the future." Elmer was also worried about being told of symptoms related to his CR's hypoglycemic episodes: "But I find the sugar cubes box is open and half of them are gone. And I don't hear about a low, or a need for sugar cubes because she doesn't tell me."

Participants felt burdened by the need to do SI and needed reassurance. Oma, "You always think 'did I miss something'? But they tell me I didn't, that's just the way he is." She was given the same assurance when he had a second cardiac arrest (coded), at cardiac rehabilitation: "The people in rehab say 'he was fine, his oxygen was good everything was fine in the morning'. So, it's just real tough to not know when they're going to get sick or what's going to happen."

Feeling caught in the mechanics of medical management

Participants spoke about hospital and office visits, and treatments associated with SI. There was always more treatment to be done; Oma was tearful when she spoke of another delayed discharge: "I thought he was going to come home in a day or two. But now, they are going to move him to another room. More light, brighter, see if that won't help some with the depression." Later on, there were more tests to be done: "Well, don't they feel like they have to? His heart is working good so they said it's not his heart. But they want to test to make sure." Nevertheless, Oma accepted the physician's recommendations for another stress test without reservations: "This was a blow because I worry about the stress test. [Physician] wouldn't do it if it couldn't help, I know he wouldn't. So I have to go by what they decide." TC had to deal with a familiar complication in treating AHF exacerbations: "Those pills they give her for taking the fluid off affect her kidneys, because her kidneys aren't that great. They said they dried her out too much. That's what causes your kidneys to shut down."

Participants had to make choices along the course of the disease which impacted quality of life. Lee's CR was recommended to have an MRI which required the removal of an implanted hearing augmentation device: "He had to go through the MRI for them to know what to do for the heart, and [the device] would have blew his head off. Once they took it out he was deaf, so he hasn't been able to hear a bit since." Elmer questioned the need for the multitude of medications: "Sometimes I think there are too many pills, but then you ask the doctor about it and one will say, 'do you want your heart to beat?' Well, yeah I would like that so there is another pill." Going through her list of pills there was nothing they could do without. "We decided it's probably better to take the pills if we want to survive." Yet he recognized the many side effects that impacted her daily life: "She'll get antibiotic for her kidney infection but the antibiotic kills off all of the good stuff too and so you end up going back to the doctor [for diarrhea and yeast infections]." While Smiley's CR's required cardioversions: "They've stopped his heart a couple times, the shock, and straightened him out," she prioritized her CR's allergy to [diuretic] as a more serious problem because of the rash and itching: "They took him off of that and now it's almost all cleared up. The new [diuretic] didn't work quite so well. Right away he started gaining weight. So they doubled him up, and now he's doing better." Elmer talked about incessant diuretic action: "Since she was discharged I don't think she's gotten any better, but stayed even. Once they got the water out of her, they kept doing it here. She spends her mornings visiting the bathroom because she is still on the diuretic."

Wearing the CPAP apparatus was cumbersome for Chewey and TC's CRs and they opted not to adhere to the recommendation. For Elmer's CR CPAP interfered with her nightly urgency and incontinence management. Oma and Chewey expressed concern to keep their CRs free of infection which in Chewey's case impacted their relationship for two reasons: it did not allow them to share a glass of water anymore and it was yet another occasion where CR chose to ignore her advice: “he reached over and drank out of my water which he is always doing; ‘I have a cold, if you get it, it will cause all sorts of problems’. So he came home and the next day his throat was scratchy and he was a little coughy.” Oma recognized it as a quality of life issue:

> If it were me, I would want the quality of life, it’s more important than the quantity. And I think that’s the way he would feel too. But it’s just really hard to live like that all the time wondering, should I do this, shouldn’t I do this. If I do this, can he afford to pay the consequences if he gets sick. But to be an ideal place, I wouldn’t allow anyone in the house, or to go anyplace. But he can’t live like that, and neither can I. You want your friends to come, your family to come, they don’t know, they might be coming down with something they don’t know. So you live with that, constantly.

Several of the CGs had witnessed resuscitation attempts on their CRs. Oma, Elmer, TC and Lee had seen their CRs on the ventilator but did not think of this as life support. Because these interventions restored life then, they were expected to do so in the future. Oma’s CR coded twice, both times in the hospital with Oma right by his side: “thank goodness it happened in the hospital, because he wouldn’t have survived it at home.” Yet when asked what she would do if CR experienced sudden death at home, Oma said: “I guess I’d call 911. What else can I do?”

In general, CGs did not feel they had any choices in prescribed treatments, especially at the end of life. Chewey anticipated “It’s just something that we are going to have to go through. It’s like being in a long, long, long, dark tunnel, if you have to go through it; you have to go through it.” She explained: “Because whatever the experts say to do, we’re going to do it. Whatever will prolong the best quality of life for him will be what we do.” Lee’s CR had to return to the hospital one last time before his death for a second cookie swallow test. This was traumatic for Lee because she had understood that [hospital] was not going to treat him for difficulties swallowing anymore. Yet the NH insisted that the test was necessary for his plan of care. Lee most poignantly quoted: “I had no choice. I think people that are taken away from you, you should have a choice, but because I couldn’t take care of him I had no choice.”

Theme 3: Trying to add color to a grey future

CGs described in two subthemes the theme of being in the dark about disease progression: first they explained how they really had very limited knowledge of how AHF progresses toward death, yet, how they managed to live with such uncertainty and finally they juxtaposed their fears and vague trepidations with hopes for the future.

Being in the dark about symptom progression and trying to light a path for preparation, knowledge and acceptance

In general, caregivers were not able to articulate the progression of physical symptoms such as shortness of breath, fatigue or diminishing cognition. TC asked a cardiologist about the future and got most organ-specific answers for the present instead: “He says right now her heart is very strong. But her kidneys are malfunctioning. They told her that she is in second or third stage kidney failure, but her heart doesn’t have damage done to it.” At another time, TC was told: “They told her she's going to live a long time, because her heart is great, so I hope so.”

Although he had questions because “sometimes he’ll sit down and want to talk about it”, Smiley didn’t think CR ever asked the doctor about a prognosis: “unless they talked to him in the hospital when I wasn’t there. He was wanting to know, if his chances of a heart attack are higher since he’s had this congestive HF. I don’t know if he ever asked.” They had a discussion with the ARNP about HF: “She was very informative, and we had literature on it. She had a folder and kind of went through that, but nothing was said about the future, about what could happen.”

While Chewey felt that “We are starting to understand symptoms as they come along now. It isn’t quite as surprising to me anymore,” she remained entirely uncertain about the future:

> He is fragile. In the last few months since he has been in the hospital he has been much better. But I always worry because it seems like everything goes to his lungs and his lungs are always a problem. So I don't know. I don't know where his health is going to go, or what that is going to become, or what that will be like. And I don't know what exactly all this means, what it leads to for him. So there are just about a million different variables that I just don't know what to expect. I don't know what his condition means, as far as him living out his life.

Only Oma had a prognosis discussion that included CR's most likely manner of dying: "He'll just have a heart attack and that will be it. It will be one where he won't come out of it." This allowed Oma to contemplate the possibility of CR's death: "If I lose him, that will be tremendously hard, but you start preparing. That sounds cold maybe, but it's something deep down that you do, because every time one of these happens, I think, 'will I take him home?'" Given an accurate prognosis discussion, Oma was able to be very specific about her CR's goals for the future: "He wants to go home and just live. We don't have to do that much, things like being able to get up in the chair, and going for a ride every now and then, visit with the family." She added: "the worst part is knowing every one of these [exacerbations] takes something out of him. And as it gets worse, caregiving gets harder and harder." When asked how she would manage the next crisis she answered: "Well you just face it like you have all the others. [] You just do, like I said, all you have to." Lee was given a prognosis, however, it was quite non-specific: "[Physician] knew he didn't have long. He just said: 'I know you know, but he can't go on much longer'."

The unpredictability of the disease made it impossible to plan ahead. Oma tells of a day when they cancelled an outing because it was too windy: "He wanted to go to K. that day, he was perfectly well. And that night he was in intensive care. That is what makes it kind of scary, because I just don't know." TC articulated how going from a state of not knowing to knowing about the disease may have made his actions more decisive but also increased his worries and concerns: "She's had two or three hospitalizations for HF. The first one, I just put her in the ambulance. And it scared me, but I didn’t know why. This last one, I was scared because I knew she was gaining weight as her breathing was so labored. It scared me worse, because the visits kept getting worse.”(TC) However, after the most recent hospitalization, TC was able to say: “This time it didn't scare me, because I knew what it was going to take to get better.” Elmer described how difficult it is to recognize just how near death your CR might be:

> What are the numbers you have just before you are ready to die? She’s had that twice now, the doctors said another half hour and she might not have lived. They get right on her when she walks in the door looking like she does. No waiting in the waiting room. Scary to think that she is that close. And she doesn’t look that way. At first glance you wouldn’t think she was that sick.

Living with existential uncertainty was challenging on many levels: “You never know what to expect. She could be here one day and gone the next; you really have to prepare yourself mentally for it.”(TC) Chewey said: “I don’t deal well with uncertainty. Knowing the good, bad, or indifferent, I am better off than if I don’t know what is going to happen.” Oma had a different opinion: “You try not to think about it too much. Just go ahead and do things. If it’s going to happen [death] there’s nothing I can do to prevent it and I’d rather he be happy with what he’s doing.” Smiley echoed the sentiment of acceptance: “I just take it a day at a time, watch as things go on. If it’s going to happen, it’s going to happen. There’s nothing you can do, but just make the best of it.”

Looking for freedom from worries in hopes for the future

Caregivers spoke about their hopes for the future with optimism, resignation or realism. Given that “the diabetes and the heart failure are problems he’s always going to have to live with,” Smiley hoped CR would win the lottery or have some other means of relieving his financial burden: “It would relieve a lot of tension. [Financial stress] might affect your heart failure.” She was realistic about the tenuousness of his condition: “If only the medications would level off and keep everything under control and we could just keep him where he's at now.” His current function was not entirely to her satisfaction but “he’s 77 years old. You can’t expect a whole lot, right?” She emphasized the importance of being able to do things: “usually, you see people that do less than you. You’re in better shape than a lot of them because we don’t just sit around.” Chewey shared Smiley’s desire for financial security for her CR: “So he can relax, concentrate on himself, and have a healthier lifestyle. I think mental and emotional turmoil takes more toll than anything we do physically.”

Elmer was planning a trip to Arizona with his family: “That should be nice. We'll be driving. CR was concerned about the bathroom issues. So we rented a camper with a wide bathroom on EBay.” Thinking about worsening symptoms in the future Elmer didn’t know how he could cope: “The idea comes to mind: to get away from it, especially when you have one of those bad days; a multitude of accidents [incontinence]. I haven’t thought that far ahead yet, I don’t want to think that far ahead yet.”

TC repeated all the medical information he had heard when he spoke of his hopes for the future:

> Her lung capacity is getting a little better slowly. Her walking won’t come back to where it was. That knee is terrible. I can hear it grinding and clicking; the front of the knee cap and the back of the knee- its rubbing bone on bone. I foresee CR getting better, everything trying to turn around for us here.

He hoped these words would also help his own melancholy: “Getting my attitude changed a little better.”

Question 3: How do caregivers use communication to explain and understand the caregiving situation?

Communication constitutes an important tool for CGs to make sense of the experience for themselves and their CRs. For the purpose of this study, CGs’ communication experiences were grouped into four themes: (1) Telling the story of AHF in your life; (2) Learning about the meaning of AHF in your life; (3) Using your words to get things done; and finally, (4) Putting the pieces together to be the best caregiver to the end.

Table 6. How do caregivers use communication to explain and understand the caregiving situation?

meaning units	subtheme
Theme 1: Telling the story of AHF in your life	
"He told me that he'd had a heart attack in the past, and that things were ok now; but that all the men in his family had died of heart disease. He is the oldest living male in his family."	Incorporating AHF into the past, presence and future of their life story
"When I found out I almost had a heart attack myself. A helicopter crew ran in, and they brought him around three times from cardiac arrest each time, I was right there."	Reliving dramatic action chapters
"He was diagnosed with Alzheimer's disease two years ago. Even with all the heart problems, he seemed to keep going, and doing whatever else he wanted to do. When he said that he couldn't do the income tax anymore that really hit home."	Important stories are happening in competing chapters
Stories of other persons' death and dying	The final chapter: other people's deaths
Theme 2: Learning about the meaning of AHF in your life	
"He knows what's going on with him and he won't talk about it." "[CR and I], we talk about everything, we don't hide anything." "You want to talk to the doctor. But you don't get to talk to the doctor until you make an office visit, pay his $75, then he'll talk to you." "I'll say "I just want to clarify with you what you think is going to happen, what you want to see happen, what you are working towards." And he'll just say "I hope I get everyone paid off."	Looking to others to help find meaning vs. running into various obstacles when trying to obtain meaning
"[ARNP] was very informative, and we had literature on it. She had a folder and kind of went through that, but nothing was said about the future, about what could happen." "They found out that she had a heart attack sometime along the way. But also, she'd live to be 100 the doctors say. So heart wise we are in good shape. Unless it changes over night or something."	Meeting the needs for a multitude of meanings while meandering in a maze of conflicting or missing information
Theme 3: Using your words to get things done	
"A lot of times, when I get real upset about him, I go down to the basement, talk to myself. He can't go downstairs."	Letting your self talk
"She gets to be head sergeant, when she can sit on one side of the counter and order me around to do this and this and make the casserole."	Talking with the CR in established patterns

Table 6. Continued

“When I get done talking to [friend] I feel much better because I know what might come, and how you have to handle it and be more prepared.”	Being listened to in conversations with friends and family
“This last time, I felt like they were talking to me, not at me. They explained it in words that I could understand; and that is what I need.”	Being talked to or being talked at by HCPs
“We got into all these doctors, during different phases of things. Finally the heart doctor said ‘I am going to be in charge, you all report to me’. Now we are getting a little better handle on things.”	
Theme 4: Putting all the pieces together to be the best caregiver to the end	
“Yeah. So there are some hopes [for CR’s health] that are unrealistic and that’s kind of hard.”	Reluctantly recognizing a separate future
“In my old age, if I start complaining about lack of attention, I’m going to have the kids read it to me and say, ‘Now, mom, this is what you wanted us to tell you later’.”	
“He figures he’s just going to live ‘til it happens.”	Sustaining the CR in his/her quest for happiness
“He would work until 72, or 74; he doesn’t really want to quit working. But he wants time off so that he can do some of his hobbies.”	
“If he had to go to a home. I don’t think he’d live very long.”	Breaking up a marriage by contemplating other settings of care
“It would be a hard decision for me to join her at the ALF because I am so used to being on my own, coming and going.”	
“This little corner right here is what I'm going to worry about. I guess we'll just have to see what life holds for us.”	Making a promise
“[Adherence] is going to be a routine that's going to be there for the rest of our lives. She isn't going to change my mind any.”	
“I’m not going to sit here and let something happen to him to precede a natural time.”	

Theme 1: Telling the story of AHF in your life

This section describes less a theme than the structural outline of CGs’ story telling. Partly guided by the interview questions and the design of the study over time, and partly a reflection of how they structured their story-telling, participants gave a more or less chronological account in four chapters how AHF became part of their life, was a development in a shared or separate past, affected their everyday lives and surely would shape their future. Plots of AHF stories were filled with drama and told with a curious mix of emotion and detachment. Of note was the fact that all CGs included stories of other people's death and dying, illuminating what they considered to be a good death and also the fears they had about their CRs' dying.

Chapter One: incorporating AHF into the past, presence and future of a life story

Chewey explained how the story of the disease inserted itself in their relationship while they were still dating: "he told me that he'd had a heart attack in the past, and that things were ok now; but that all the men in his family had died of heart disease. He is the oldest living male in his family." All participants told how they first learned of the diagnosis for their CR, either as a natural progression of existing heart disease (O, Lib and L), or diabetes (E, TC, C), or as somewhat of a surprise, after ruling out pulmonary etiologies (S). They told stories about why their CRs had developed HF: family history, a history of smoking, cancer or even life style. Five CGs had a shared past with the CR which included the development of the disease; two of them entered the relationship later, either after AHF had been diagnosed (C), or while it was being recognized (S). These two CGs felt that caregiving was a role they could choose, rather than having it be a natural expectation and human obligation that came with aging together.

Living with AHF threatened the story of their lives together, and impacted everyday life in the presence as described in Question 1. AHF also altered expectations for aging and retirement: "It's not what we wanted for our Golden Years, but it's what we have to do."(E)

Reliving dramatic action chapters

Caregivers had numerous chapters about crisis events and emergency hospital admissions. They all contained elements of surprise and fear in watching their CRs' struggle. Oma talked about repeat life-threatening hospitalizations: "The last hospitalization was in December he coded twice and, so that's been very difficult. About three years ago he was in with a Strep B infection, he about died that time. And now it's this again [another cardiac arrest]."

Caregivers used medical terminology and seemed matter of fact about resuscitation, for example Lee witnessed external defibrillation on her CR when the implanted defibrillator failed to work: "That's why [physician] did the shocking thing, that's quite a deal. I got to witness that." However, they never actually called any of the medical interventions *life* support. There was never mention of relief after the acute crisis because they had to transition into descriptions of lengthy recovery periods. The following are excerpts from their stories. "He passed out, and that really scared me."(C) "When I found out I almost had a heart attack myself. A helicopter crew ran in, and they brought him around three times from cardiac arrest each time, I was right there."(L) Oma told the story of two of CR's three cardiac arrests which all happened to occur at the hospital:

> And [physical therapist] yelled 'CR' and ran over and checked his pulse, ran back and touched the emergency button then started CPR. Oh, it was just awful to see him there on the floor. And then you think back, and it's probably stupid. But someone says 'he's lying on his glasses wrong' so I went over and got his glasses but by that time tons of people were coming.
>
> The next time I was there helping pull him up bed. The nurse was looking away and I said 'he's gone again'. They got help in there.

Smiley told the story of one exacerbation when she found CR barely able to breathe. They had to decide whether he could get dressed and should they call an ambulance "He was in bad shape. He could hardly talk, because he couldn't breathe. So he just sat on the edge of the bed because he wasn't even going to try to get dressed. I think he was scared." TC told of an unexpected admission during a routine visit in the diabetes clinic: "The nurse said, 'Miss CR, we're not going to worry about your insulin today. We are going to get your breathing straightened out. The doctor says go straight to the hospital and have them admit you'."

Important stories are happening in competing chapters

While AHF dominated their days it certainly wasn't the only matter of importance in CGs' lives. CGs articulated what other themes contributed to their life stories. Librarian described a fairly well adjusted life until the new diagnosis of Alzheimer's disease threatened the familiar and almost comfortable 26-year long story of heart disease:

> Now, he was diagnosed with Alzheimer's disease two years ago and he said he couldn't do the taxes anymore. That was two months after the pacemaker. Even with all the heart problems, he seemed to keep going, playing golf and doing whatever else he wanted to do. When he said that he couldn't do the income tax anymore, that really hit home.

There were events which questioned the caregiving role itself. Outside opinion introduced a perspective which Oma found demeaning of her caregiving: "The neighbor made fun of his arm. But if a person is scarred, that's not the inner person who counts. And she said she could never take care of CR with him being sick like that." Elmer's diagnosis of dementia threatened the foundations of his self perception as a life-long CG, as did the realization of their own aging and potential future health problems for all the CGs. In Chewey's case it was CR's financial health which in her stories warred with his physical health, as well as her own life story filled with responsibilities as a dedicated teacher, mother to the children from her first marriage and daughter of aging parents. Smiley's competing chapters included responsibilities to children from a previous marriage and the fact that she had cared for her previous husband until his death from cancer. Talking about her current caregiving situation actually revived some of the grief she still felt from losing this husband many years ago and may have made her emotional investment more guarded in her current relationship: "I suppose it makes a difference, since I've been married before. I think your feelings are a little different."

The final chapter: knowing of other people's deaths

Participants all shared several stories each of the various deaths they had witnessed among family and friends. These stories were important in shaping their ideas of what a good death should be like. Oma cared for her mother-in-law who suffered from osteoarthritis and required intense care. During this time she learned that her CR was incapable of being a CG and did not cope well with death and dying. It prompted her to get long-term care insurance for herself. Her own mother retained independence to the end and rather than being cared for by her children preferred to move to a NH where "she lived about a month and a half. She just gave up. She was so unhappy." However, her death itself provided a consoling memory: After spending Mother's Day with Oma, her mother went back to the NH. "And she went to sleep, she told me, 'if I go to sleep, don't you mourn for me'. She says 'That's the way I want to go. And not many people get to go the way they want to.' So I always remember that." Oma's sister died from an aggressive cancer which made Oma wonder about the benefit of seeking treatment to the very end, but she didn't know how this could translate to her own CR:

> The doctor did not tell us that she could have treatment or you could go without treatment and see what happens. He just said the treatment might help. So she went for the treatment, but then she was just sick, it affected her mind. If she hadn't [had treatment] we could have taken her to the places she wanted to go, do the things she wanted to do. But we didn't have time. When she died he stood by her bed, and yelled at my daughter, "I told you she was going to die". So I don't want to do that to CR.

Elmer's mother had diabetes and had been non-adherent to treatment all her life. She died suddenly from septicemia after a traumatic night at the hospital. At the time, the family decided to forego autopsy which left Elmer with lingering fears that the same might happen to him. Having witnessed his father's grief and loneliness after his wife passed away may explain some of Elmer's fear: "What is going to happen when I come home and she is dead on the floor? That is when my job would start, trying to live without her. It sure was lonesome the four days she was in the hospital." Elmer's father had significant death awareness and exercised some control over his own dying:

> They diagnosed it as acute leukemia. They told us it's something you get, and it's over shortly. They beat around the bush a bit, but finally dad asked how much time he had left, wanted to get down to the facts. The doctor looked at me like 'should I tell him or not?' and I said, 'you had better tell him this, he can handle this. It's the unknown he can't handle'. So the doctor told him it could be 30 days. He lasted three months. Dad wanted to know about pain, and the doctor said that everything would be fine for three months, until the last day, and then you would have pain. And he was right. Pain, and a day later, done.

TC witnessed several deaths in CR's immediate family, all accompanied by an emergency response. One death specifically influenced his reaction in one of CR's emergency transports. CR's sister had been transported to the ER with an acute episode of HF: "They told them not to lay her down because of her heart failure, and they laid her down anyway so she passed away." When it was CR's turn to be transported by ambulance, TC told the medic: "She don't want to lay down and she ain't gonna. If you try I am going to tag ya." The police officer on scene recognized how serious TC was and supported him, saying to the medic "if he hits you, it's going to be your fault! You had better not lay her down!" TC spoke about grief and reconciliation as necessary components surrounding the death of a loved one because he himself was estranged from his father at the time of his death.

Chewey's grandmother had pancreatic cancer in her old age and died peacefully at home with home healthcare support. Recently Chewey witnessed a friend die from SLE: "He was out of intensive care, so they finally let him go home. He was there one night and they had to call an ambulance to take him back to the hospital and that is when he died." Currently, a couple was in the hospital:

> She is similar to my husband; she is diabetic and has congestive heart failure, and she just found out that she needs dialysis. And her husband was taking her two to three times a week for dialysis. While she was there, *he* had a massive heart attack. And they worked on him for over an hour and they were able to revive him, and put him on some support. And he is doing

> fine! So when you say, do you want to be put on support, I would say at that point, yes! So now he is doing fine, but his wife is in intensive care and seems to be going downhill. I don't know if she will be leaving there or not.

Chewey did not offer to make the connection that her CR's disease progression was more likely to mirror the wife's from the scenario above, than the husband's.

Librarian's mother died from dementia and even though she received full home healthcare support she was a burden to Librarian's sister who cared for her. This prompted Librarian to want to write a letter to herself reminding herself not to become a burden to her own children.

Smiley's husband had lung cancer and wanted to die at home. Hospice care was facilitated by his physician. He was pain-free and suffered a stroke the day before he died which was managed by the hospice team. His children were in attendance and the entire experience was "definitely positive". On the other hand, "my dad died of emphysema and I watched him suffer toward the end. I'm thinking, if CR fills up with fluid, it's gonna be similar to that, and that's not fast."

Lee knew of hospice care from her sister's death and she was suspicious of their methods: "I think they overdosed her." This may partially explain the late transfer to hospice before CR's death: "Never did they come and talk to me [about hospice transfer], never." The entire transfer was very traumatic for Lee because of the unpreparedness, and the large number of people involved and invading her home: "When I came driving in here you would have thought something horrible had happened. There were two great big trucks there, and CR was in one and a bed in another. I had no idea what was going to happen." Getting CR settled went smoothly with the hospice staff and Lee went on to describe his dying:

> Then we had that one night with him at home, and then he died the next morning at 7:30. I was with him and he wanted to kiss me. He did. Three times he wanted to kiss. [Crying] Then he said 'one more'. Then he squeezed my hand and said he loved me and just—gone. Instantly, never moved. I figured he'd move or shake or.... He just said goodbye and left. That is such a beautiful memory. He was just so sweet and he just looked so

> perfect. He didn't have any worry looking on his face or anything like he did over at [NH]. Because it's like he was home. I thought it would bother me terrible to have him taken away again, but it didn't.

Theme 2: Learning about the meaning of AHF in your life

Caregivers constructed meaning over time, with a select group of people including the CR, friends and family, and HCPs. As became apparent from the discussion of SI, CGs struggled to understand AHF as a disease and to view it in context with the CR's other chronic illnesses and the process of aging. Three subthemes described how they tried to find coherence. CGs looked to others to help find meaning, and some found the type of meaning they needed while others were confused by conflicting or missing information. Finally CGs encountered various communication barriers in their search to find meaning.

Looking to others to help find meaning vs. running into obstacles when trying to obtain meaning

Constructing the story of the disease with the CR was challenging for Librarian due to CR's dementia; and Oma and Chewey, due to their CRs' apparent state of denial. Oma said: "He knows what's going on with him and he won't talk about it. The myeloma he wants nobody to know that. I think he hasn't dealt with it, and if you don't talk about it, it doesn't happen." Smiley had to mediate in the story between CR and the medical team:

> CR always has to comment about how the doctors are trying to rip off Medicare. So he went into the office this morning. He says, first thing they had to do an EKG again. Well, he has irregular heart, so I can see why they'd do that, especially if he's retaining fluid.

TC and his CR had a different relationship: "We get along real good though. We'll sit and talk for hours, about our kids, grandkids mostly. So we talk about them, and her brothers, how they are doing; what they are doing." There were parallel stories of others to consider who also had AHF and gave a foretaste of what was in store for CGs and CRs alike. TC told the story of CR's family history:

> Her brother's been in the hospital for the same thing, got out a couple days later, and was back in two days with congestive heart failure- again. The month of October he spent all but 8 days at home. He was in the hospital that many days, and has been back several times since then. The last time they found pneumonia on top of it. And her sister passed away from congestive heart failure quite a few years ago, it was almost instant. She never complained about being sick or anything. And I know it runs in the family because she had three brothers have heart attacks, two of them passed away from them, her mother passed away from it. Her whole family has had diabetes, so that's the family trait there.

Similarly, Elmer co-wrote the story with his CR: "We just hang in there with each other. Oh yes, we talk about everything, we don't hide anything." Throughout the interviews, Elmer described his experience, often full of emotion and strong opinions. Yet, it was becoming apparent that he took the lead from his CR in responding to situations that he perhaps did not fully understand cognitively anymore.

Participants had certain trusted persons with whom they were able to develop the story in tandem: "My best friend, we've been friends for 50 some years; we've been through a lot together. She can tell me a lot of things, explain, listen to me, and you know she's never going to tell anybody else."(O) TC still grieved the loss of such a trusted friend 16 years ago: "I would like to talk to one guy, if he were alive. He was my best friend. He died; he had something like heart failure in his lungs, too." Lee freely shared all her experiences and feelings with her large extended family. Chewey stated that she did not have a trusted friend; she'd be most comfortable speaking about things with the ARNP at the hospital, or even me, the researcher. While we were relative strangers we understood her situation and needs. Librarian had similar sentiments, considering herself a private person and not in the habit of sharing personal experiences with friends: "I talk an awful lot, but I don't talk about those things that I feel are really personal with my friends." She was of the opinion that: "I think that they observe and can see some of the difficulties that we're having." However, because she considered me an HCP: "I'm still saying it to you." In general, it appeared that CGs wanted to protect family members and not burden them with what their concerns were about the disease. Only when it came to any kind of planning for the future did they try to involve their family members, this is described in more detail in the discussion of the ethical intention.

Accessibility was a big issue in conducting timely communication for the purpose of learning and knowing: "You want to talk to the doctor and say 'hey, this isn't working, let's get something else.' But you don't get to talk to the doctor until you make an office visit, pay his $75, then he'll talk to you."(E)

CRs themselves often were a barrier to learning about anything from symptoms to how they were feeling emotionally. Oma wanted to know how CR was feeling about the new diagnosis of myeloma, but as usual, she got no answer "because he doesn't want to talk with me!" TC's CR didn't want to wake him when she had chest pain "Because I didn't want you to lose your sleep." Oma's CR delayed telling of his symptoms because he didn't want to go to the hospital yet again. Elmer's CR was stoic about pain because she felt there was no help for it anyway. Although Chewey witnessed them on a daily basis, CR never actually complained about his symptoms, perhaps because he did not want to contribute to her anxiety. Librarian's CR was not able to express his concerns of any kind verbally, although his behaviors showed discomfort such as itching, shortness of breath or incontinence. Lee's CR was cognitively unable to verbalize anything about his experience.

On the other hand, CGs encountered barriers when they tried to speak of their own problems and concerns: "It's hard to talk to CR about my stuff. He's like I said, self-centered. If it's not about CR it doesn't interest him."(S) Librarian could not speak to her cognitively impaired CR about her own concerns other than resorting to angry outbursts which didn't address her problems per se, but did relieve emotional stress. Oma was unable to negotiate capacity to act in her own time schedule with her CR, because he turned it into an issue of respect by saying she made him feel like a burden.

Chewey could not bring up advance planning topics because it created such anxiety in her CR and ended up making her feel intrusive: “I’ll say ‘I just want to clarify with you what you think is going to happen, what you want to see happen, what you are working towards’. And he’ll just say ‘I hope I get everyone paid off’.”

Meeting the needs of a multitude of meanings while meandering in a maze of conflicting or missing information

CGs’ primary sources of information about AHF were HCPs. Participants varied in the type of understanding they sought from HCPs.

Oma mostly needed reassurance and a feeling of being cared for as a person. She gave many examples of the caring she experienced from physicians: his family physician would check in on him even at the hospital; another specialist went to visit him in the ICU: “She went up and read his chart and said ‘hi’ to him. I didn’t get a bill. She took the time; she wanted to see what was going on, to make sure everything was going ok.” The physician who placed his pacemaker kept them updated: “Sometimes they would call 2-3 times a day when things changed.” Because this CG felt “surrounded by good doctors” and felt respect for herself and CR she was willing to share physicians’ uncertainty in making treatment plans: “The cardiologist would be just standing outside his door and say ‘I wish I knew what to do’.”

As described in symptom interpretation, there were many times when participants relayed factual information as they had understood it from their HCPs. However, they didn’t always get the answers they were looking for: “Well, I would like to know if this could be something that is the beginning of something, or if it could lead to more serious congestive heart failure or cardiac arrest, or whatever.”(C) Elmer reported: “She’s got pain in her all the time. What do you do? I don’t like it, but the doctors, they kind of say, ‘yeah, go do it, and go live with it’.”

It helped when they could partner with HCPs to answer questions about the disease. Oma felt pride in having helped the physician determine the primary event in CR's last cardiac arrest:

> His oxygen would drop and his heart rate would go low, and that's when he would code. And they didn't know which happened first. But the second time, I was helping him up in the bed, helping the nurse. And I looked up at him and saw, and his lips weren't blue or anything so they knew it was his heart rate, so they put in the pacemaker. He started getting better.

TC understood how their habits would determine outcomes for CR so he was not threatened by this question: "They asked me what do we do at home. I explained what we do and they said, "Well, you're doing everything possible to keep her from being back up here." Elmer felt that CR was a knowledgeable partner in managing her diabetes: "She's had diabetes for 26 years so she can explain to the doctor what's going on. And I think they like that, they can kind of sit back and listen to this person and think well maybe she does know something." Being included in mutual learning was especially important when they felt they had to correct their CR's story: "I think the doctors don't realize how he really is. He was telling [the doctor] how he exercises every day. I said, no, I can't even get him to go out on a driveway and walk with the walker."(Lib)

Smiley took advantage of formal learning opportunities: "[ARNP] had a meeting with us up in the hospital. She was telling us exactly what congestive heart failure is, and about the diet and what to do and what not to do. She was real good at explaining it." Together with CR she attended "a heart healthy seminar. It was about eating and all that. At first he didn't want to go and then after we went, he was glad he did." She also uses a recipe book from the American Heart Association in her cooking: "I feel it's beneficial to me because who knows, this could happen to me."

There were times when participants received conflicting information. Chewey expressed worry based on her last hospital experience:

> The two doctors, the intern and the cardiologist disagreed, and then a third cardio came in and disagreed with both of them.

> So it got to be pretty complex and you start to wonder if anyone knows what is going on, and who has answers, who is right and who is wrong."

They were aware of risks in making medication choices, especially Elmer and TC who were dealing with sensitive kidneys in their CRs. Physicians alternated diuretics and the reason for switches were not always clear, for example for the usual weight gain of three pounds in one day "one doctor might tell her to take a different pill for a day or two, until she loses it." But as soon as she was in balance again: "her other doctor tells her, 'well, we can't have you on this because your kidneys are acting up,' so they take it away from her."(TC) They were unclear about the general treatment plan, for example, Lee did not know if CR was transferring to the NH to rehabilitate or to die: "You couldn't tell that. They [physicians] didn't talk to him in any terms. The nurses were just more or less dutiful. They made him get up and walk and exercise because that is part of the program." CGs and CRs were tired of getting advice from people who did not fully understand the extent of their suffering: "Everyone has an answer: If she would go to bed earlier, instead of eleven pm. But CR says, 'Have them walk in my shoes for just one day and they can feel the pain and all that goes with it'."(E) Despite all the worries about AHF they had for their CR's they held on to statements such as these: "CR's heart is beating strongly; they aren't worried about his heart."(O) and: "The way they told me, she's going to live until she's 80, at least, because her heart is so strong."(TC) Elmer did see the ambiguity in such a statement: "They found out that she had a heart attack sometime along the way. But also, she'd live to be 100 the doctors say. So heart wise we are in good shape. Unless it changes over night or something."

Smiley made recommendations for content to be developed for a support group for AHF CGs. First, she said you would have to learn what the disease is, what symptoms to look for even if your CR isn't recognizing them. Next she wanted all CGs to be invited into CRs' medical encounters "because he didn't always understand everything they were telling him. You pick out things you wanna hear, and you listen for them. So you need another opinion in there to help to keep it straight." She felt CGs would benefit most from just listening to each others' experiences. "I might suggest caregivers alone for a meeting or two, and then maybe bring in the patients. So the caregivers kind of get used to each other and the things that they're going through." She suggested topics related to adherence (medications and sodium restriction) as topics for joint discussion: "Say if CR had a problem and he wouldn't listen to it from me, if it came from somebody else— I think that caregivers can help each other to help patients." Smiley suggested a nurse to lead such a group as "someone knowledgeable", and she suggested to mix it with CGs and CRs of other chronic illnesses, "like arthritis or lung disease" because "[those disabilities] might curtail some activities, and maybe someone else could suggest activities that they would be able to do [as a] group together. Talk about activities and how hard to push yourself." Regarding conversations about symptom progression and advance care planning (ACP), she said:

> There might be a lot of people out there that would have questions on that. Yeah, that would be a good one. That would be a hard one. That's why you would need a nurse or a doctor or somebody with a little bit of input on that, I think. It might be comforting to patients to know what to look forward to, and caregivers, too.

Theme 3: Using your words to get things done

Communication techniques among CGs and CRs served therapeutic purposes, and where a continuation of long-established relationship patterns. Communication techniques between HCPs and CGs served to establish relationships and achieve medical goals. These latter techniques were more or less successful.

<u>Letting your self talk</u>

Participants described how they had to have a talk with themselves sometimes, to relive the burden of being a CG: "Sometimes I want to walk out the door and scream. I think it would make me feel better."(TC) Oma escaped into the basement: "A lot of times you know, when I get real upset about him, he can't go downstairs, I go down to the basement, talk to myself." Librarian had to vent her anger, then walk away and have a talk with herself, to forgive herself and face the rest of the day.

Talking with the care recipient in established patterns

CGs and CRs had communication patterns which had been established over a long time and were designed to support the CR's continued self worth and autonomy. Elmer describes "She gets to be head sergeant, when she can sit on one side of the counter and orders me around to do this and this and make the casserole."(E) Smiley did careful communication involving indirect suggestions and avoiding confrontations, to encourage CR's adherence. "It has to be his idea. He has to figure it out for himself, because you're not going to make him go to the doctor." At times she resorted to involving third parties: "Sometimes I could probably mention some things to his daughter and then she can come back at him and say, 'how are you doing with this or that?'" She did not want to get caught in the middle and admitted: "So the communication around that is tricky sometimes." Chewey wanted to capitalize on CR's fear to continue adherence: "I think he got a good scare, so he's really watching what he eats. I'm just hoping he continues to be scared."

Oma took her CR to an orchard and directed communication at a positive future as strategy to encourage her CR: "I ask him 'what's the plan, what are you going to plant? Where are you going to plant it?' So we're planning the future, trying to get him to think of something else." Oma and Lee resorted to intuition as a technique to guess at their CR's needs: "He leans on me a lot when he's sick, without talking. But you just know. Just the way he'll look at me, it's almost like 'help me', you know. So I go down every day, he expects me to."(O) Lee told of deciding to forego further aggressive care for her CR: "We didn't have to discuss it. It was just something that you feel between the two of us."

Being listened to in conversations with friends and family

Caregivers used family and friends to share emotions and find encouragement. After talking to her friend on an almost daily basis, Oma said: “When I get done talking to her usually I feel much better because I know what might come, and I know how you have to handle it. And I think you’d be more prepared.” TC talks to friends “Just how CR is feeling and how I feel once and awhile, that lightens the load.”

Being talked to or being talked at by healthcare providers

Having a long-standing relationship with the MD allowed CGs to bring up difficult topics: “[Doctor] has been his family physician for several years. They get along wonderfully. Our cardiologist is the same way. I’ve talked to him the whole way, and I told [cardiologist] today I think he’s depressed.”(O) On the other hand, CGs did not think it important to share their entire story as laid out in *telling the story of AHF in your life*, with their CRs’ physicians “I don't feel that it is important to tell CRs doctor about my story.”(Lib) Expectations were different for her own personal physician: “I went for my checkup and told [doctor] how things were going. She just glossed it over, so I felt dissatisfied with that. She was more interested in my cholesterol count. I was disappointed that she didn't listen.” When asked whether she would talk about death and dying with familiar physicians, even Oma said : “I probably wouldn’t. I mean, I think I could, if I had to, if I were faced with that.”

Communication styles were examined critically, TC told: “Last time, I felt like they were talking to me, not at me. They explained in words that I could understand; and that is what I need. If it hadn’t been for that I wouldn’t have known what to do.” Interactions that combined information sharing and casual conversation were much appreciated: “The communication with the nurses has been fantastic. They treated her just like a mom, which made her feel good. [ARNP] in there has been really great. She comes in and talks to CR all the time.” Lee gave a moving example of communication gone-wrong. After the traumatic transfer of CR to home hospice care, and with Lee clearly in shock, one of the HCPs present, or perhaps it was a chaplain sat her down and tried to explain to Lee her present state of confusion:

> She told me this thing about half of your brain is what's going on right now and the other half can't record it. Then when this stuff—it can record it on this side, then this one would start asking, be able to ask the questions. I'd never heard of such a thing. It made no sense to me. Because I was like 'what is this'? I mean, it was way over my head.

Elmer was skeptical of communication styles: "They are so very kind, they seem like they want to be part of your family, very genuine." But then he continued: "I don't like to deal with all the specialists. Every doctor and every nurse comes in to introduce themselves; after about the 15th one I don't want to know your name because I'm not going to remember it anyway." Chewey was wondering what the purpose of the communication technique was:

> I am just trying to figure out what they are doing. They are not speaking to me directly. When a doctor comes in they will talk directly to CR. And sometimes when he is confused about something they will ask "did you have such and such this morning" and I will know that he did or didn't and I will correct his answers. They will look at me like "I'm not asking you, I am asking him". So then I thought they might be trying to see if he knew. So I stopped doing that because I didn't know if they wanted the answer or wanted to know if he knew the answer. Do they really want to know? Or are they just asking? I'm not really part of this interaction.

Participants commented on presence or absence of coordinated care. "There may be teamwork among the doctors but it doesn't sound like that is going too well." (C) Elmer described how one physician finally emerged as the go-to-person: "We got into all these doctors, during different phases of things. Finally the heart doctor said 'I am going to be in charge, you all report to me'. Now we are getting a little better handle on things." TC learned to insist on coordination: "They always confer with each other. That's the only way CR would have it." TC told them "You can't keep bouncing CR around like this. She's not a yo-yo." Elmer made use of another strategy at doctor visits:

"They always tell you to take two people because when you get home you won't agree on what was said so at least maybe one of you has a chance of heard right." So now they both go into the exam room. During CR's last hospital stay, Chewey noticed a change:

> They had a wipe board where everything was written down. The nurses, when he was checked last, all of his vitals, everything was written down so that I could see it, and they could see it. We all knew what was going on. I felt more like I was a part of a team then with the nurses, yes. I thought they were excellent.

Theme 4: Putting all the pieces together to be the best caregiver to the end

Participants spoke about their intentions to find happiness for themselves and their CRs within the circumstances that were given to them in a life with AHF. The four subthemes acknowledge future separation and the breaking up of a marriage but are balanced by the desire to support the CR in his/her quest for happiness and making a promise to continue to be a caregiver.

Reluctantly recognizing a separate future

CGs were quiet about their own intentions for happiness after the CR's death in the future but for the present they wanted to take care of their personal health. Speaking to her own physician about her feelings of nervousness, Librarian reported: "Well, I wanted to say if I was tense, if she thought a tranquilizer would help, but that never even came up. She never asked me about my feelings, so I'm just going along with what I'm doing." Smiley needed to make plans for her financial future so when her son was remodeling his basement they had a conversation about the feasibility of her living with him: "He says, you take your pick anytime. Now he just got remarried. I wouldn't want to impose on him unless it was absolutely necessary."

CGs were able to articulate their own ethical intention for CRs' futures. Smiley had the wish for CR at the time of dying, to die quickly: "No suffering, because he's not pleasant to be around when he’s suffering. I hope it’s not something where he’s an invalid and me to take care of. I don’t think he’d be happy in a nursing home.”

CGs described how they sometimes felt helpless in their caregiving role and therefore unable to pursue their ethical intention to relieve the CR’s distress. Lee was anguished watching care for CR in the NH: “I felt terrible. Every day the nurses put on an upper thing that came down and held you down (a restraining vest).” CR had a DNR status: “No CPR for CR because he had all broken ribs. They would never, ever give that to him. They’d just crush him to death.” Her ethical intention for him was: “I just don’t want him to suffer. Like if he chokes to death or something like that rather than have a heart attack. Because I’ve seen him have so many, I’m not scared of that. He could have died from any of those.” She very clearly stated their joint understanding of the good life for CR: “The next time he has a heart attack I would wish that it was over for him. He hates this kind of life.” And yet, his death, while she knew it had to be, would threaten her own happiness: “I’m afraid of him dying. I don’t really know how I'm going to cope with that. I'm not afraid for him because I know where he’s going. But I'm afraid for myself.”

Elmer faced his own and physicians’ frustration in trying to support CR in pain control and adherence to dietary restrictions: “She’s got pain in her all the time. What do you do? I don’t like it, but the doctors, they kind of say, ‘yeah, go do it, and go live with it’.” Regarding adherence to dietary recommendations, physicians have told CR: “CR, we’ve done everything we can do for you. Go home and figure out what you need to do to survive.” Elmer couldn’t help but agree: “That’s maybe a little strong, but that is my opinion.” He said “it’s hard, but we’ve been so close to this thing [death], and have recovered.” So while it is difficult, “look what we did last time we cracked down and got going. So maybe I have fallen into line with what [physicians] think.” Elmer had fleeting thoughts of escaping his ethical intention in caregiving: “Is this where you call the divorce attorney?" But then he was able to displace the entire issue: "I guess I haven't thought that far ahead yet, I don't want to think that far ahead yet."

Participants realized that there were actions toward the good life in big and small things that could not be realized, Smiley: "Yeah. So there are some hopes [for CR's health] that are unrealistic and that's kind of hard." Librarian, unable to keep CR from scratching himself bloody, said: "I don't know what to do. I guess I learn how to live with it maybe."

Chewey admitted not to be committed to looking for the good life exclusively in caregiving: "Right now I don't have my heart and soul in anything, but I have it in everything. I am spread out and kind of torn in a lot of different directions. My job is extremely important." She had already sacrificed access to some of the good life by marrying her CR, because like she herself, her parents were not able to separate his financial from his physical health: "It's a sad situation," she said "my parents have written me out of the will because I am married to him." This needed to be done to protect the farms, to keep things in the family. Although it was a mutual agreement, "it didn't feel good at all. And sometimes I wonder how I got myself into all this."

Smiley voiced a couple of examples where she had decided to place her own need for happiness above that of her CR's even though she understood that all he wanted was her company and some togetherness:

> He was going to go rake up some rough spots in the yard and plant grass seed. I was supposed to carry the bucket out and plant the grass seed. I had something else I had to do and I said I can't do that right now.

Smiley and her CR also had differing ways of walking, he needed to stop frequently and rest, or as he called it, "look at things", and she needed to keep moving in order to prevent back spasms: "So I'd just as soon go to the mall and walk, or shop by myself."

Participants felt they should be better people as CGs, for example be able to perform nursely duties (C) or Librarian: “I have to be patient, ‘Be patient’, is what I should say to myself.”

Learning from what it was like to be a CG, participants made plans not to become a burden themselves. Librarian was going to write a letter: “In my old age, if I start complaining about lack of attention, I’m going to have the kids read it to me and say, ‘Now, mom, this is what you wanted us to tell you later’.” Oma told: “I have long term care [insurance], so I know where I will have to go because I will *not* be a burden to my kids.”

Sustaining the CR in his/her quest for happiness

Participants saw their CRs making daily choices between adhering to treatment recommendations and their own needs for happiness. Smiley articulated her CR’s ethical intention for the rest of his life: “He figures he’s just going to live ‘til it happens. He does watch what he eats. I’m not saying he does everything right, he’s diabetic and he doesn’t watch all of his sweets, either, but he does to an extent.” Elmer suffered with his CR when she boycotted her own chance toward a better life by breaking dietary restrictions: “Sometimes she doesn’t use good judgment. And recently she just really gets down on herself because she knows that she shouldn’t have eaten that last candy bar, but she did. It’s a self induced problem.” Oma was clear that CR’s ethical intention for a good life excluded “to have to go to a care center. He says, ‘I don’t ever want to have to go there’. We laughed about it, it wasn’t really funny. But we discussed it. He said, ‘I don’t ever want to go there’.” TC knew about his CR: “she doesn’t want to be a burden on anyone. She doesn’t want to be resuscitated. That is her biggest thing.” Lee had a visible demonstration of CR’s ethical intention every day she arrived at the NH: “He was waiting at the door with the wheelchair because he was going to go home. Every day. He was coming home.”

Chewey wanted to protect her CR from his own ethical intention which was “all about doing the right thing” [to settle all his financial promises]: “There are an awful lot of takers in his life and not enough givers. Sometimes I feel like I have to protect him from that.” She also wanted to support his wish “that he would work until 72, or 74; he doesn’t really want to quit working. But he wants time off so that he can do some of his hobbies.” Consequently, “knowing that about him, I just don’t see him just giving up on anything; himself or his work until he absolutely positively has to.” Chewey did not consider that AHF might force a premature retirement for her CR. The only reason why CR might be forced to retire, according to Chewey, was “a medical condition: if he would have a stroke, or if something happened to his eyes or hands.”

Breaking up a marriage by contemplating other settings of care

Nursing home as a last resort

SI and contemplation of symptom progression led participants to discuss other settings of care. The thought of nursing home placement filled CGs with dread. Oma said: “The worst thing would be, if he had to go to a home, move there. I don’t think he’d live very long.” She had tried this in the past: “This was an excellent nursing home. But he’s not one to be around people who can’t talk, or are mentally challenged. So who did they set with him at his table? Two people who didn’t talk, and didn’t eat.”

TC elaborated about taking CR to a NH: “Yeah, if she needed a nursing home I would, but I would hate to. As long as I can take care of her though, there ain’t no way.” He listed all the jobs he could be doing for her: “I can feed her, I can bathe her, but she can do all those things on her own. It will be a long time before she says she isn’t able to do that.” His children would of course struggle with the idea but even TC’s son said: “Dad you aren’t getting any younger, your age is creeping up there, something could happen, what will you do then?” And TC promised him “if I can’t take care of mom then she'll have to go into a home," absolving his children from having to take over care for their mother.

Lee, whose CR actually was in a NH described how it conflicted with the promise they had made to each other in the past: "and that was just a big thing that we had decided that we would never do that to each other. We'd just take care of each other." She consoled herself with the fact that CR was mentally not aware of being in a NH.

Such cognitive decline would also make NH placement an acceptable option for Librarian: "I think if he gets so that he doesn't recognize me or the family, I can move him to a nursing home and move there where the girls would be closer for me. So that's something I have thought about." All CGs stated that the CG role was not transferable to other family members beyond them because they all would be too busy with their own lives to take on such a role, or because they were not suitable to provide such care. TC explained about one of his daughters who had half-heartedly offered to become CG to CR: "but those two don't always click, they have head butting contests. CR would be better off in a nursing home and my daughter agreed with me."

Changing settings of care required caregiver sacrifice

Librarian was concerned about her own health and ability to care for CR: "The other day I was coming home from somewhere I thought, 'what if I have an accident, who's going to take care of CR?' If we were in a place like [ALF], there would be somebody there all the time." She was actively planning a move to an ALF with a memory care unit for CRs progressive dementia. However, living in a locked unit required sacrifice on her part: "I don't think I'd like that keying yourself in and out all the time. That would bother me quite a bit. I don't want to be where I have to be unlocking and opening the door just to get out." She was also concerned about the quality of care in an ALF: "I don't know how they treat them, if they take total care of them. I'm sure they have to, though, if he gets bad and incontinent, they probably have to." TC would prefer for CR to go to an ALF, but when asked whether he would join her there he said: "Oh, I doubt it. It would be a hard decision for me because I am so used to being on my own, coming and going."

Caregivers prefer to plan settings of care with the CR

Elmer and his CR were doing joint planning for a move to a setting with progressive levels of care. Such joint planning would be a relief for Oma who tried to discuss it with her CR:

> We talked the other day a little bit. And he said to me, 'you'd probably just put me in a nursing home'. And I said, 'Not as long as I can take care of you, but if you were bed ridden, then I couldn't do it'. He didn't ever say that it would be ok, but I think he knows that that's what it would be.

Smiley was able to see it more pragmatically: "There's times when you can't get out of going to a nursing home. If he needed nursing home care, dependent on how bad he was and what the circumstances were, I would have to draw the line at caring for him." The thought of a NH was still quite out of Chewey's frame of reference, she simply commented "I would imagine if we are to the point of having to go to a nursing home, then that is probably something that we would do."

Making a promise

Considering their own thoughts about what happiness meant for themselves, and given all that they knew about their CRs' ethical intentions for the good life, CGs voiced certain promises for their caregiving. When first faced with the disease, TC wanted to "Get her out of here and have her completely well. When they said her kidneys were shutting down, I told her, 'Well, I have two good ones. You can have one of mine'." Facing the realities of the disease, however, he settled "to help her get back on her feet, just be her provider, I guess. Her husband, which is my main thing."

They were going to uphold marriage vows “that is part of the game we play when we say ‘I do’(E), care to the best of their ability, and minimize the threat of dying from AHF:

> This little corner right here is what I'm going to worry about. Like I told her: 42 years more. I guess we'll just have to see what life holds for us. Like I said, you could walk outside the door and get hit by a car or something, fall down and break a leg. I hate to say it, but sitting in the hospital, you could have a heart attack. (TC)

They promised to face the future together and wanted to keep life as normal as possible: “We’ll keep living our lives the way we want to, just the way we always have.”(O) They were going to continue to search for safe foods, like Smiley looking for a certain low-sodium spice at the grocery store: “I couldn’t find it. I had four people in that store trying to help me. I don’t think they have it in there. I’ll keep looking.” They were going to continue to encourage adherence: “She's getting better about yelling at me for that, she knows it's going to be a routine that's going to be there for the rest of our lives. She isn't going to change my mind any.”(TC) All of them were committed to keeping up with a rotating schedule of medical appointments.

They spoke about protecting their CR to the end: “I know I can’t turn him. I know I can’t help him, but I’m not going to sit here and let something happen to him to precede a natural time.”(L) They considered NH care only as a last resort. “I will take care of her as long as I can, that is my job.”(E)

Question 4: How does appropriation of symptom interpretation and communication shape caregivers’ ethical intention for advocacy and making treatment choices over time?

This last question synthesizes findings from symptom interpretation and communication in a pattern that emerged throughout the duration of the study. Findings are grouped into themes within the time line of the study period including 3 interviews and the follow-up phone call, and are associated with events during this time (hospitalizations, life at home or rehabilitation, NH placement or deaths) as displayed in table 7. One finding of note unrelated to SI or communication in three CGs was the fact that they all experienced a health crisis after transfer of the patient back to the home setting.

Table 7. How does symptom interpretation and communication shape caregivers' ethical intention for advocacy and making treatment choices over time?

Symptom interpretation	Communication	Advance Care Planning (ACP)
Interview #1: Hospital (1), Home (5), NH (1) **Being filled with trepidation at the thought of the care recipient's return home**		
Fear about another bad event occurring and unsure what the right response should be.	Wondering what the new caregiving role will entail.	Going through the motions of completing AD/LW without really knowing what it means
Interview #2: Rehabilitation (1), Home (5), Deceased (1) **Building confidence and trying for a new normal routine**		
Feeling more confident with symptom interpretation vs. lacking control to direct care.	Feeling relief over CR improvement or accepting CR decline.	Knowing what you want but not knowing how it should affect the plan of care
Following medical recommendations on a continuum from adherence to risk-taking.	Recalling encouraging rhetoric from HCPs vs. being unclear about how to act and what to expect.	
Interview #3: Home (5), Hospital (1), several ER visits (2) **Developing new strategies while wishing for more professional guidance**		
Learning to care for the CR at home.	Acting decisively in times of crisis vs. negotiating proper course of action with the CR.	Talking about ACP around the family table
Adjusting to continued caregiver burden and patient symptoms.		Feeling more or less safe in the cocoon of HCP silence
Follow-up phone call: Home (3), Deceased (2), Unknown (1) **Coming to the end of the path vs. continuing to walk in the shadow with your eyes to the ground**		
Maintaining the course while needing to be alert to subtle new changes.	Grieving and constructing a positive memory.	Not knowing what to do with that which you feel certain about and that which you can't fathom
	Being resigned to the permanence of AHF.	

Being filled with trepidation at the thought of the care recipient's return home

During interview #1, one CR was hospitalized, five had been discharged to home and one was transferred to a NH. CGs were fearful about symptom interpretation and needed to talk about their responsibilities as CGs. Most of the CGs went through some sort of attempt at AD/LWs without really knowing what it implied for the CR's care.

Fear about another bad event occurring and unsure what the right response should be.

Elmer had much experience with recurrent events: "It seems anytime we have a problem it's at 2:00 in the morning. It's just wild. So every time we go to bed, we kid each other: Well, I'll see you at two!" When I asked Lee what she feared most now that her spouse was transferred to the NH, she replied: "I guess more of the fearful things that you don't really know. I've never seen anybody die." TC had similar fears: "If something were to happen to CR I don't know what I would do, how I would react. I don't want to find out, either! That would be catastrophic on my part." Chewey explained her own significant anxiety after CR's discharge: "It comes from not knowing what would happen if CR became incapacitated. What would happen if I lost him. There is a lot of nothing formulated. A lot of not knowing where I would stand." Smiley reported after hospital discharge that she was more vigilant at the time, because she didn't quite trust CR's improvement yet. TC fell ill with the 'flu for two days shortly after CR was discharged which he attributed to having been under a lot of stress up until that point.

Wondering what the new caregiving role will entail.

All CGs were recruited when their CRs were either still hospitalized with an exacerbation of AHF (O), had been discharged home (Elmer, TC, Chewey, Librarian and Smiley) or transferred to a nursing home (L). Accordingly, all participants were adjusting to different care settings. They experienced initial trepidation about whether they were going to be able to handle the specific caregiving tasks required in each setting and how it would affect their own lives.

Being at her spouse's bedside in the ICU, Oma shared: "Like I tell him, we've been through it before; we'll get through it again. It's just, some days I can face it easier than other days. I have moments where I lose confidence that I can do it again." Chewey was struggling how to manage CR's sodium intake more effectively: "The hardest part is knowing how to cook anything. We have been experimenting with things, and I am not so sure we are going in the right direction. We haven't really cooked anything because we don't know what to cook!" Librarian saw her role responsibilities change because the hospitalization seemed to have worsened CR's dementia: "He's had a lot of physical problems, but he always stayed active and if anything ever came up, he could solve any problem he had around the house and the car. Now, everything is up to me, to do it."

Going through the motions of completing AD/LW without really knowing what it means

Oma's CR was unable to participate in ACP due to his critically ill condition; Lee and Librarian had to make ACP decisions for their CRs because they were limited in their participation due to cognitive impairment. Oma recalls a conversation with the physician about CR's prognosis: "I think they've said he'll just have a heart attack and that will be it. He won't come out of it. Because they have marveled 'well how many more times can you do this?' and they don't know." Oma completed a standard AD requesting no heroic efforts at his hospitalization but she never learned how these directives would actually play out in the event of his dying. In the same way, Lee did not know how CR's DNR status would affect his care: "I have talked to the doctor about that (wanting him to die with the next MI). If he had a heart attack right now I guess I would you just sit with him and hold his hand. But they probably would take him to the hospital here." The care she observed did not seem to fit with EOL care: “On Friday they told him he had to do the therapy and he was so weak. They made him get up and get in a wheelchair and they made him walk. They really were cruel about it, making him walk.” Lee was therefore deprived of palliative care interventions for her and her CR at the NH. Librarian, on the other hand, had a thorough discussion with a physician weighing CR’s prognosis for both AHF and dementia, and obtained an OOH-DNR status. Yet she had no clear idea of how to manage worsening symptoms or sudden death at home other than calling 911.

TC was prompted by his son to pursue an AD for CR. Staff at the hospital promised to send the necessary forms in the mail and they finally arrived six weeks later by which time much of the impetus to complete it had faded for the family.

Elmer and his CR completed standard ABA AD/LW forms in conjunction with estate planning at their lawyer’s office. There was no discussion about disease-specific implications of such traditional AD/LWs, nevertheless Elmer and his family felt well prepared for the worsening of his dementia and CR’s chronic illnesses. Elmer was unable to articulate how these documents were going to shape CR’s EOL care. But he said: “We have [two sons]. I’d imagine that they would both step forward, both help. CR sat down with them last month and went over the will, where everything is, how we’d like to see things handled.”

Building confidence and trying for a new normal

During the second interview, one CR was in rehabilitation, five CRs were living at home, and one CR had deceased. CGs were generally feeling relief over their CRs improvement although recovery was slow. They began to feel more confident in SI and were committed to adherence to medical recommendations even if it involved discretionary self management and risk-taking. Throughout, CGs heard mostly encouraging communication from HCPs but remained unclear about the long-term plan of care or prognosis. The bereaved CG recalled her acceptance of the CRs decline toward death yet she found no acknowledgement of this understanding among the NH staff. She therefore experienced an acute lack of control over the CR’s EOL care. CGs were able to articulate their CRs goals for care but did not know how to incorporate it into their plans for care.

Feeling relief over CR improvement or accepting CR decline.

TC and his family were much relieved: “They are all excited to see that she is getting along a lot better. She has really improved. She has lost about 75 pounds and her heart wasn’t damaged at all with the heart attack.” Even with discharge to skilled care, Oma was still uncertain about her CR’s improvement due to his continued depression: “I don’t know. If I would see the spark, I would say no, he won’t die. But I don’t, and yet he tells me he wants to live.” Lee was very aware of her CR’s limited time left: “He’ll never make it that long. I don’t think they ever thought he’d even be here this many days.”

Feeling more confident with symptom interpretation vs. lacking control to direct care for the CR.

TC was learning to assemble the pieces of the AHF puzzle and take decisive action: “She'd been complaining about not sleeping for three nights. She was afraid she wouldn't wake up, evidently. Finally, I just told her, ‘This is enough of this stuff. I'm taking you to the doctor.’" Elmer was very pragmatic: “As soon as it gets to where she can’t breathe well we get to the doctor. There is no way to really anticipate, you handle it when the need arises.” Smiley returned CR for a brief stay at the hospital after observing “he hadn’t been sleeping good. Then he had this—I don’t know, in the morning his breathing is real heavy sometimes. Then he had a chest rattle and no appetite.”

Lee on the other hand, felt helpless in directing care for her dying CR, for example when he was wheeled off for physical therapy: “He just begged and they wouldn't listen. That just hurt my feelings. I told them, I said, 'He is so weak, and I know he can't do this.' The nurse just said, 'This is not for you to say.'"

Following medical recommendations on a continuum from adherence to risk-taking.

Many comments regarding adherence were about a sodium-restricted diet and medications. Smiley described her CR's sodium titration: "He was good this morning. He didn't have much breakfast with salt. So he'll have a Subway sandwich for lunch. I think he kind of adjusts that way." Librarian admitted that "When I give him the diuretic, he has a serious problem with getting to the bathroom on time. I know they say he's supposed to take it every day, but I really have not given it to him every day." She justified this by making sure that his weight remained stable. TC reported doing the recommended exercise therapy: "She has been going to cardio rehab. Since this last trip to the hospital she has been good about keeping up with [exercises]. She has a home series she has to do which she does every day religiously." Chewey's CR took the most risks, continuing his butterfly collecting in remote, inhospitable places:

> So I decided I wasn't going to let him go alone. Because the last several times he's gone even with me, let's see, he has broken his ankle in two places, broken his leg twice, and the congestive heart failure problem. So I get really anxious if I think he is going out there and I feel like something bad is going to happen to him, like I am never going to see him again.

Recalling encouraging rhetoric from HCPs vs. being unclear about how to act and what to expect.

TC told: "[Physician] gave her a clear bill of health. That she can do just about anything she wants. [] Right now her lungs are clear, her heart is good; there is no fluid on her chest at all right now." Oma on the other hand heard some discouraging comments: "The other day one of the nurses told me they had a student read his file and say, 'I can't believe that man is still there'. So, it's that bad, I know." This incidental information was never followed up with more in-depth ACP from the HCP perspective. Lee, whose spouse was finally taken off the rehabilitation pathway, was not made aware of a choice for hospice care until less than 24 hours prior to her spouse's death. This meant for two days she had to agonize about his move to a double room in the NH and realizing that she had broken her promise to him. "I came home and I just kept thinking about what am I going to do? He's going to know it's a nursing home when he gets down there and there's some other person in the room." Lee was not guided to understand that her CR would not recover his cognitive abilities just because he was moving to a double room.

Knowing what you want but not knowing how it should affect the plan of care

The time surrounding Interview #2 revealed several missed opportunities for ACP. Oma was not aware of any communication of her CR's AD/LW to the skilled care facility; however, she experienced several conversations regarding CR's goals for physical rehabilitation to help guide therapy toward recovery while there. She was able to articulate his goals for quality of life clearly: to be awake enough to sit in the chair for a few hours, watch sports and news on TV, visit with family, or maybe even go to the casino on occasion. Such clear articulation of goals is essential in formulating goals of care in the context of a prognosis discussion.

CRs and CGs who negotiated adherence to medical recommendations did not experience discussions of adherence within the CRs' goals of care with their HCPs. This resulted in conflict and anxiety between CRs and CGs who were concerned about CR lack of adherence. Lee experienced fragmented communication from all HCPs involved in the care of her dying spouse: starting with the failure to arrange proper EOL care as part of the hospital discharge, ruling out home care due to associated costs, and not offering the hospice alternative either at home or the NH. Confusion continued at the NH with days of attempted physical rehabilitation and another diagnostic test, while at the same time failing to report his ever-increasing weight to the attending physician. Final treatment plans were sudden, moving the CR home with hospice care the day before he died, with a complete lack of preparation given to Lee for this hurried and sudden transfer. Lee had a minor motor vehicle accident and experienced a health crisis of her own in the time surrounding CR's death to the point where she had to be hospitalized for six hours to rule out a blood clot in her leg.

Developing new strategies while wishing for more professional guidance

At interview #3, five CRs were at home, one had been hospitalized again, and one had experienced more than one ED visit. CGs were continuing to learn about managing AHF at home and adjusting to the permanence of the disease which included soliciting practical support of various kinds. In some relationships, the CG took decisive action in a time of crisis; in others, there was negotiation of the proper course of action with the CR. There were conversations around family tables regarding plans for the future and some CGs had specific questions that they would have liked to have answered by their HCPs while others were unaware of all that remained unspoken from the perspective of their HCPs.

Learning to care for the CR at home.

Contrary to themes of fear about another bad event occurring, and wondering what the new CG role should entail experienced by other CGs after CR-discharge to home, Oma experienced an increase in hope and self confidence after her spouse finally transitioned from skilled care to home. She received much support in this from the home healthcare company: "They listen, they want to know his goals and they work on that very hard. They just start teasing about something to get him going. It's a happy laughing time in the house which is nice to have." Unfortunately, Oma did not feel free to discuss her continued worries about potential NH placement in the future, “the worst thing would be, if he had to go to a home, move there. I don’t think he’d live very long. That would be hard, and it would be hard to share.” She also struggled to balance quality and quantity of life for her CR in terms of keeping him free from infection and imposing some social isolation on him for that purpose. Despite Oma’s hope for her CR, she herself continued to experience depressive feelings about taking on caregiving once again: “I like it bright and sunny in the house, but he has to have it darker, because of his eyes. It’ll get dark again, when he comes home.”

Adjusting to continued caregiver burden and patient symptoms.

Struggling at home with AHF, CGs explored options for future NH placement. Elmer said “with her health, we are already talking about the Lutheran home here in B.” And TC reported that “we have a gentleman who is supposed to come in and bring some paperwork in regarding long term care from one of the nursing homes.” Chewey scheduled an appointment with the dietitian at the local grocery store to learn about low-sodium foods; however, because her CR did not want to participate she cancelled it. After all, she did not see herself as his CG. CGs employed outside help for house cleaning or home health care. Librarian joined an informal support group of friends: “These good friends are coming to [fast-food chain restaurant] now, so I can have coffee with them, which I really appreciate.” CGs mobilized family support both for themselves and their CRs with some discernment because they did not want to burden friends and family unduly. Chewey was especially clear about this: “Everyone I know is kind of maxed out themselves right now.” Oma on the other hand could report: “The kids are coming this weekend, and my daughter is in town so I get surrounded.” Lee continued to receive tremendous emotional support from her social network of friends and family and displayed the attitude that “I decided the day of the funeral I was not going to be one of these women that just sat around and murdered themselves [in grief].”

Decisive CG action in time of crisis vs. negotiating proper course of action with the CR or HCP.

TC’s CR was currently hospitalized for recurrent AHF. TC had recognized the subtle signs of weight gain and SOB but did not take her in until she had the more obvious sign of chest pain. He said: “This time it didn't scare me, because I knew what it was going to take to get better. They took care of her right away. They said they caught it in quick enough time.”

Smiley gave an example of needing to respect her CR’s autonomy in making decisions after he had one of his diuretics changed:

> This [diuretic] didn’t work quite so well. Right away he started gaining weight. When he had gained four pounds, I said ‘you think you should call the doctor?” ‘No, it’s just because I ate too much last night.’ Well, when I wasn’t around he must’ve called the doctor because I heard him later on the phone. They had told him to double up to two pills instead of one. So now he’s doing much better. It has to be his idea.

Elmer had ongoing interactions with HCPs about CR’s infections and recurrent incontinence. Finally, after weeks of despair her anger emerged and he found her reclaiming her autonomy empowering:

> I guess I kind of thought, good for her, now maybe we’ll finally get something looked at. Otherwise she was using the pills and just putting up with it. Until we finally said, wait a minute and looked at the pill list and saw when we bought them. And then we started seeing a pattern, why we didn’t see it before I don’t know.

Talking about ACP around the family table

There had been no prognosis discussion with four of the seven participants: “Not that I have heard, [] I haven’t heard anything.”(S) However, some family conversations about ACP had taken place, Smiley told: “CR’s daughter is real good. While he was still in the hospital, I went and visited with her, because I wanted to tell her some things that I would just as soon not say in front of him." TC had a conversation with his son-in law while on a hunting trip:

> We sat around and talked for 15 minutes about mom. He thinks the world of CR. So we talked about how she's been getting along and all that. I told him that this last trip to the hospital scared me. We both thought we were going to lose her. I said, 'we've been married for 42 years, she is my soul mate and I don't know what I will do if I lost her.' I told him he'd have to lock me up for a long while.

He concluded: "Just talking about it helped." Participants agreed that "those conversations are not easy, the boys don't want to hear about it," (E) and they and or their CRs preferred to procrastinate discussing ACP. "Things like that, I kind of like to procrastinate. I don't want to think about it too seriously until it gets here, but you do need to make some plans."(S) Both Chewey and Smiley added that the patient's unwillingness and denial were barriers to such discussions.

Feeling more or less safe in the cocoon of HCP silence

There were no discussions about ACP or goals of care during these hospital, ED and doctor's visits at the time of interview #3. Interviews revealed that participants had no clear understanding of the purpose of ACP beyond filling out AD/LW forms. Asked whether they had discussed EOL care with CR's physician, Elmer said: "I don't know that we have talked to him personally about it, but we have things on file at [hospital]." Some confused it with financial planning or believed that the formal ABA AD/LW documents which are standard practice in hospitals and law offices would be enough to guide care according to their CRs' wishes: "You already have the living will; that is taken care of," Oma said. But even getting such formalities accomplished was not a systematic process, TC described: "And then a nurse, the other day down at therapy gave CR paperwork for advanced directives for healthcare. I have to get those filled out; she got busy and forgot to give them to us."

Discussing the role of a HCA, participants agreed that they needed to be selected carefully to avoid conflict when they were called upon to advocate for the CR. TC whose CR wished for no resuscitation, anticipated: “My son will have power of attorney. [] the girls, I know would be so sad that if she could be resuscitated they would try.” Librarian explained that her son had religious objections to CR’s DNR status and she would have to clarify that she was asking him to respect her and CR’s wishes against his own values and beliefs. Oma described her children’s opinion that CR had survived so many close calls; they would feel uncomfortable denying him life support at any time.

There were no discussions to inactivate ICDs. Librarian, who clearly stated that she would prefer for her CR to die suddenly or in his sleep from AHF rather than dementia did not know that an ICD would provide a type of CPR to prevent sudden death: “Oh, really? I guess I’ve not really seriously thought about that.” Lee’s CR who had exhausted the battery life of his ICD and had no plans for a new ICD implantation nevertheless experienced external shocks toward the end of his life.

Chewey expressed anxiety about the lack of ACP in all three interviews. “There is a lot of anxiety because I am not one that handles unknowns very well. I always plan my future and follow that path and this is like falling off the earth and floating out in outer space.” She wanted guidance with the process because her CR was not receptive, so I gave her the contact information for the social worker at [hospital] after the first interview, and she wrote down specific questions to ask about goals of care in the second interview. Yet, in our final conversation she reported

> I tried at one point to talk with him about getting together and talking about things. And he gets real agitated and starts hitting on his head… It always seems to be a bad time to talk about things. He always presents it as if I am hounding him about things. He doesn’t like to talk about anything now. So no, we haven’t. It makes me feel like it’s never going to get done.

Coming to the end of the path vs. continuing to walk in the shadows with your eyes to the ground

Overall, there was an impression of the continued toll of disease and caregiving on CGs during our two-month interviewing periods. This prompted the final follow-up phone call which was added to the study as a modification. The follow-up phone calls occurred in August, which was anywhere from two to eight months since interview #3 for the individual participants. Only Chewey did not respond to invitations to participate in this phone call.

Grieving and constructing a positive memory

At the time of the follow-up phone calls there had been two more deaths: Both Oma and Librarian's CRs had died 2 months after our last interviews as described in their respective vignettes. All three CGs described the events in detail, including several positive events that lent meaning to the dying and loss. They preferred not to dwell on any negative aspects of the dying, for example the hectic transfer to home in Lee's, the CPR in the drive way in Oma's, or the negotiations with the EMS team in Librarian's case. Prior to CR's death, Librarian had had a conversation with her son and daughters about respecting their wishes for the OOH- DNR status and her son had come to understand his role in representing them against his own religious beliefs. Oma still grappled with some feelings of guilt for having gotten exhausted in her caregiving: she felt that it had contributed to CR's depression towards the end. She described how, following the ambulance to the hospital her son was still trying to console her that CR would be just fine again by the time they would arrive at the hospital, but she said, "I knew this time was it." Lee was able to give voice to her anger over the mismanaged dying of her CR without resentment but framed in her spiritual need to forgive. Lee also had received bereavement follow-up from hospice staff. There was no follow-up from HCPs with Oma and Librarian. Oma benefitted from the support within her social network. Despite the formal lack of preparedness for the actual dying moment, all participants told stories that were consistent with their wishes for their loved one at the end. Lee recalled the visibly calming effect of bringing CR back to his own home. Oma remembered CR dying at home, although he was officially taken off life support at the hospital, and Librarian was grateful that CR died suddenly and quickly, and not from Alzheimer's disease.

Being resigned to the permanence of AHF.

The three remaining CGs summarized their current lived experience of caregiving with some resignation. Elmer continued to be "always a wee bit on edge, wondering what we'll find next". Smiley was "learning to manage" which mostly referred to negotiating her CRs temperament, and TC accepted that "it is never going away". They reported continued symptoms of shortness of breath and fatigue related to AHF in their CRs. Symptoms from other chronic illnesses for example diabetes and neuropathy, arthritis or fibromyalgia, or re-emergence of cancer were generally perceived to be more troubling. Two CRs suffered from incontinence related to their diuretic therapy and CGs found this to be seriously interfering with their daily lives. CGs also questioned whether their CRs' returning fatigue was due to medications, specifically antihypertensives and antidepressants, or whether it was progression of the disease. It was challenging for CGs to encourage their CRs to follow medical recommendations for example exercise therapy, diet restrictions or to wear the CPAP mask at night.

Maintaining the course while needing to be alert to new subtle changes

While participants gave an overall positive picture of managing AHF at home, and seemed to recognize familiar symptoms of SOB, fatigue and edema, they did not necessarily recognize the seriousness of other, new developments which may have indicated worsening of CRs' conditions: Elmer's CR had continued with weekly clinic visits since the last interview mostly for decreasing blood pressure. She had fallen several times at night, on the way to the bathroom, each time necessitating a phone call to the son, to help lift her off the floor. She could not wear the CPAP mask because of her night-time urgency. TC's CR had two office visits in the eight months since the last interview. She too had given up on CPAP and following an exercise routine. Smiley's CR had eight to ten office visits in the 10 weeks since the last interview to follow his worsening renal function, which prompted him to "limit" his fluid intake by switching from beer to green tea and flavored water. He was also being evaluated for CPAP therapy.

Not knowing what to do with that which you feel certain about and that which you can't fathom

None of the above mentioned developments were accompanied by ACP discussions. All three CGs were planning for a future of well-being with their CRs either with AD/LW (E) or without (S and TC). Smiley continued to feel uninformed about general ACP for her CR but had transferred all of his medical records to a Texas hospital where they were planning to spend the winter; however, Smiley was cautious "we're planning on it but you never know how he'll feel." TC had clearly lost interest in ACP, saying "it was not a priority right now" since they were looking forward to the birth of a new grandchild. Elmer and his CR were planning another trip to Arizona with family support and Elmer was excited about the new scooter CR had received for increasing inability to walk. Neither her hypotension nor her functional decline had prompted any new ACP discussions with HCPs.

Question 4 Summary

SI and communication themes along the time line of this study gave insight about CGs' experience of planning for the future from transfer ring the CR back home up until some of their deaths or into continued caregiving. After going through the motions of completing AD/LWs in the hospital without really knowing what it meant for the future they were *filled with trepidation at the thought of the care recipient's return home*. Settling in with the CR at home *they tried to develop a normal routine* as they developed more confidence in SI and were adherent to the degree where they knew what they wanted but did not know how it should affect their plans. In continuing to learn about caring for their CR at home and adjusting to CG burden they felt the need for talking about ACP around the family table and they felt safe to varying degrees in the cocoon of their HCPs' silence regarding the future. *They developed new strategies but wished for more professional guidance*. Finally, *some arrived at the end of their path while the others continued to walk in the shadow with their eyes to the ground*. Bereaved CGs were building a positive memory of their CG experience and the inevitable death of the CR. Those who continued in the CG role were so wrapped up in caregiving they failed to recognize subtle new changes. They had certain intuitions about their CR's decline but they did not know what to do with that which they felt certain about and that which they couldn't fathom, because there was no one to talk to about it.

CHAPTER 5

CRITICAL REFLECTION AND APPROPRIATION

The purpose of this hermeneutic-phenomenological study was to understand the meaning of how CGs experience themselves in the daily acts of caring for their spouse with advanced heart failure (Question 1). As part of their entire experience I more specifically explored how CGs explained and understood symptoms of advanced heart failure (Question 2) and how they used communication to explain and understand their caregiving situation (Question 3). Finally, I explored how symptom interpretation and communication shaped CGs' ethical intention for advocacy and making treatment decisions over time (Question 4).

In keeping with Ricoeur's methodology, findings from this study are discussed under two headings: critical reflection and appropriation. Critical reflection examines results in the context of current scientific literature, separately for each of the four research questions and creates a rich and eloquent description of the meanings attached to being a CG, interpreting symptoms, communicating and pursuing their ethical intention over time. Appropriation summarizes and reviews findings in terms of nursing implications and need for further research with special attention to the three foci of this phenomenologic inquiry identified in Chapter 2: perceived control; communication, decision making and reciprocity; and including family values into decision making.

Critical Reflection

Demographics of this group of CGs matched the general CG population as described in the literature in terms of being Caucasian, mostly female and older (Barnes, Gott et al., 2006a; Dracup et al., 2004; Kang, Li, & Nolan, 2011).

Question 1: How caregivers experience themselves in the daily acts of caring for their spouse with AHF

All participants embraced *becoming a caregiver in the spirit of human affinity*. CGs saw caregiving to be a human obligation and viewed it as part of natural aging in the context of chronic illness yet for some it materialized as an unexpected or even intrusive element in their lives. As such they struggled with setting boundaries around the CG role to preserve their own self identity. In *striving to restore dignity and respect to their own dispossessed selves and those of their CRs* they had to examine their own strengths and weaknesses as they were being constantly challenged and transformed by the experience. They were aware of the tension between negotiating dignity and respect and emphasized the need to align self-determination with their CRs' waxing and waning capacity and competence. They coped by reframing what they could not change, and by reclaiming sovereignty to act as autonomous CGs whenever they were able to. CGs needed to *gather their resources within civil society to shoulder the responsibilities of caregiving*. They identified several burdens which required them to stay connected to the web of society and rally practical support to counteract social isolation feeling set aside. CGs wanted to be partners in the healthcare network of their CRs but struggled against feeling disallowed and discounted. Through metaphors they captured the essential meaning of their experienced selves as *being fearfully vigilant, at the mercy of the disease and its treatments, while worrying about that which remained unspoken*.

Becoming a caregiver in the spirit of human affinity

CGs accepted caring or caregiving for their CRs on the basis of duty, love, reciprocity and even utilitarianism. These motivators are found on Ricoeur's continuum of friendship. As discussed in Chapter 2 as part of Ricoeurs's philosophical lens, friendship is based on respect for the other and from the other and is necessary to have self esteem which ultimately confers capacity to act with autonomy towards the ethical intention of being a CG. Love, duty, reciprocity and utilitarianism operationalize mutual dependency and vulnerability, and point to the need for outside caring within just institutions to enable human beings to perpetuate society and make civil life possible. In support of the continuum of friendship, Engster (2001) summarizes *care theory* with a focus on caring activities and implications for moral and political action. He presumes (1) that all human beings require care at some point in their lives, (2) caring is therefore good and essential if we value survival as a society, (3) all human beings have a right to receive care when in need in order to sustain the web of society, (4) human beings have a claim to caring simply because we are part of the web of society and (5), because we all need caring, we all must provide care based on our own dependent existence. Reflections on findings in this study are therefore philosophically based on the assumption that while spousal caregiving in itself is an intimate task grounded in self-esteem of the CG, it is clearly not a private task, which relies on collaboration and resources within the larger web of society, or just institutions.

The retired six CGs named AHF caregiving as an evolution of caring in a committed spousal relationship in normal aging. This included a history of chronic illness for all of them. Caregiving in HF differs fundamentally from the mutual care provided among healthy aging couples. In a study by Hwang et al. of non-HF specific care tasks among aging couples comparing 338 partners of HF patients compared to 1202 partners of healthy individuals of advancing age, HF CGs were found to provide significantly more personal and emotional care in addition to typical HF care (Hwang, Luttik, Dracup, & Jaarsma, 2010).

From these six older spouses, only the one caring for an AHF CR who also had Alzheimer’s disease (84 years old) expressed surprise at the unexpected total dependency of her CR, as something she did not feel prepared for and causing her chronic anxiety. The experience of caring for an AHF CR with concomitant Alzheimer’s disease is not described in the literature, although a retrospective longitudinal cohort study of Medicare beneficiaries showed that within the middle-old cohort (76-85 years old) the prevalence of dementia among HF patients was 21.3% (Ahluwalia et al., 2011). There are no recommendations on how to incorporate dementia care with AHF care and there is no evidence how having dementia may influence HCP' AHF treatment plans. This particular CG clearly articulated that the behavior changes related to dementia were more challenging to manage than the functional losses and incontinence related to AHF. She was accepting of the interaction between AHF and dementia, whereby activity intolerance from AHF prevented him from wandering as is often a problem in dementia CRs. It could be hypothesized that in the case of the CR with dementia, he was kept on the continuum of friendship through the memories and love of his CG because he himself as a person had disappeared. The CG chose to follow the call for care as it would have been issued from the person he once was, with the need for dignity and self respect that she knew him to have valued in the past (Fredriksson & Eriksson, 2003).

The youngest CG in this study was not ready to perceive herself in the CG role and experienced a great deal of anxiety related to her CR's illness experience. Such heightened state of anxiety and decreased emotional well-being compared to older spouse CGs was found in a study by Dracup et al. (2004). The authors hypothesized that burden imposed by the disease interfered with other caring duties, in this case a teaching career and commitment to children and grandchildren. This CG's tendency to link her CR's physical and financial health illustrates Dracup et al.'s hypothesis that lost productivity and fear of forced early retirement contribute to younger spouses' emotional distress. Consistent with a sample including younger spouses from Bakas et al. (2006), there was less involvement in the CR's care, vivid descriptions of decreased perceived control, and less preparation for the caregiving role as well as financial concerns. Finally, this CG's emphatic insistence on being a wife and partner rather than a CG resonated with the experiences of four middle-aged women living with chronically ill spouses who perceived the illness to be like a stranger intruding on their marital relationship and demoting them from wife to carer (Eriksson & Svedlund, 2006) or princess to maid in a sample of CGs for stroke survivors (Cao et al., 2010).

Striving to restore dignity and respect to the dispossessed caregiver and care recipient

Ricoeur's philosophy of ethics stipulates a respectful relationship with oneself as the other as the cornerstone for relationships with other persons and within just institutions. CGs recognized the asymmetrical distribution of dignity and respect on the continuum of friendship between themselves and their CRs based on the entire illness presentation (Fredriksson & Eriksson, 2003). *Reflecting about their own strengths and weaknesses while being challenged and transformed in the CG role*, CGs described various sources of esteem as well as situations where they felt unsure intellectually, emotionally and physically. They constantly assessed where either they themselves, or the CR were lacking for dignity or respect and engaged in negotiations about fairness, courtesy and the tension between protecting mutual sensibilities in daily activities and caregiving tasks.

To maintain self-esteem, CGs needed to hold on to their own identity within the CG role, feel confident in the role, and maintain a purpose outside the caregiving relationship that is, stay connected to and being valued by the web of society apart from the CG-CR dyad (Imes, Dougherty, Pyper, & Sullivan, 2011). Mastering new skills gave them confidence in how they handled themselves and their caregiving role. This resonates with findings of CG engagement related to perceived control and being prepared for the CG role as described by others (see Chapter 2).

Participants experienced chronic or acute illness events which they related to CG stress. They rarely sought help for themselves except in emergencies, for example an episode of atrial fibrillation, but it gave them cause to worry about being able to fulfill the CG role and for some, led to conversations with friends and family about advance care planning for the CR. It is well known that most older CGs have chronic illnesses of their own and there is evidence that links especially emotional and mental health issues with increased CG strain and burden (see Chapter 2). CG depression was found to be positively related to CR depression and worsening health (Pihl, Jacobsson, Fridlund, Stromberg, & Martensson, 2005) so it was not surprising to hear stories of depression, anxiety and other stress-related illness manifestations in this group of CGs for extremely ill CRs. CGs neglected their own health maintenance and visiting nurses did not routinely assess CG health (Bradley, 2003). In a sample of 50 spousal CG-CR dyads, Saunders found lower self esteem, CG depression and impaired CG health associated with decreased CG-HRQL (Saunders, 2009). She recommended depression screening and routine physical assessments, for example for hypertension, performed by advance practice nurses in the home or clinic setting. CGs welcomed such interventions (Ãgren, Evangelista, & Stramberg, 2010; Brannstrom, Ekman, Boman, & Strandberg, 2007c; Garlo, O'Leary, H, & Fried, 2010; Imes, Dougherty, Pyper, & Sullivan, 2011) and the opportunity to speak about their caregiving experience (Saunders, 2009).

It is noteworthy that one CG who participated in the CR’s rehabilitation program experienced an improvement in his own health and another anticipated learning preventive health behaviors from her CR’s treatment plan because she suffered from similar cardiovascular issues. Finally, the case of newly diagnosed dementia is probably the most important reminder that CG support requires planning for their evolving healthcare needs.

Joint rehabilitation, teaching of health promotion and planning for future care needs should be considered in future models of care for older couples suffering from chronic illness. More research is needed to test interventions for CG HRQL and related outcomes in healthcare utilization for both CGs and CRs.

Participants needed to *negotiate dignity and respect* not only for the CR but also for themselves in intimate daily acts of physical care, adherence and symptom management, and in seeking time and space of their own. Generally, these negotiations occurred within established interaction patterns and were complicated by the introduction of vulnerability, dependence and burden into the relationship. CGs felt acute loss of self respect in moments of anger directed at themselves or their CR which interfered with their ability to meet the CR on their respective places on the continuum of friendship. They needed to develop strategies to negotiate respect and deal with frustration, sadness, irritation and even anger while at the same time witnessing helplessness in their CRs.

Such tension in the context of living with chronic illness was described by Delmar et al. (Delmar et al., 2006) from the perspective of CRs in terms of independence, self-responsibility and self-control in CG-CR relationships. CRs were either able to invite CG support and retain a feeling of independence because they believed in a model of human inter-dependence, or they struggled with feelings of guilt and inadequacy based on a more individualist, liberalist view which made dependence on others less acceptable. The importance of not only giving respect and dignity but also claiming respect and dignity within the CG-CR dyad becomes more evident in discussions of symptom interpretation and communication and the implications for shared care in AHF.

Caregiver anger is not well described in the literature but has been associated with potentially harmful behaviors (Macneil et al., 2010) and was a source of self-blame, guilt and depression in CGs of patients with Alzheimer's disease (Bursch & Butcher, 2009).

Building on the need to preserve dignity and respect, CGs sought to *align self-determination with the CR's waxing and waning capacity and competency*. Participants were constantly vigilant yet realized that their CRs could still function independently many times. This was confusing, because while they could "sometimes almost forget" about the AHF, it did not allow them to shed their worries all-together, relieve them of their responsibility for symptom interpretation and observing adherence, or even allow them to make more concrete plans for their days since the next exacerbation could be just around the corner. They wanted to offer appropriate support and encouragement and needed to assess on a daily basis the CR's capacity (Clark et al., 2008); however there was evidence of marital tension when CGs felt used at those times, when their CR had capacity. Surfacing marital conflict in times of medical stability was a theme in a grounded theory study of 45 spousal AHF CGs over 12-18 months by Hupcey et al. (2011). These spouses listed therapeutic communication including relationship counseling as one of their palliative care needs.

CGs gave considerable thought to infusing CRs' lives with purpose and meaning as described by Clark et al. (2008). The importance of maintaining a purpose for, and sharing purposeful activity with the CR was an incidental finding in Sebern and Woda's latest study (2011) testing a shared care intervention and an exploration of the experience of wives caring for their husbands following a stroke (Cao et al., 2010). The need for purpose reflects Ricoeur's philosophical assertion, that meaning in human life arises not only out of being but also requires capacity to act (Ricoeur, 1991).

Additional factors in self-determination were appreciating the CR's continued contribution to everyday life while at the same time having to take over most of their duties in the relationship. CGs had to take on unfamiliar tasks for their CRs and let go of some of their own tasks that had always filled them with pride, which challenged their self esteem and self perception. They derived little satisfaction out of learning car maintenance, yard work or balancing the accounts but grieved over not being able to keep a clean house, participate in volunteer activities or maintaining their social relationships. The same type of role changes and new duties for CGs with resultant shifts in relationships were described by Imes et al. (2011). Not being able to continue previously shared activities or activities previously done separately within the parameters of the relationship, produced feelings of loneliness and social isolation in CGs (Cao et al., 2010).

In *holding one's own by reframing or reclaiming sovereignty,* CGs differentiated between situations where they perceived themselves as either *patients* or *agents* in narrating the story of being a CG (Ricoeur, 1992) and they described coping skills for either situation. Coping has been conceptualized as ongoing cognitive and behavioral adaptation to external or internal demands perceived to be exceeding a person’s resources (Folkman, 1997). Positive coping skills presumably restore perceived control in the caregiving situation. Coping strategies impact stress-related health outcomes and may be a target for intervention (Taylor & Stanton, 2007).

Coping strategies among CGs of persons with Alzheimer’s disease were categorized as being engaging, or disengaging by Garcia-Alberca et al (Garcia-Alberca et al., 2011). Accordingly, in the role of *patients* when CGs felt without control over their situation, they used engaged cognitive restructuring by using humor, or reframing challenges, burden or even prospects for their own future in the context of aging and found it helpful to normalize their own suffering. In the role of *agent*, they reclaimed capacity to act by engaged problem solving as in taking care of their own health, employing caregiving skills successfully, seeking support in talking to others and restoring emotional balance by expressing their feelings. CGs used disengaging coping strategies of problem avoidance, wishful thinking, self-criticism and social withdrawal, when they neglected their own health, and as will be evident later, in symptom management and communication. In their study of 80 CGs, Garcia-Alberca et al. found that coping strategies partially mediated between CG burden and CG mental health. More specifically, disengagement strategies, more than CG burden and irrespective of CG/CR demographics or clinical characteristics, explained states of higher CG anxiety and depression.

Whereas CG anxiety and depression contribute to earlier institutionalization in persons with AD, they may be associated with increased healthcare utilization in AHF (Trivedi, Piette, Fihn, & Edelman, 2012). Addressing CG anxiety and depression therefore has CG-centered as well as economic benefits. It has been suggested that fostering engaging coping strategies focused on problem solving early on in the disease when solutions for clinical improvement are available, and focused on emotionally engaged coping later on, when palliation becomes the goal, better meet the needs of CGs and what they define as respite care (Chappell, Reid, & Dow, 2001).

Gathering your resources within civil society to shoulder the responsibilities of AHF caregiving

Spousal caregiving of AHF CRs occurs mostly in the community setting, which using the Ricoeurian concept of just institutions, in this case would be comprised of family, healthcare systems and policy, the food industry and society in general. CGs must rely on resources from these just institutions to manage the responsibilities of caregiving.

With *Feeling burdened,* CGs listed six major CG burdens which required support from the larger community. Excluding the burden of financial impact, identified burdens echo findings from Pressler et al (Bakas, Pressler, Johnson, Nauser, & Shaneyfelt, 2006) which were dealing with CRs dietary restrictions, depressive moods, monitoring signs and symptoms, and obtaining information or communicating with HCPs. Following are reflections on all six major burdens.

(1) Enduring frequent clinical encounters and being at the beck and call of the CR while trying to negotiate time for yourself is a burden well-described in the CG literature (see Chapter2). CGs centered their days around caregiving, described numerous office and ED visits as well as several hospitalizations, and told about the social support or lack of support they experienced surrounding these events. CGs felt tied to their CRs' HCPs trusting that they held information to provide for continuity of care. More recently, Hwang et al. (Hwang, Fleischmann, Howie-Esquivel, Stotts, & Dracup, 2011) described factors most associated with disruptions of daily schedules to be CR's illness severity and social support. They reported the impact of caregiving on daily schedules of AHF CGs to be higher than that of CGs of cancer patients and comparable to that for CGs of stroke

patients. Social support was felt to be most deeply lacking during times of exacerbation but extended into periods of medical stability when more practical help and friendship support was wished for (Hupcey, Fenstermacher, Kitko, & Fogg, 2011): CGs expected social support from friends and family, and informational support from HCPs. Practical, friendship, emotional and informational support was necessary for CGs to navigate clinical encounters and negotiate time for themselves.

(2) Finding safe foods was a dominant theme among this group of CGs. Participants spoke about food being poisonous vs. safe, misleading and confusing, expensive, inaccessible and impractical to fit into daily schedules, eating out or traveling. For various reasons, food had high emotional content for most and was difficult to reconcile with multiple dietary restrictions. Food was subject to negotiation, a creative challenge, a source of anxiety and conflict between CG and CR, and a source of continuous learning needs.

In general, there is poor adherence to a low-sodium diet among HF patients despite its benefits. A three gram sodium restriction was proven effective in improving event-free survival defined as the composite end point of time to first ED visit, hospitalization or death within a 12-month follow-up period for 136 patients with NYHA class III/IV HF in a recent study by Lennie et al. (Chung, Pressler, Dunbar, Lennie, & Moser, 2010). In a sample of 246 patients in the US and Australia, 75% reported following a low sodium diet all or most of the time, although 24-hour urine sodium excretion indicated only a 25% adherence (Lennie et al., 2008). Consistent with findings in the current study, using semi-structured interviews for 20 HF patients in a Southern city, Heo et al found that all participants believed food had an effect on their health, and some were able to connect sodium with water retention and fat intake with plaque development while others held vague misconceptions about basic impacts of sodium and cholesterol. Factors negatively affecting adherence were lack of knowledge, social situations and food as source of pleasure. Positively affecting adherence were social pressure and encouragement from others. Findings from a qualitative study interviewing 20 HF patients in the UK added how the sodium restriction interfered with socialization, introduced conflict at home between the patient and other family members who did not follow the same diet, and the fact that the selection of low-sodium foods was limited and unpalatable (Bentley, De Jong, Moser, & Peden, 2005), all of which was replicated among CGs in the current study. CGs in this study also emphasized the importance of being included in dietary teaching because patients could not retain the information, and because CGs usually prepare the food.

Michael Owen Jones (Jones, 2007) in his presidential address to the American Folklore Society October 2005, pointed out that dietary management among patient populations is most commonly explored in terms of barriers to proper self care, and reduced to availability, accessibility and cost. Interventions typically include knowledge transfer and skills acquisition, and are measured in adherence behaviors and physiologic outcomes.

> "For many patients, however, it is not only a technical issue but also a social, emotional, and ideational one: a matter of self-reflection concerning causes, struggles with the relationship between identity and eating, and efforts at coping with meanings of illness and symbolism about food." (Jones, 2007, p. 29)

Jones holds food manufacturers, advertisers, and the entertainment industry responsible for turning humans into what they eat. Successful interventions instead should be "Inverting the problem" (Tripp-Reimer, Choi, Skemp Kelley, & Enslein, 2001) suggesting that HCPs reexamine certain beliefs, for example that biomedicine is "right", "non-compliant" patients do not care about their health, traditional beliefs must be changed rather than built upon, that all it takes is education, and failure to adhere is the patient's fault. CGs in the current study suggested teaching that includes practice in label reading, trips to the grocery store, and exchange of recipes and strategies to make foods more palatable. Jones would add to this respect for the symbolism of food and concerted efforts by just institutions to decrease sodium intake in the general population. Tripp-

Reimer et al. (2001)would add consideration of cultural background, acceptable modifications of traditional foods and traditions related to eating in the social context.

(3) The financial impact of AHF on society in general is well known (see Chapter 1). Retired CGs listed the cost of medications and home care as most limiting in their lives (Hupcey, Fenstermacher, Kitko, & Fogg, 2011) but felt generally well-covered for acute and chronic care by Medicare and/or additional third party payors. This is consistent with the lack of description of financial burden among CGs in other qualitative studies (see Chapter 2) and in more recent studies of older CGs (Piamjariyakul, Smith, Werkowitch, & Elyachar, in press). However, the youngest CG who was still working experienced much anxiety over her own and her CR's financial health. This is reflected in other studies which include younger or non-spousal CGs, or CGs with known low socioeconomic status (Dracup et al., 2004; Hwang, Fleischmann, Howie-Esquivel, Stotts, & Dracup, 2011). From a perspective of just institutions, Ricoeur debates the need of just allocation of scarce resources within the healthcare system against the needs of the individual. While more research is needed to determine the impact of healthcare reform on AHF care, if any, it is clear that CGs are instrumental collaborators in reducing healthcare costs by minimizing acute healthcare costs through symptom interpretation and supporting adherence at home (Piamjariyakul, Smith, Werkowitch, & Elyachar, in press). Reflections on the final three burdens of fighting depression, symptom interpretation and communication are described in detail in questions 2 and 3 and summarized here.

(4) Fighting depression in the CR and themselves was described as a significant burden in reflections under Question 2. Summarizing reflections within the literature, fighting depression is especially challenging for female CGs and may be one of the hardest tasks in AHF caregiving. Despite the high prevalence of depression among CRs there is under-recognition and undertreatment concurrent with a resistance to taking antidepressants, which is illuminated among participants in this study.

(5) Findings for the burden of SI constituted an entire theme with four subthemes discussed in detail in Question 2. Summarizing reflections within the current literature show SI as performed by CGs to be *invisible care* and providing a source of knowledge that is outside and in addition to clinical findings for AHF. CGs displayed vigilance around the clock which in addition to typical vigilance behaviors described in Alzheimer's disease also included CGs desire to have the CR and HCP collaborate in symptom interpretation and management, always having to learn more about the evolving disease and complex treatment regimen, and living with the unpredictability of the disease on a daily basis. There is increased vigilance after discharge and with use of home telemonitoring. CGs experience self-doubt with more frequent ED visits. Their attempts to facilitate adherence may introduce conflict into the CG-CR relationship, yet they recognize themselves to be first-responders and link to HCPs when there is a worsening of symptoms. CGs recognize their CRs' lack of participation in SI which may be due to cognitive impairment or CRs' desire to protect the CG from their own suffering. Specific needs for HCP guidance were identified.

CGs felt at the mercy of the disease and its medical management which was reflected in their metaphors and rings true with chronic sorrow left unacknowledged. They are not guided to understand the disease trajectory of AHF and are too involved in the daily tasks of caregiving to recognize steady decline.

(6) Communication, described in Question 3, was experienced as burdensome in epistemological terms of learning about AHF, communication techniques, and in pursuing the ethical intention for caregiving. Epistemologically, CGs are *running into obstacles when trying to obtain meaning*. Barriers are due to the uncertainty of the disease itself, related to characteristics of the CR, and inherent to specialist care as well as limited HCP time and resources. In *meeting the needs for a multitude of meanings while meandering in a maze of conflicting or missing information* CGs identify information needs depending on whether the CR is medically stable as opposed being

acutely ill. CGs need to corroborate, supplement or correct the CR's story which is often experienced as being intrusive or unwelcome. Making decisions for the CR is burdensome, and balancing messages of hope against their own intuition and fears leaves them in turmoil. CGs identified communication needs which were consistent with recommendations in the AHF palliative care literature. Findings in *Using your words to get things done*, resonated with burdened communication techniques in the CG-CR relationship, communication with HCPs, and difficulties incorporating values and preferences into care conversations.

In order to cope with identified burdens, CGs needed *to stay connected to the web of society and rally practical support to not feel alone and set aside*. The need for social support for CGs is well described in qualitative studies of the HF CG experience (Kang, Li, & Nolan, 2011). This study contributes insight into the delicate negotiations of respect and dignity necessary to involve family and formal CGs in practical support and formal settings of care.

All CGs experienced a loss of activities, those pursued on their own as well as those shared with the CR before AHF and they described strategies to prevent becoming socially isolated. They described how small their world had become and the effort it took to keep it from collapsing all together. This resonated with themes of *A Shrinking Life*, *Forced to Take Responsibility*, and *Struggling to Keep Going* as described by Öhman and Söderberg in their phenomenology of close relatives living with persons with various chronic illnesses in Sweden (Öhman & Söderberg, 2004). CGs experienced a reduced sense of individual freedom and an increased sense of responsibility for their CR. They had to struggle to manage their duty and relied on an inner sense of community and solidarity.

More recently, ten CGs of stroke patients in Canada listed reasons for engaging in fewer pleasurable activities as not having the time, being too tired, not wanting to leave their CR and being too busy with various clinical appointments for their CRs. Activities had to be either purposeful or therapeutic and were focused on the CR. It was difficult to maintain the usual activities because they had lost their meaning without the CR's participation, or they felt guilty enjoying them without the CR. They welcomed permission from the CR or other family members to "escape" occasionally. In regard to exercising and seeking out physical activities for themselves, these CGs of stroke patients preferred physical activities they could share with their CRs, for example to attend rehabilitation together (Cao et al., 2010). This points to the possibility and potential benefits of having joint physical rehabilitation as experienced by one CG in the current study.

The final subtheme of *being a partner in the healthcare network vs. feeling disallowed and discounted* more specifically described how interactions with HCPs and home healthcare providers either increased or decreased CGs perceived control in the caregiving situation. CGs needed to have their experience and capacity to act validated and affirmed. While this seemed to generally occur with home healthcare providers and in times of crisis in the hospital setting CGs pointed out occasions when HCPs were inaccessible, CGs felt excluded from conversations or could not find appropriate providers to meet their CRs' special needs. The fact that there are not enough male nurses or that home healthcare in less reimbursable needs to be addressed within the context of just institutions.

CGs particularly suffered from a lack of coordinated care that acknowledged the complex illness manifestations of their CRs including those not related to AHF and they felt that they needed "to play the game" in order to get their needs met. In a review of 1,259 patients suffering from coronary heart disease (CHD) indexed in the National Health and Nutrition Examination Survey from 1999-2004, Boyd et al. (C. M. Boyd et al., 2011) found three-quarters of adults with CHD suffering from at least one additional clinical or health status factor contributing to complexity of care, and as prevalent and sometimes more strongly associated with hospitalization than CHD itself. They suggested that strict adherence to chronic disease domain practice guidelines directed solely at CHD may be associated with harm. More research that includes older populations with multiple comorbidities is necessary to develop guidelines which would allow HCPs to prioritize treatment not only according to factors related to the chronic disease domain of HF but more inclusively to clinical factors (for example, more than four medications, urinary incontinence and use of blood thinners), and health status factors (for example, cognitive impairment, mobility difficulty, various sensory impairments and mental distress).

Question 2: How caregivers explain and understand symptoms of AHF

Figuring out this new shape in the illness landscape

Most participants had lived with their CRs more or less comfortably in terrain defined by landmarks of chronic illness such as obesity, diabetes, lung disease, or even cancer, when over time they saw themselves being inexorably moved towards the towering shape of AHF which began to cast its shadow over their entire illness landscape. Living in the shadow of AHF cast a different light on how they had understood illness so far, challenged them to see things new and different and required them to act in unfamiliar ways. Participants *felt threatened by the term heart failure* because it named their journey as one with a dead end. They preferred to *define the meaning of AHF* as a disease of too much fluid rather than a weakness of the heart muscle, as if finding solace in the image of a river of symptoms flowing beside them, sometimes rising over its shores but always returning to its riverbed. Constantly watching the river, they were *being affected by the symptoms of AHF*. They worried, and were ready to pull back their CR from the reach of the river, yet they often felt helpless. *CGs were disturbed how AHF was changing the CR* on their shadowy path along the river and they had to *multitask to manage the multiple manifestations of the entire illness experience* as they tried to incorporate additional weight into their already heavy pack of comorbid illness.

Participants *felt threatened by the term heart failure* as a diagnosis and I have encountered this among CRs and CGs in clinical practice on a regular basis; however the implications of feeling disconnected from your own diagnosis in HF have not been described in the literature. Summarizing findings from a precursory search of the internet for the symbolic meaning of the heart show that throughout human history, the heart has been perceived to be the seat of good and evil, thought, reason, emotion, courage and love, or the soul in general. Dissociated from the anatomical function of the heart as muscle, having a "broken" heart would make it difficult to "open your heart" or "give your heart" and would lead to lack of joy, directing a person to deal with issues of anger and loneliness, not love, instead. These popular perceptions of the heart have not been explored scientifically but may speak to CG and CR's feelings of depression or anxiety in terms of lacking courage or hope for the good, or the fear of losing your soul and ceasing to exist all together. Exploring such generally unexpressed perceptions of the heart in EOL conversations could add more depth to palliative care conversations and eliciting goals of care for CGs and CRs in AHF.

In *defining the meaning of AHF,* CGs observed the "can't do, can't walk, and relying on others" as described by Horne & Payne (2004). They defined HF to be a condition of too much fluid rather than a weak pump to manage the fluid. Participants spoke in medical terms in order to explain that while their CRs' *had* AHF as a chronic condition (walking along the river), they were only at risk for death when they were *in* AHF acutely (drowning in the river). CGs recognized and were therefore most concerned about the symptoms related to fluid retention. The fact that CGs had only a vague understanding of AHF pathophysiology but were well-informed of the effects of symptoms on their CRs was found elsewhere (Clark et al., 2008). CGs mentioned the same symptoms described by Imes et al. (2011), specifically breathlessness, lack of energy and fatigue.

In *being affected by the symptoms of AHF*, participants observed shortness of breath which was scary, left CGs feeling helpless and was a strong impetus to seek medical help. Gysels (2009) studying CGs of patients with COPD, HF , motor neuron disease or cancer who suffered from breathlessness found that such breathlessness chronically affected CRs' ability to function, became worse at times and was the most difficult symptom to manage. CRs tended to panic, and could not take advice for self-help strategies; this strained the CG-CR relationship. CGs were ill-prepared to deal with breathlessness and had to learn through experience when chronic breathlessness turned into an acute exacerbation requiring medical help. There is currently not enough evidence to support oxygen therapy for breathlessness in AHF unless there is documented desaturation(Cranston, Crockett, & Currow, 2008). It is not clear why some CRs in this study were on home oxygen, however, it did make CGs feel better to be able to offer their CRs oxygen. CRs did not receive opioids for relief of breathlessness and did not perceive their CPAP masks to be interventions for breathlessness except at night, for sleep apnea. A controlled double-blind cross-over study of two opioids and a placebo showed decrease in breathlessness in all three arms of the study. While no more effective than placebo, the opioids were well tolerated in these AHF patients. Use of CPAP in AHF, especially in an acute exacerbation in the prehospital setting was found beneficial in a retrospective review of pre-hospital documentation of emergent AHF admissions. Of the 387 AHF participants, 38.5 % used CPAP prior to coming to the hospital and had significantly higher SaO(2), and lower blood pressure, heart and respiratory rates. The *American College of Chest Physicians Consensus Statement on the Management of Dyspnea in Patients with Advanced Lung or Heart Disease* (2010) recommends regular assessment of breathlessness, oxygen therapy if there is documented hypoxemia; pursed lip breathing, relaxation therapy, and CPAP. Supervised administration of opioids was recommended in conjunction with EOL conversations only.

Decreased activity tolerance and constant fatigue was attributed to AHF, side effects of medications or a natural part of aging, and recognized as the primary limiting factor for continuing life as it was. CGs empathized with daytime fatigue but suffered with their CRs from interrupted night time sleep as described in a study by Brostroem (2001). Similar to Brostroem's findings, none of the CGs in this current study had mentioned their own sleep deprivation to their CR's HCP which was consistent with their statements that they would not expect to share their own health problems and CG burden-related issues with their CR's HCP.

CGs recognized intermittent cognitive impairment (CI), mostly labeled as memory loss. They saw how it affected self care negatively and it made them more vigilant as a consequence. As summarized by Gaviria (2011) more is becoming known about CI in AHF, and its effects on, for example, attention, and executive function which impair the individual's ability to plan, engage in abstract thinking, be aware of context and show appropriate restraint in social situations. The intermittent nature of CI due to transient hypoperfusion or overstimulation of the sympathetic nervous system requires CGs to balance respect and esteem as they shift between self care and shared care. CGs were concerned that HCPs frequently did not appreciate the extent of the CR's cognitive deficits. Recognizing CI is especially challenging in individuals with preserved attention and language abilities, and social skills to mask symptoms of CI. While they may appear more capable than they are, they may not be competent to make important treatment or life decisions (Gaviria, Pliskin, & Kney, 2011). A phenomenology conducted by Sloan & Pressler (2009) with 12 participants who had all scored low in neuropsychological tests illustrated some participants' unawareness of their deficits. Those who were aware attributed it to always having had a poor memory, normal aging, or AHF. These participants made recommended accommodations to maintain self or shared care and did not see themselves as being different people. However, they did perceive themselves to be more vulnerable, as if in a land they had never visited before. Because they were unable to meet many of their previous responsibilities due to functional decline they felt old, useless and embarrassed and had to *re-cognize* their cognitive, physical and social vulnerability. They especially wanted to hide CI from their family members. They found that CI made it difficult to explain their symptom experience when they were in acute physical distress. Despite their CI, these participants *re-cognized* their nearness to death, saying they needed to reconcile with it each in their own way, every day.

CGs struggled in fighting the CRs' feelings of depression, and their own. CGs found logical explanations for depression in CRs' loss of function, feeling like a burden, or even the dreary weather, and they tried to combat it by infusing the lives of their CRs with purpose and value. They were not convinced that anti-depressants were the answer because they seemed to make the CR drowsier when he/she was already sleeping most of the day. While depression is described to contribute to burden especially for female CGs (Hwang, Luttik, Dracup, & Jaarsma, 2010; Janssen, Spruit, Wouters, & Schols, in press) and to be one of the most difficult tasks of AHF caregiving (Bakas, Pressler, Johnson, Nauser, & Shaneyfelt, 2006), the two male CGs certainly gave moving accounts of how they, too, had to fight depression in their CRs and themselves. The mutual effects of depression and HF are not fully understood. Summarizing evidence on the association between AHF and depression, it has been hypothesized that functional losses, psychosocial stress and a chronic sense of fatigue due to HF may induce depression, which in turn exacerbates HF due to increased sympathetic nervous system activity and higher levels of inflammatory markers. At a prevalence of 13-77.5 % in HF patients, depression increases mortality yet HF patients are inadequately treated for depression (Artinian, Artinian, & Saunders, 2004). Participants in this study illuminate how symptoms of depression may not be recognized and reported, and as was the case with one CR, even if reported will not be treated by their HCP. Deliberate education of the

CR and CG, and perhaps even HCPs is necessary when depression is suspected. Treatment options include pharmacologic and non-pharmacologic strategies (Artinian, Artinian, & Saunders, 2004).

Some CRs were on antianxiety medication, but only the CR who had suffered a life-long anxiety disorder actually seemed to benefit from it. Anxiety has a prevalence of 18-63% among HF patients and was linked to physical decline and increased rates of hospitalization over a six-month period; however, more research is needed to explain the underlying physiological mechanisms of anxiety and their effect on HF (Shen et al., 2011).

It was disturbing for CGs to see how AHF had changed the care recipient: Along with depression, CGs saw personality changes including self-centeredness, restlessness and anxiety, which they attributed to the CR's awareness of limited time left, the interference of the disease in accomplishing daily or life goals, or the need to *re-cognize* themselves socially, physically and in nearness to death (Sloan & Pressler, 2009). Such *person loss* was also described by CGs in the Gysels (2009) study. These CGs felt that the CRs' personality changes threatened the CR-CG relationship and CG motivation for caring. Pressler et al. found that CGs found managing patient behaviors was a most difficult caregiving task (2009). CGs did not feel equipped to address these changes with their CRs, but would have appreciated HCP guidance to understand and support their CR.

CGs had to multitask to manage the many manifestations of the entire illness experience. They described numerous other symptoms observed in their CRs related to coexisting disease states and medication regimens. They acknowledged that it was difficult to discern which symptom was due to which disease process and they saw the same questioning modeled by CRs' HCPs. For example, breathlessness could be attributed to COPD, diminished lung capacity after lung cancer, a simple cold or the actual AHF. Drowsiness and irritability could be related to diabetes or fatigue or anxiety from AHF. Difficulties walking could be arthritis, weakness due to normal aging or lack of energy from AHF. CGs and CRs seemed to have a higher comfort level reacting to the chronic condition which they had dealt with the longest; for most this was diabetes. They recognized that some of the same health behaviors were required to manage multiple conditions. They felt they had to be most vigilant for symptoms of AHF because they were learning about the life-threatening nature of exacerbations. These findings coincide with a descriptive qualitative meta-analysis of three mixed methods studies (Vaughan Dickson, Buck, & Riegel, 2011). All of the 99 AHF patients had at least one comorbid condition with diabetes being the most common non-cardiac condition (36%). Participants reported dietary adherence, and monitoring, interpreting and differentiating symptoms to be most challenging. For example, when they were on both a weight loss and sodium restricted diet should they weigh once a day or once a week? When they felt tired, should they check their blood sugar or just assume that it was fatigue related to AHF? Was their ankle swelling due to arthritis or HF? These authors found that patients prioritized symptom management based on their experience with each condition, and the perceived threat of each condition. Fragmented specialty oriented disease management instructions forced patients to pick one self care behavior over another rather than developing strategies that served all their chronic needs more inclusively.

Other symptoms immediately affecting quality of life were not necessarily related to AHF: there was arthritis or fibromyalgia pain, nausea and vomiting or incontinence related to medications, or dementia. Only one CR experienced angina pain. This is consistent with the fact that cardiac pain is rare in AHF (Hunt et al., 2005). Six CRs experienced chronic musculoskeletal pain and CGs felt helpless in relieving this pain because non-steroidal antiinflammatories are contraindicated in AHF (Masoudi & Krumholz, 2003). One CG in particular reported that his CR was hesitant to use her prescribed “narcotics” for fear of addiction and wanted to save this resource for only the worst episodes of pain which generally occurred at night. Patient barriers to use of opioids among older persons are well known (American Geriatrics Society Panel on the

Pharmacological Management of Persistent Pain in Older Persons, 2009). A comprehensive treatment plan for palliation of pain should include the patient’s complete illness experience and offer appropriate pharmacological and non-pharmacological strategies for pain relief with ongoing assessment, evaluation and education tailored to CR and CG needs (Lorenz et al., 2008).

One CR suffered from serious nausea and vomiting most likely related to concurrent diabetes and renal disease. His CG felt hopeless in finding relief of this symptom, because there did not seem to be coordinated disease management between the various specialists caring for her CR. The multidimensional contributors to pain and treatment-related symptoms in AHF benefit from a comprehensive treatment approach for example with palliative care (Goodlin et al., 2004).

Urinary incontinence required 24-hour caregiving by three of the CGs in this small sample, was managed independently by two CRs and part of institutionalized care for one CR. CGs experienced a loss of dignity, sleep deprivation and an altered relationship with their CR due to caring for their incontinence. They tried to keep it hidden from extended family and friends, and they were frustrated or even angry when their efforts to maintain a regular toileting schedule failed. These findings coincide with family CGs’ perspective in a study by Hayder and Schnepp (2008). These German CGs focused their efforts on maintaining continence, struggled with CR-dependence due to incontinence, and experienced shame in caring for the incontinent CR. They too described that it altered the relationship and led to disappointment or anger when their efforts in maintaining continence failed. Urinary incontinence was a private concern and only shared with closest family members. They did not consider it a reason for institutionalization unless the incontinence was in combination with dementia.

Most CGs in the current study observed troubled continence after administration of diuretics. In a survey of 296 HF patients, 45% and 57% reported urinary incontinence and overactive bladder (OAB), respectively. OAB worsened with advancing disease, increasing depression and fatigue, and higher body mass index, but was not found to be associated with use of diuretics, gender or age (M. H. Palmer et al., 2009). A review of the evidence by Ekundayo (2009) focusing on OAB and use of diuretics in the elderly found that OAB is common in older patients especially in conjunction with use of loop-diuretics, and is associated with poor quality of life; however, more research is needed to understand this association. It is important to note that CGs took the liberty to titrate diuretic use against the need to remain continent (Clark et al., 2008), reversing the process they saw modeled by HCPs, who gave CGs and CRs the freedom to titrate diuretics against weight gain as needed. This illustrates the naturalistic decision-making process described by Riegel and Dickson (2008) whereby HF patients select self care behaviors based upon situational requirements. Such situation- and value-based decision making took on special significance when one CG expressed that she almost preferred her CR to die from AHF rather than enduring the indignities of end-stage dementia.

In conclusion, the prevalence of comorbidity in HF patients is well known. Supporting findings from this study with those from a sample of 1,259 subjects with coronary heart disease taken from the National Health and Nutrition Examination Survey (1999-2004), 56.7% had concurrent arthritis, 25.5% COPD, 24.8% diabetes mellitus, 48.5% urinary incontinence and 29.9% dementia (C. M. Boyd et al.). Differentiating between concordant (including any kind of vascular disease, diabetes and COPD) and discordant (including among others dementia, cataracts, depression and arthritis) comorbidities in a 5% random sample of CMS beneficiaries from the Chronic Conditions Warehouse data base, Ahluwalia et al. (2011) were able to show that the prevalence of concordant conditions decreased in the oldest old cohort, whereas the prevalence of discordant conditions increased. Within the five-year window of their study, 62.7% of the HF patients had died, presumably from a combination of AHF and concordant conditions. Survivors into the oldest cohort had instead developed discordant conditions such as dementia (39.6% as opposed to 9.9% in the young old). There is little evidence for pharmacological treatment in multiple, often competing disease states because evidence from RCTs on individual treatment strategies or pharmacological agents have excluded persons suffering from multiple chronic conditions. According to Masoudi and Krumholz (2003), research should focus on ideal dosing, and appropriate use of life-saving agents in HF patients with coexisting illness states. Findings from the current study would suggest that CGs and CRs are interested in research focusing on management of musculoskeletal pain, and more scientific or creative approaches to managing side effects of AHF treatment, particularly incontinence and nausea and vomiting as well as hypotensive episodes and fatigue.

Given multiple disease states, CGs needed guidance to coordinate or prioritize their caregiving efforts for example should they encourage rest and energy conservation or physical therapy, or socialization and getting out of the house. These considerations had significant impact on CG and CRs' quality of life.

Being afflicted with symptom interpretation

Participants were confronted with the need to act as guides and guardians in this strange new landscape as they walked along the river with their CRs. Being newcomers to the customs, rules and regulations of the AHF region themselves, they clearly stated that *being responsible for SI was burdensome and overwhelming*. They yearned to share their CRs' experience and to elicit their support in performing SI but *felt forlorn at the frontier of symptom interpretation*. CGs dutifully stopped in at well-lit stations with their CRs along their shadowed path to learn that they were going the right direction, get advice and encouragement. Whenever their CR was swept away by the river, they jumped in after them to be picked up by the rescue boat where they stood by as CRs underwent rituals of revival. There was not much they could do after surrendering their CR to the crew and they *felt caught in the mechanics of medical management*.

Findings for *being responsible for SI is burdensome and overwhelming* reflect invisible care which was described by Clark et al. as monitoring boundaries and risks including SI and energy management (2008). Clark's participants talked about using intuition, and constantly learning new manifestations of AHF in their CR which created a supplemental knowledge base to complement the clinical assessment performed by HCPs. Being available around-the-clock, responsible for keeping the CR safe and keeping up the CR's spirits was felt to be both a comfort and a strain (Brannstrom, Ekman, Boman, & Strandberg, 2007b). CGs' behavior resembled that of CGs in Alzheimer's disease where "vigilance" reflected CGs' continual oversight of their CRs' activities. Mahoney (2003) termed five characteristics of vigilance to be (1) watchful supervision, (2) protective intervening, (3) anticipating, (4) always on duty, and (5) being there. In the context of SI in this study about AHF caregiving, these five themes were additionally associated with the desire to have the CR and HCP collaborate in symptom interpretation and management, always having to learn more about the evolving disease and complex treatment regimen, and living with the unpredictability of the disease.

CGs reported increased vigilance after hospital discharge which replicates findings by Hupcey et al. (2011), and may have been necessary in view of shortened hospital stays, continuing aggressive interventions into the home setting (Braunschweig, Cowie, & Auricchio, 2011; Cowie et al., 2002) and increasing use of telemonitoring at home. While telehealth has shown improvements in patient outcomes, their impact on CGs is understudied (Polisena et al., 2010).

CGs felt responsible to prevent exacerbations, which is corroborated by a finding that the more often a patient had visited the ED, the less positive CGs felt about their role as CGs (Hwang, Fleischmann, Howie-Esquivel, Stotts, & Dracup, 2011). They struggled with guilt, helplessness, anger and doubt in trying to promote treatment adherence which in turn affected the CG-CR relationship (Hupcey, Fenstermacher, Kitko, & Fogg, 2011).

Finally, CGs recognized their role in encouraging the CR to seek medical help when they suspected an exacerbation (Clark et al., 2008).

CGs felt *forlorn at the frontier of symptom interpretationof the SI struggle* because they did not get enough information from their CRs about symptoms. As discussed earlier the fluctuating cognitive performance of CRs made it difficult for them to participate in SI (Gaviria, Pliskin, & Kney, 2011). This was incomprehensible to CGs who grew exasperated at their CRs' lack of guidance. CGs also felt that their CR wanted to minimize their own distress or protect the CG (Imes, Dougherty, Pyper, & Sullivan, 2011). CGs therefore particularly expressed the need for HCP guidance to manage breathlessness (Gysels & Higginson, 2009), understand the personality changes in their CRs (Gaviria, Pliskin, & Kney, 2011) and manage symptoms related to comorbidities and medication side effects (Goodlin, Wingate, Pressler, Teerlink, & Storey, 2008).

CGs understood much of AHF treatment to be a balancing act between not enough and too much, and good and bad effects of medications and interventions and as such *felt caught in the mechanics of medical management*. They had to make decisions every day, sometimes with serious consequences about life at all, and other times about quality of life. Little remains known in the literature about how CGs negotiate the numerous treatment "choices" of AHF care. Weller Moore (2002) describes a process of dissociation of self which happens as CGs try to survive the roller coaster of AHF disease progression. CGs in this current study described the grief and chronic sorrow which went unrecognized except by the one trusted friend or family member that most of them confided in.

Feeling at the mercy of the disease and its treatment is well expressed in CG stories and metaphors in the current study, and is a defining aspect of the essence of caregiving in AHF. CGs received little guidance in understanding the implications of exacerbations and resuscitation in connection to the disease trajectory of AHF (Hupcey, Fenstermacher, Kitko, & Fogg, 2011; J Penrod et al., 2009; J. Penrod, Hupcey, Baney, &

Loeb, 2011). While they clearly stated that each exacerbation took something from their CR, and were generally able to articulate at which point the CR would have lost all that defined quality of life in each individual case, they were too wrapped up in the daily struggle and routine of caregiving to recognize a precise point that demarcated loss of quality of life (Aldred, Gott, & Gariballa, 2005). HCPs did not offer an outside perspective acknowledging the burden of illness, treatment and caregiving to facilitate such insight and they did not present the option to switch to a discerning focus on palliative or hospice care. These findings illuminate how CGs are tasked with SI only towards continued aggressive care and not empowered to discuss comfort care for the CRs holistic illness experience anywhere along the course of the disease.

Trying to add color to a grey future

Continuing to labor in the shadow along the treacherous river of AHF, participants' view into the distance remained dim. They depicted *being in the dark about symptom progression and trying to light up a path for preparation, knowledge and acceptance* but reported being unsuccessful in this endeavor for many reasons. Forced to live in anxious uncertainty CGs focused their efforts on *looking for freedom from worries in hopes for the future*.

Current evidence for failure to discuss symptom progression in AHF was documented in Chapter 2. In this sample of CGs to end-stage AHF CRs, information needs for symptom progression and options for EOL care were high (Parker et al., 2007). Findings in the current study confirm that *being in the dark about symptom progression* provoked anxiety and questions in CGs and illuminated how questions about the future to HCPs were left unexplored and unexplained and any communication or teaching centered on managing current symptoms only. They were forced to take life one day at a time and to fully immerse themselves in the day-to-day caregiving situation (Eriksson & Svedlund, 2006). Living one day at a time was not a coping strategy but an imperative based on

HCPs' unwillingness to discuss the future. Even when there was an actual prognosis of being at the end of life, CGs were not guided to recognize care and treatment directed toward that end. This forced them to continue to care towards survival as opposed to preparing for dying and death (Harding et al., 2008) and denied them *to light up a path for preparation, knowledge and acceptance.* CGs were unable to make plans for their future, or even the day ahead, because medical management led them to believe that acute interventions could manage AHF for a long time to come and they needed to stand by at all times to identify exacerbations immediately (Barnes, Gott et al., 2006b). Their experience resonated with 'disruption, incoherence and reconciling' as described by Mahoney (2001). CGs were unprepared for the possibility of sudden death, and although two CRs had a DNR status they were not given advice on how to handle sudden death at home, which made it unreal to them that while sudden death could potentially be treated aggressively in the hospital there was very little chance of survival if it occurred in the out-of-hospital setting (Murray et al., 2002).

In *looking for freedom from worries in hopes for the future*, CG hopes for the future ranged from being intuitively correct (Aldred, Gott, & Gariballa, 2005) to being unrealistic (Cosgriff, Pisani, Bradley, O'Leary, & Fried, 2007). All CGs were aware of the unpredictability of the disease and their CRs' existential fragility every day, only one felt that she could forget about her caregiving role for days at a time. This is different from experiences of patients in less advanced stages of the illness who tended to think about their mortality only during exacerbations (Willems, Hak, Visser, & Van der Wal, 2004), and more consistent with patient experiences in advanced illness stages with concomitant cognitive impairment where patients reported to reconcile with mortality every day (Gaviria, Pliskin, & Kney, 2011). Yet, perhaps because CGs did not recognize the degree of deterioration in their patients in the day-to-day routine of caregiving (Aldred, Gott, & Gariballa, 2005), they were "hoping for the best" although they knew on some level that "the worst" would happen eventually (Selman et al., 2007). CGs hopes for the future in terms of symptom recognition, interpretation and management were grounded in the knowledge that AHF was there to stay as a chronic condition, even if their CR in one case believed he “was over it”. They did not expect improvement but hoped for medical stability (J Penrod et al., 2009), and they wanted relief of daily stress, specifically financial stress for their CRs, relief of non-AHF symptoms such as incontinence and arthritis, and relief of their own chronic state of anxiety or even depression. Because they were unable to anticipate the progression of symptoms in any detail, they were fearful of the future and how they would handle worsening of the CR’s condition. CGs focused their hopes on managing symptoms to achieve short-term goals instead, and used engagement coping skills ranging from humor, family visits, small outings and even the bright lights of the casino designed to add color to their otherwise grey days with meaning and quality of life.

Question 3: How caregivers use communication to explain and understand the caregiving situation

Communication is an important component in the experience of being an AHF CG and has not been described phenomenologically in the context of the current US medical model. This study sought to elicit the lived experience of communication from the CG perspective within the philosophical frame work of Paul Ricoeur, where communication is assumed to be a tool to achieve capacity to act toward being a CG in AHF and to fulfill the ethical intention in the role of caregiving.

Participants freely began by *Theme 1: Telling the story of AHF in your life* which was a chronological account of how AHF had emerged in the past, was shaping their present and sure to challenge their future. Their stories were enriched with tales of dramatic AHF action full of sudden sickness and salvation in the medical system, but they did not neglect to tell of important competing events unrelated to AHF which moved their lives. They ended by sharing their experiences with other people’s dying and death because they could not speak of that dreaded event for their own CR at first. In Theme 2, CGs talked about *the meaning of AHF in their lives* and how they tried to construct this meaning with other people. They found that in learning about AHF they needed to meet the needs for a multitude of meanings or get lost in a maze of conflicting or missing information. They encountered a variety of obstacles in their CRs and HCPs when trying to obtain meaning. In Theme 3, CGs described how *they used their words to get things done*. This entailed listening to their own voice and that of the CR. They elaborated on how good it felt to be listened to by friends and family when they articulated their own fears and worries. And they emphasized how they felt the difference in conversations with HCPs when they were either talked at or talked to. In the final Theme 4, they submitted themselves to the difficult task of spelling it out *and putting it all together to be the best caregiver to the end.* This entailed reluctantly recognizing a separate future for themselves and their CR. They articulated few intentions for themselves but continued to focus on sustaining the CR in his or her quest for happiness. This involved articulating the CR's intention for the preferred way to die. They hated thinking about relinquishing the CG role and likened NH placement to breaking up a marriage. After reflecting on the meaning of being a CG to their CR it became clear that they made various promises to stay true to in the future.

Telling the story of AHF in your life

This was considered to be an ontological question of who the CG knew him or herself to be in the role of CG and how CGs use communication to share their own world (Kvale, 1996). As described in the sixth study *The Self and Narrative Identity* of Ricoeur's *Oneself as Another* (1992), sequential chronicling of events constitutes the configurational dimension of the plot of a life story. Yet, the chronology was interrupted or enhanced by three episodic events. First, there were action chapters: accompanying the CR through AHF entailed multiple medical encounters, and crises and hospitalizations which were threatening on the existential level. Secondly, CGs described competing chapters of episodic (e.g. diagnosing dementia) or chronologic (e.g. recognizing your own aging) particulars of their lives which did not center around AHF but were necessary to understand their entire lived experience of being an AHF CG. According to Ricoeur the episodic events within the plot of the life story *prefigure* formal conditions for understanding, meaning they need to be *understood* in order for the life story to make sense. Dialectically, it is configuration, or the chronological sequence of events which *prefigures* the possibility to *explain* or construct the life story.

Building further on Ricoeur's hermeneutic philosophy, humans build life stories of *being-toward-death* not only from events of the past and presence, but they project into the future, a characteristic that leads to action and allows them to continue to develop their narrative identity. The third episodic element that came up in their story telling, not surprisingly, therefore dealt with other people's death and dying, or watching a movie about dying (*Steel Magnolias*). Such vicarious experience allowed CGs to share with me their understanding, expectations and fears for their CRs' dying and illuminated the origin of their ethical intention at the time of dying for their CRs (Begley, Glackin, & Henry, 2011; M. K. Kirkpatrick, Ford, & Castelloe, 1997).

In the context of patient-family centered care, Theme 1 supplies a knowledge base to the clinician which adds richness and direction to an individualized plan of care for the CG-CR dyad, addresses reciprocity and distributes the responsibility for decision making between the HCP, CG and CR in collaborative manner within a shared care model (Sebern & Riegel, 2009; Zambroski, 2008). *Incorporating AHF into the past, presence and future of their life story* showed that CGs understood the development of AHF in their patients on a fundamental basis, that they considered their involvement as CG as natural or elective, that AHF threatened their presence on a daily basis and that they had questions about AHF implications for their own and the CR's future in order to plan effectively and with the least amount of anxiety. *Reliving dramatic action chapters* illustrated their perspectives on exacerbations and how they were looking for guidance, affirmation and emotional support to see these events in the context of the illness trajectory. *Important stories are happening in competing chapters* vividly speak to important CG concerns about meeting the CG role while dealing with developments in the rest of their lives which might impact the CG role, most importantly the development of dementia in one CG and one CR. *The final chapter: knowing of other people's death*s clearly showed that CGs have experience with dying and death, have strong ideas about a good death and are not afraid to be invited into discussions about how they can be part of allowing for a good death.

Such insight gives guidance for HCPs on how to address barriers to palliative care in AHF as mentioned by Stuart (Stuart, 2007) in Chapter 2. (1) CGs believed HF to be a treatable disease only because it was approached so by HCPs, their experience of symptoms in their CR made them well aware that another outcome could be just as likely. (2) They felt that they had no choice but to accept aggressive interventions which put them at odds with their own intuition especially at the end of life, as illustrated by resuscitation in the driveway and a cookie swallow shortly before death. (3) CGs were not asking for certainty in prognosis, only for all possible prognoses. (4) As will be more apparent later, CGs had a good understanding of their CRs goals of care, preferred to do ACP with the CR and would have welcomed a discussion about ACP with HCPs. (5) To be discussed later as well, CGs recognized when there was failure to incorporate EOL care into their homes which was apparent in all three deaths that occurred during the study.

Learning about the meaning of AHF in your life

CGs did a great deal of communication toward the epistemological intention of learning and knowing about AHF (Kvale, 1996) which were expressed in three subthemes. (1) They had conversations with others to make sense of the AHF experience, observed other patients' illness progression and constantly tried to add to understanding of their own CR's illness in clinical encounters. (2) Whether aware or unaware of it, CGs voiced conflicting interpretations of their CRs' condition. (3) Finally, several barriers to learning became apparent.

Looking to others to help find meaning meant seeking out conversations with the CR and friends and family about their CG experience and worries for the future. CGs and CRs learned about disease progression from other HF patients in their circle of family or acquaintances (Piamjariyakul, Smith, Werkowitch, & Elyachar, 2011). The degree to which CGs could construct the story of living with AHF with their CRs was determined by their CRs' cognitive status, willingness to be involved in conversations of issues related to AHF, and the characteristics of communication patterns in their relationship. Consistent with recent findings of Imes et al. (2011), communication about AHF with the CR was a struggle. When conversations about the future and end of life were avoided it was stressful for the CG and affected some relationships negatively. However, when there was acknowledgment of symptoms and disease progression, it provided for more intimacy and a deepening of the partner relationship. CRs were felt not to participate in symptom interpretation, presumably because they wanted to protect their CG from the seriousness of the condition (Imes, Dougherty, Pyper, & Sullivan, 2011). Living in an altered relationship of *discordance*, where each partner was trying to protect the other from pain was also found among couples after myocardial infarction (Svedlund & Danielson, 2004).

CGs mentioned trusted friends or HCPs as communication partners. Such conversations required mutual understanding and respect as well as confidentiality. Talking to others has been found helpful in qualitative studies describing the AHF caregiving experience (Kang, Li, & Nolan, 2011). Most CGs did not want to burden family members indiscriminately with communication of their own worries (Hupcey, Fenstermacher, Kitko, & Fogg, 2011).

Participants described *running into obstacles when trying to obtain meaning*. Harding (2008) named barriers in obtaining information in HF to be related to the uncertainties and unknowns of the disease itself which was exemplified by CGs inability to get answers to managing non-AHF symptoms of incontinence, a rash or obesity; related to the CR, as with cognitive impairment, or unwillingness or inability to collaborate with the CG; related to specialist care which failed to incorporate all the components of each CR's complex illness presentation; and finally, related to staff time and resources which spoke to some CGs' feelings that HCPs were inaccessible, especially during times of medical instability at home. CGs also mentioned examples when they were unable to assert their own practical or emotional needs with their CRs. HCP inaccessibility and wishing to discuss psychosocial issues with their HCP were two palliative care needs expressed by participants in Hupcey et al.'s study (2011)

HCPs were the primary source to help CGs *meet the needs for a multitude of meanings vs. meandering in a maze of conflicting or missing information.* While one participant mostly needed emotional support, others had very specific information needs such as disease progression, explanations of current treatment plans, and managing symptoms unrelated to AHF. This is consistent with findings of information needs during times of exacerbation and medical stability as identified by Hupcey et al. (2011) including information for future planning and ADs, treatment options and information for daily caregiving decisions. CGs also often felt the need to correct the CR's story when it was factually untrue and had implications for decision making (Gaviria, Pliskin, & Kney, 2011). Most CGs felt such intervening was not welcomed by their CGs but they took it upon them to protect the CR as described by (Sloan & Pressler, 2009). Because they felt to be holding significant knowledge about CRs' illness experience it helped to partner with HCPs in constructing meaning and a treatment plan which is consistent with patient-family centered care (Cahill, 1996; Gallant, Beaulieu, & Carnevale, 2002) and a cornerstone of dyadic shared care interventions (Sebern & Woda, 2011).

This subtheme illuminated the many conflicting messages CGs heard when their CR was in the care of multiple providers. It was worrisome to them and left them wondering about the general treatment plan. They clung to well-intentioned assurances of hope, readily subjugating their own intuition and fears to the offered expert promises. This mirrors findings from Selman et al. (2007) whose eleven CGs in a sample in the UK experienced the same lack of knowledge about disease progression and treatment options beyond aggressive care and who hoped that it would get better but knew in their heart of hearts that it wouldn't.

Recommendations for a support group for AHF CGs given by one participant were interesting in that they addressed information and learning needs in all the areas suggested by Hupcey et al. and consistent with needs identified in a group of AHF patients in and their CGs in palliative care with David Bekelman (2011). In this latest study of a palliative care intervention for 50 end-stage HF patients, CGs received facilitated communication with their CR in outpatient palliative care for AHF. Topics most addressed were care coordination, ACP, and psychosocial issues. The recommendation was to accompany standard HF care with palliative care at all stages of the disease, facilitated by a dedicated HF-RN and social worker.

Further exploring the need for dyadic collaboration, the inherent potential for conflict in the relationship, and the importance of mood, depressive symptoms and negative well-being due to failed collaboration, Sebern and Woda (2011) developed the Shared Care Dyadic Intervention (SCDI), built on Riegels‘s work in self care and shared care in HF (Riegel et al., 2009). SCDI was designed to enhance shared and self care in HF, CG preparedness, dyadic relationship quality and CG and CR health status and incorporated communication, decision making and reciprocity as shaped in the context of each dyadic relationship. Eleven dyads with HF participated in a twelve-week intervention delivered face-to-face in joint and separate sessions in CG-CRs' homes. Topics included understanding self-care in HF with an introduction of communication and reciprocity skills; taking care of yourself and each other, including an assessment of pleasant activities and barriers to these; how to respond in emergency situations; and incorporating decision making and reciprocity in the context of care values and preferences. Based on mutually defined values and preferences, CGs and CRs developed plans for the future utilizing formal and informal resources in caregiving in the web of society. Outcomes of the intervention in this feasibility study showed high satisfaction for CGs and, probably related to cognitive fluctuations, some confusion and failure to remember for CRs. CGs learned how the patient thought and needed to feel useful; and they learned how to improve their own health, communicate with HCPs, and manage anxiety and depression for the dyad.

Similarly, acknowledging the need for not only managing the disease but also psychosocial and marital issues, a nurse-led Community Case Management program in a home-based setting in Idaho emphasized *presence* as an intervention through the entire course of HF. This involved authentic, committed, long-term relationships between ARNPs and their patients. The focus was on evidence-based management of the disease as well as narrative-based management of the entire illness experience. The ARNPs provided coordinated care, targeted education, emotional support, advocacy and personalized interventions for CGs and CRs. Their most asked for interventions were education, supervision of adherence and therapeutic presence (Anderson, 2007). ARNP-led outpatient management of HF has shown to decrease unplanned hospitalizations and associated costs (Naylor et al., 2004; Rich, 2003). More research is needed how such care models affect patient-family-centered outcomes, utilization and cost.

Using your words to get things done

This theme with four subthemes describes how CGs used and encountered communication as a technique to achieve various purposes (Kvale, 1996). CGs found that communication served therapeutic and relationship-building purposes or to achieve the goals of CGs, CRs or HCPs.

By *letting yourself talk*, CGs told how they expressed their emotions, to cope with frustration, burden, grief and even anger and illustrated one of the engagement coping skills described earlier (Garcia-Alberca et al., 2011). *Talking with the care recipient in long established patterns* was more complex and individualized for each couple, but generally geared towards boosting the CR's self esteem, mood or adherence. CGs pointed out traps in communication, or the emotional effort of such communication which might benefit from counseling interventions or a support group as described above. Importantly, some CGs said that words were not always necessary to achieve a therapeutic connection within the couple. Some things were felt without needing to be expressed, practically merging the two partners into one. Such strong connections could be seen as a gift to any HCP, knowing that if he can heal one partner he has healed both. Regardless of marital communication patterns, the CG-CR dyad should be treated as one (Saunders, 2003) and marital quality must be taken in consideration given findings by Coyne et al. (2001) which linked marital quality and 4-year survival in AHF.

Being listened to in conversations with friends and family was an opportunity for CGs to share emotions and find encouragement. Social support and involvement with children, friends, neighbors and nurses was found to have a positive effect on caregiving (Martensson, Dracup, & Fridlund, 2001) and CG health and esteem independent of CRs' severity of illness or number of comorbid conditions(Hwang, Fleischmann, Howie-Esquivel, Stotts, & Dracup, 2011).

HCP communication styles were examined critically by CGs in the subtheme *being talked at or talked to by healthcare providers*. It was important that HCPs use language at the level of the CG's understanding, included the CG in conversations, paid attention to their concerns, provided information in a clear, consistent and timely manner, provided a trusted presence and had an understanding of the entire illness experience not just the heart. Information needs varied according to whether the CR was medically stable, unstable or even dying which was consistent with findings of communication needs in the study by Hupcey et al. (2011). Having a trusting relationship with the HCP allowed CGs to approach difficult topics, just as they expected that the HCP would in turn address difficult topics, such as EOL preparation with them. The fact that CGs expect HCPs to initiate ACP is found elsewhere (Harding et al., 2008).

Putting all the pieces together to be the best caregiver to the end

This fourth theme is directly derived from Fredericksson and Ericksson who added the dimension of communication as “something good” (Fredriksson & Eriksson, 2003, p. 139) toward Ricoeur’s ethical intention to seek happiness with and for others in just institutions. Participants enunciated four subthemes. First, they *reluctantly recognized a separate future* for themselves. Second, they were committed to *sustaining the CR in his/her quest for happiness*. Third, they took this opportunity to discuss NH placement and *likened contemplating other settings of care to breaking up a marriage*. Fourth and last, they found strength in *making a promise* of what they would do to continue caregiving.

Participants had a clear sense of their own needs for happiness although they *reluctantly recognized a separate future from their CR*. Most importantly they were aware of the need to take care of their own health, or financial security. This recalls their need to restore their own dignity and respect and their perceptions of CG burdens as discussed earlier under Question 1. However, they took no active steps toward those goals for the time being, as if their ethical intention for happiness was suspended, for the future, not the presence.

The presence held thwarted ethical intentions: inability to relieve the CR’s suffering and frustrations with adherence and CR’s self destructive behaviors. They felt trapped momentarily and needed to work through the ethical intentions that could never be, like a long and joyful retirement with the CR. Two CGs were able to assert their own intentions in the midst of caregiving, but perhaps coincidentally, both of them felt less invited into caregiving by their CRs. Some CRs were ready to voice their wishes for a good death for their CR: it should be quick and pain-free, preferably while the CR was asleep. Participants wanted to be the best CGs they could be. The two who felt like intruders into their CRs self cares clearly suffered from feeling like outsiders. All CGs wanted to have no regrets over their caregiving role in the future. Four of them also expressed that they did not want to become a burden to others in the future, when it was their turn to become infirm. This echoes comments of CGs of Alzheimer's disease patients (Bursch & Butcher, 2009).

In *sustaining the CR in his/her quest for happiness* CGs observed their CRs' behaviors and found them to make choices between happiness and adherence, as in a candy bar against euglycemia. They saw CRs bargaining for salty food, trying to avoid clinical encounters and trying to come home. CGs trusted their CRs with these decisions out of respect, well aware of the consequences and how it might cause either distress or happiness for both the CG and CR. Based on these observations, CGs were able to articulate their CRs' ethical intentions in a way that was consistent with choices for life and death. Such insight into the other's intention became important for those CGs who had to make decisions for the other when the other was incapable. Discussing each other's ethical intentions is an important component of facilitated ACP to allow for dying that is consistent with the life that was lived (L. Briggs, 2004).

Nursing home placement inserted itself into the discussion of future caregiving intentions. Participants felt they were *breaking up a marriage by contemplating other settings of care*. They considered it a last resort and only after all their own caregiving resources were exhausted, or the CR would be cognitively unaware of the transfer. CGs saw NH placement as a family decision and most preferably agreed upon in advance by the CR him/herself. Aside from the youngest CG, all other CGs and their families had discussed what to do when the CG was to become unable to continue in the role. They did not think caregiving could be transferred to any other family member if the spouse CG should become infirm.

Considering their own CRs' intentions for happiness and the good life, CGs answered the call of the other as expressed by Ricoeur as "where are you?" in *making a promise*. When they answered "here I am and this is what I stand for", they framed their promise within the parameters of AHF and their CRs entire illness experience as well as the marital relationship and commitment. CGs planned to keep on being a CG to the best of their ability, to accompany the CR through all the stages of the disease and to keep life as normal as possible at each stage. This was consistent with Penrod's findings in EOL caregiving trajectories where CGs sensed a disruption in the CR's steady state and made adjustments *to establish a new normal* state (J. Penrod, Hupcey, Shipley, Loeb, & Baney, 2011). CGs had *to challenge the normal* frequently as the CR's condition declined but they were often unaware of insidious decline because they were so immersed in accommodating day-to-day. AHF CGs were especially challenged *to build a new normal* in the last few days or hours before death when suddenly and often surprisingly all other options were exhausted. According to their studies on the trajectory of dying for AHF patients, CGs were often shocked at the suddenness of transition to dying (J. Penrod, Hupcey, Baney, & Loeb, 2011). Such insight into the CG role at the end of life is necessary to help CGs keep their promise, prevent feelings of abandonment and to continue to offer palliative care to them and their CR.

Question 4: How appropriation of symptom interpretation and communication shape caregivers' ethical intention for advocacy and making treatment choices over time

This final question offers a view over time regarding SI and communication as expressions of CGs ethical intentions for caregiving, and more specifically, how they related to their needs for ACP. ACP involves conversations about preferences, values and contingencies for EOL care, and naming a primary and alternate healthcare agent (HCA). Ideally, a document is created which captures a person's wishes; however, it is the conversations with the HCA and HCP which are crucial to successful ACP. Any document created remains dynamic and needs to be reviewed periodically as a person's healthcare needs change. Such a process has been found successful in articulating patient preferences and improving HCAs' understanding of patient wishes in a study by Kirchhoff et al. (2010) in disease-specific EOL planning for a population of 313 patients with endstage renal disease and AHF and their HCAs. The study showed the importance of a trained facilitator for such conversations as well as correcting patients' misperceptions about the success of certain medical interventions such as the benefits of CPR in older people with multiple chronic illnesses. Study participants were highly satisfied with the quality of communication, dispelling the fear that such conversations were unwelcome or stressful.

American Heart Association consensus guidelines (Hunt et al., 2009) endorse ACP in the AHF population, including a discussion of all possible outcomes and their treatment modalities including palliative care, and the usual disease trajectory in HF (Goodlin, Quill, & Arnold, 2008). None of the CGs and their CRs encountered such conversations but experienced the standard American Bar Association process for documentation of ADs and LWs only.

Being filled with trepidation at the thought of the care recipient's return home

Interview #1 occurred after hospital discharge for all but one CG. CGs *expressed fear about another bad event occurring and being unsure what the right response should be*. Their fears were based on their experience that exacerbations were going to happen again, and that they could be fatal. Such fear was described by Barnes et al. (2006a), was partially remediated by discharge teaching geared toward increasing perceived control in the CG (Bull, Hansen, & Gross, 2000a) and addressed their question of *wondering what the new caregiving role will entail*. Receiving the CR back into the home setting was stressful. Consistent with findings elsewhere, during and after the hospitalization, quality of life was worse for CGs (Luttik, Jaarsma, Veeger, & van Veldhuisen, 2005), there was increased vigilant behavior (Hwang, Fleischmann, Howie-Esquivel, Stotts, & Dracup, 2011) and CGs tended to experience more illness (Hupcey, Fenstermacher, Kitko, & Fogg, 2011).

CGs still recoiled from having had to face mortality, were open to discussing these fears and were looking for guidance on how to cope with them. Unfortunately, the process they encountered was one of *going through the motions of completing AD/LW without really knowing what it means*. There were three prognosis discussions resulting in two DNR statuses, however, these discussions did not provide clarity for CGs on how they would impact care provided for the CR. Only one of the CGs experienced a semblance of discussion of the typical AHF trajectory but it failed to prepare her for how to respond to sudden death at the home. There was no discussion of turning off the ICD. One CG in particular, who was facing the imminent death of her spouse in the NH, needed preparation for how it would happen, a need that went unacknowledged. As is common for decision making at the end of life in AHF, three CRs were unable to participate in these discussions, leaving a certain amount of burden for the CG and family. The hospital experience initiated a family request for AD/LW papers which were sent to their home with great delay and not completed within the time frame of this study. The hospital experience also led a family to consult their lawyer to review estate papers and include the AD/LW provisions as a matter of course without discussions with the HCP. Clearly, hospitalization gave CGs realistic impressions of their CRs' fragility and a strong impetus to prepare for death now or in the future. Their actions showed ACP at the time of discharge to be a reasonable option and should be explored in further research.

Building confidence and trying for a new normal routine

Interview #2 occurred after most CRs had been home a while and CGs were *feeling relief over CR improvement.* One CG was still struggling most with her CRs depression in rehabilitation, and the other had just experienced her CR's death. Both of these CGs *had accepted their CR's decline* but while one of them saw gradual improvement with daily discussions of the CR's goals of care, the other *felt lacking control to direct care* for her dying CR and had no understanding what the plan of care was toward dying. His dying went seemingly unacknowledged by the HCPs she saw working around her. She clearly expressed a family value in wanting him to have a peaceful death with her holding his hand, right there in the NH. This value was constantly interrupted by rehabilitative activities and another trip to the hospital. She felt abandoned by his cardiology HCPs despite the daily phone call from the palliative care physician who she had met only once and who from the distance was unable to assist her tangibly. This feeling of abandonment has been described among patients who entered hospice care and is a common reason for them not to choose hospice care (Zambroski, 2004). The two CGs of the declining CRs illustrate opposing ends on the continua of perceived control, decision making-communication-reciprocity, and incorporation of patient-family values. Regardless of the fact that one CR died and the other lived, only the CG who experienced increased perceived control, was involved in decision making-communication-reciprocity and saw the CRs values and goals addressed, felt supported in the role of CG.

Most CGs at home were *feeling more confident with symptom interpretation* and were able to take decisive action when their CR looked decompensated. CGs described *following medical recommendations on a continuum from adherence to risk-taking* which was never incorporated into a discussion about CR goals and values in the outpatient setting. CGs frequently *recalled encouraging rhetoric from HCPs* in the hospital. They held on to memories of being involved in decision making-communication-reciprocity as if to reassure themselves and increase perceived control, yet in the realities of daily living with AHF at home nagging questions emerged and they were *unclear about how to act and what to expect* for the progression of the disease. They were not invited to address these questions in the outpatient setting.

ACP at this stage was described with the subtheme *knowing what you want but not knowing how it should affect the plans for care*. The one participant whose CR was still in rehabilitation did not know if the DNR status had transferred with him or if it even should have transferred. One step ahead, the CG of the CR who also suffered from dementia sought an out-of-hospital DNR status for her spouse because she was preparing to move to an ALF. She did not know if his ICD had been turned off and wondered if she should call 911 or the mortician in case of her CR's death. While it must be assumed that the dying CR's DNR status transferred to the NH it did not lead to palliative or hospice care for the CR. The examples of the rehabilitating, still defibrillating and dying CRs illustrate the difficulty of transferring hospital decisions into the community setting and the lack of palliative care provision (see Chapter 2). The dying CR's transfer to hospice care less than 24 hours before his death was unfortunately typical for AHF patients (Zambroski, Moser, Roser, Heo, & Chung, 2005).

Developing new strategies while wishing for more professional guidance

During Interview #3 most CGs were continuing to *learn about care for the CR at home*. One CR finally returned home from rehabilitation and his CG's adjustment to having him home again was made easier by the presence of home healthcare providers. She continued to have questions about his goals of care and quality of life but didn't feel she could address them with either home health or his HCP. Her degree of worrying about NH placement and her moving statement about the loss of sunshine in her home was a reflection of the CG burden she was experiencing despite outside support.

Interestingly, *adjusting to continued caregiver burden and CR symptoms,* most other CGs were also engaged in conversations about transitions in care. It was necessary to rally informal and formal practical support and to attempt self care. There were several moments of crisis when CGs *took decisive action vs. negotiating the proper course of action with the CR or HCP*. This subtheme illustrates the need for SI in combination with good communication grounded in respect for the CR and his/her capacity and competence as discussed earlier. It appeared that CGs and CRs needed to bestow upon each other perceived control for decisive action either openly (TC) or covertly (S). The CG with newly diagnosed dementia was very able to perform symptom interpretation yet he was relieved when his CR took over decisive action for herself. Capacity to respond to symptoms with decisive action is partly grounded in the continuum of friendship which shapes communication and negotiation about what to do with symptoms. HCPs need to identify issues of dignity and respect and ineffective communication to best support perceived control for decisive action within the CG-CR dyad.

Participants were worried about the unspokenness of all possible outcomes and tried to cope with it by *talking about ACP around the family table* with the CR and friends and family whenever they could. While such conversations were difficult they brought emotional relief and closeness (Lorenz et al., 2008).

Neither during the several ED visits and one hospitalization, nor the numerous outpatient visits were there any conversations about ACP or prognosis. CGs *felt more or less safe in the cocoon of HCP silence*. Participants revealed common assumptions about ACP: it should be initiated by their HCP, their HCP knew their wishes even if they never had a conversation about it and filling out standard AD/LW documents were sufficient to guide care at the end of life with AHF. CGs were aware of needing to select HCAs carefully to ensure that their wishes would be carried out. They were able to anticipate conflict in some situations but wished for HCP guidance to help clarify issues before they became a problem at the dying CR's bedside (L. Briggs, 2004). CGs never mentioned that they needed certainty in prognosis before they would consider doing ACP.

Coming to the end of the path vs. continuing to walk in the shadow with your eyes to the ground

The follow-up phone call occurred anywhere from two to eight months after interview #3 and found two CRs deceased and ongoing caregiving for three more CGs. Unfortunately the youngest CG did not follow up on invitations to participate in follow-up which was of concern, because she experienced the most anxiety and according to all findings was at greatest risk for decreased HRQL, social isolation and marital strain.

All bereaved CGs still *grieved and constructed a positive memory* around their CRs' deaths. Librarian had received expert support for the CR, herself and her family at the ALF through the presence of a nurse; there were no attempts at resuscitation in view of the well-communicated OOH-DNR status although one family member reflexively called 911 anyway. Oma on the other hand had never been prepared for what to do in case of sudden death and activated the emergency response team. Her son's belief that CR would recover like many times before illustrated how family members are unaware of the AHF patient's decline and do not recognize when symptoms of living with AHF turn to symptoms of dying from AHF. At the time of my call the CGs had reconnected socially, felt better physically and emotionally and had resumed some of their old activities. This is consistent with findings that while there is a 20% incidence of complicated grief in CGs of Alzheimer's disease patients, most CGs show resilience after the death of their CR with depression and grief returning to near normal levels within a year of the death (Schulz, Hebert, & Boerner, 2008). All three bereaved CGs chose to phrase their memories positively, as a story they could live with and tell with some authenticity.

The three remaining CGs described a theme *of being resigned to the permanence of AHF* in their lives. Their stories still sounded grey with ongoing attempts to insert color. Symptom experiences in their CRs had intensified although CGs did not report them in that manner. They all had plans for the near future. One plan, to wait for the arrival of a new grandchild required just *being*. The other two CGs wanted to travel, which required *doing* on the part of the CRs' and naturally these CGs were a little guarded about their prospects.

There had been no further prognosis or ACP discussions despite new symptoms and frequent clinic visits. CGs were *not knowing what to do with that which they feel certain about and that which you can't fathom*. TC was clearly not interested in ACP at the time even if it had been offered. Elmer may not have been cognitively able to desire such a conversation. And Smiley intuitively worried and took precautions in symptom interpretation but continued to keep a safe distance from all decision making functions.

There is consensus among HCPs that it is difficult in outpatient HF care to identify proper times for addressing prognosis and ACP, that CGs and CRs are reluctant to talk about these issues, and that it is more important to address biomedical issues. (Tung & North, 2009). This phenomenology has shown that CGs worry about prognosis and all possible treatment options, and wish for conversations about it. However this study did not elicit information from HCPs regarding what CGs and CRs actually expressed in clinic encounters. Content analysis of audiotaped HCP-patient interactions during routine clinic visits for 52 older HF patients seen at two VA Medical Centers yielded 25 patient-initiated statements inviting ACP. Twenty-one of these statements were not followed up and four statements actually led to ACP. In the 21 missed opportunities, physicians tended to deflect questions back to the biomedical aspects of the visit, denied or contradicted the patient's emotion or preference, hedged responses for requests for prognosis, or inadequately responded to the underlying emotion or need (Ahluwalia, Levin, Lorenz, & Gordon, 2011). These authors found that ignoring indirect patient requests for ACP or discussion of progression of symptoms may actually lengthen a clinic visit because patients made repeated attempts. IT was suggested that anytime a patient wanted to talk about the future constituted an invitation for ACP and discussion of symptom progression. Withholding information about the illness trajectory was not helpful in maintaining hope for CGs and CRs (Clayton et al., 2008; Hancock, Clayton et al., 2007a) whose path along the river was already shadowed. CGs in this study welcomed landmarks along the way and may have been better served by vague shapes in the future that would take on more clarity as they came nearer.

Appropriation

This study is the first phenomenological exploration of the lived experience of being a caregiver to a spouse with AHF in the US. Grounded in the Philosophy of Ethics by Paul Ricoeur, and using hermeneutic phenomenology to derive rich descriptive data from text, it reflects a mode of nursing science which recognizes health and life as a process of becoming among human beings who are in constant interaction with other humans and just institutions. Findings from this study provide philosophical underpinnings of respect, friendship, self-esteem, capacity to act and the ethical intention for much of what is known in the literature about AHF caregiving so far. The study adds to current theory guiding AHF care by giving voice to caregivers, who are instrumental in supporting the CR in outpatient management of AHF.

Nursing interventions can be seen within the context of the caregiver trajectory for AHF as described by Janice Penrod and her colleagues at Pennsylvania State University, PA. With a research program using qualitative methods such as concept analysis, ethnography, grounded theory, ethology, participatory action research and case studies designed to build theory and shape practice her team is striving for interventions which support the situational state of uncertainty as a characteristic of the AHF caregiving trajectory at the end of life. Given that uncertainty as a state of being cannot be “fixed”, and the CG experience is at least partially shaped by HCP behaviors, she argues that uncertainty must be supported through interventions specific to each phase of the caregiving trajectory (Janice Penrod, 2011). The caregiving trajectory in AHF parallels the course of the disease trajectory of gradual decline punctuated by acute, life-threatening exacerbations which can be treated aggressively returning the CR to a state of improved, same or slightly diminished function and ending with a gradual dwindling, or a sudden death anywhere from outside the hospital to inside an ICU. In accompanying the CR along the illness trajectory, CGs repeatedly confirm their suspicions of a change in health, challenge the change and try to establish a new normal until they acknowledge that the end of life is near. Being in a state of knowing that death is near may range from hours to months. During this either very short or lengthier time, CGs begin to build yet a new normal, this time in anticipation of losing the CR. This process is briefly interrupted by the actual loss of the CR and challenges CGs to reinvent their solitary new normal in bereavement (see figure 2). Penrod and her team argue that each new phase is an opportunity for interventions. CGs need to have more time acknowledging the end of life and building a new normal, reducing some aspects of CG uncertainty and offering HCP support in preparation for death (J. Penrod, Baney, Loeb, McGhan, & Shipley, 2012).

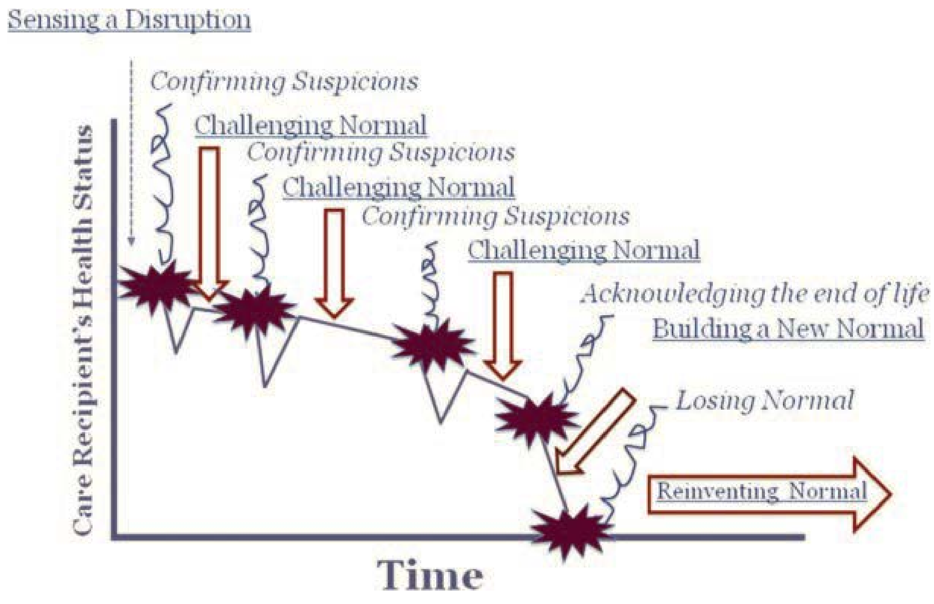


Figure 2. The unexpected end-of-life caregiving trajectory (J. Penrod, Hupcey, Baney, & Loeb, 2011)

Being fearfully vigilant, at the mercy of the disease and its treatment while worrying about that which remains unspoken illuminated how all CGs were aware of their CR's tenuous condition and suffered in anticipation of the loss, each in their own way. Yet, they had little opportunity for meaningful discussion of their CR's plan of care within that context with HCPs. It also became apparent how CGs keep their eyes to the ground, looking for symptoms threatening to make their CR stumble along the foggy river, which made it difficult for them to see what they had left behind or what was looming in the future. CGs described little perceived control, often felt excluded from communication and decision making and generally were not asked about their family values or preferences for care in the mechanics of AHF treatment regimens. CGs had made certain promises to their CRs but did not receive the necessary information from HCPs on whether or how they could keep each promise along the way.

Several opportunities for interdisciplinary interventions were identified. They are summarized according to similarities under the following headings: Shared Care Dyadic Intervention, Advance Care Planning, Palliative Care, and Support Group.

Shared Care Dyadic Intervention (SCDI)

SCDI (Sebern & Woda, 2011) was described earlier as an intervention directed at the theme of *meeting the needs for a multitude of meanings while meandering in a maze of conflicting or missing information*. The current study provided the phenomenological foundations for all elements of the intervention, highlighting the need for conversations about the role of CG and CR and associated communication skills with HCPs, the need for mutual care and respect, finding pleasurable activities and purpose shared between partners, how to respond to sudden death outside the hospital with or without a DNR status, planning for the changing healthcare needs of the CG and CR, and respecting reciprocity in the context of family values and preferences. CGs added the aspect of joint rehabilitation as a pleasurable, empowering and healthy purposeful activity for couples.

SCDI outcome measures for CGs included CG preparedness using a subscale from the Home Care Effectiveness Scale (Archbold et al., 1995); relationship quality/strain using the Dyadic Relationship Scale (Sebern & Whitlatch, 2007); CG health status using RAND SF-36 (Ware & Sherbourne, 1992); and anxiety and depression using the State-Trait Anxiety Scale (McDowell, 2006) and the Patient Health Questionnaire-9 (Cannon et al., 2007) respectively. Emergent care utilization was measured using CMS data. To assess how the intervention was received by CGs and CRs, the investigators used the Shared Care Instrument-3 which has three subscales for communication, decision making and reciprocity (Sebern, 2008). This intervention needs to be replicated and tested in larger and diverse populations.

Advance Care Planning (ACP)

Participants described how not knowing about symptom progression caused anxiety and left them unable to plan for the future. Living one day at a time was not a coping strategy but a way of life forced upon them by being kept in the dark about the future. The fact that CGs had realistic intuitions about the fragility of their CRs', were not looking for a certain prognosis for their CR, only all possible prognoses, and preferred to do EOL planning with their CR and family at times of medical stability opens the door for timely ACP and goals of care conversations and can relieve HCP of some of the fears and perceived barriers.

Nursing interventions that address a typical prognosis and disease trajectory can be tested for their effect on perceived control, anxiety and depression as well as CG and CRs' willingness to discuss goals of care and engage in meaningful ACP.

ACP is a communication intervention. One model of ACP in the form of a document of Iowa physician orders for sustaining treatment (IPOST) is currently being phased in as a state-funded initiative in the NH population and for persons with terminal illness and their families in Linn County. This particular intervention follows "Last Steps" of *Respecting Choices* designed by Hammes and Briggs (L. Briggs, 2004; L. A. Briggs, Kirchhoff, Hammes, Song, & Colvin, 2004) and practiced in LaCrosse, WI since the 1990s. In Johnson County, "First Steps" of the same model is being used under the name of *Honoring Your Wishes* and addressed at healthy adults, illustrating the ongoing nature of ACP conversations over the course of a lifetime. Research is needed how this model incorporates patient preferences for care at the EOL and how it affects CG/HCA satisfaction with care. Eventually, the effect on healthcare utilization and cost need to be investigated. None of the CGs in this study had experienced ACP but illuminated the usefulness of such conversations in many ways.

Palliative care (PC)

Palliative care is a holistic set of interventions to manage signs and symptoms toward quality of life for persons with a life-limiting illness presentation, and their families. Unlike hospice care, PC is not by definition care toward death as an outcome, and does not preclude continued clinical management of individual components of a disease, for example, dialysis or angioplasty. PC may therefore accompany persons over months or even years as they progress along the disease trajectory of one or more chronic illnesses. PC therefore offers to balance both the burden of symptoms and treatment in the CG-CR experience and has been recommended as treatment approach for AHF patients (Goodlin et al., 2004). Unfortunately, fewer than ten % of all AHF patients receive PC services (Pantilat & Steimle, 2004). In a review of the scientific literature of the use of PC in AHF, Hupcey et al. (2009) found that most HCPs equate PC with hospice care and find it unsuitable to meet AHF patients' needs. While PC is a philosophy of care and in theory could be incorporated into any physician's practice, it is understood by most to be a specialty service, requiring introduction of another care team, and is not available in all hospitals or to primary care physicians. Interviewing six nurses and three HF physicians it became clear that PC was associated with EOL care and therefore introduced late in the patient's disease. However, coordinated HF management teams generally offer palliative interventions as part of routine HF care, for example, addressing ADs early on, and offering financial and family counseling.

CGs in this study expressed many palliative care needs including symptom management of multiple coexisting conditions; difficulties managing practical needs in daily life including incontinence, dietary adherence and the burden of frequent clinical encounters; caring for their own health and the spousal relationship; staying socially connected and being a partner in the healthcare network. While CGs did not know what PC was, they asked for interventions within the PC scope of practice. Nursing interventions are needed to identify PC needs, for example in a goals-of-care conversation with the CG and CR, and incorporate PC needs into treatment plans along the entire disease and caregiving trajectory. More HCP education is needed to clarify the umbrella purpose of PC. As a matter of *just institutions* HF HCPs should review their services to include all aspects of PC or collaborate with PC specialty services. Financial reimbursement for these services must be advocated. As PC grows its practice, more research can be done to measure its impact on patient, caregiver and healthcare cost outcomes.

Support group

The last participant in this phenomenology was asked to freely associate about components desired in a support group for CGs of AHF CRs. She included several of the topics covered by the SCDI and affirmed the benefit of group/peer support for CGs and CRs, as well as the need to have some sessions separately for CGs and CRs. She preferred that the group be led by a nurse for certain didactic topics and ACP, and wanted to have feedback from the group collaboratively linked back to physicians, for example, to assure that they were welcome to participate in their CR’s office visits. This CG suggested inviting CGs caring for CRs of other chronic illnesses which would widen the scope and impact of a support group. According to findings from this study it is to be expected that CGs’ burden of SI and encouraging adherence are ongoing topics in the context of SCDI or a support group. A support group would also be a platform for sharing stories of hope, exacerbations, resuscitations and treatment choices made along the path of caregiving which could serve to lift the fog clouding prognosis and the future by learning from others. By listening to other CGs/CR losses of function due to AHF, CGs gain insight into their own gradual downward trajectory and may become better able to articulate what they need each time it is time to challenge a new normal.

The current study has already informed the creation of a support group for CGs and CRs at the regional hospital study site. Findings from the conclusion of the study will refine recommendations and may include particulars from the SCDI. Delivering SCDI content, assessment of palliative care needs and opportunities for ACP within an ongoing group setting make for a feasible, relatively low-cost intervention and could be piloted using some of the SCDI outcome measures.

Raising New Questions

This final section presents opportunities for nursing interventions and research which could not be summarized under the previous topics, in the order of their appearance in Critical Reflection in Chapter 5.

The difference between the one younger CG and the six older participants in states of anxiety, financial concerns and perceived control in the caregiving role was apparent. Other studies including younger spouses and adult child CGs confirmed this finding. HCPs should assess a CG's self-perception in the role and target nursing interventions at the different adaptations required by older vs. younger CGs. More research is needed how anxiety, financial concerns and perceived control affect HRQL and healthcare utilization for diverse CRs and CGs, as well as the spousal or adult child-parent relationship.

The prevalence of dementia and increasing cognitive decline among AHF CRs is high yet there are no recommendations on how to incorporate dementia care into AHF caregiving and treatment plans. An older study by Sherbourne et al. (1999) found that chronically ill adult outpatients in primary care valued mental health outcomes highly when selecting preferences for care, and whether the same holds true for CGs merits further inquiry.

CGs perceptions that CRs needed to have a have a purpose, and that CGs valued a joint purpose and activities can be explored phenomenologically to build theory for nursing interventions which support CGs in defining and finding purpose for their CRs and themselves. Such a study would build on findings from *re-cognizing vulnerability* (Sloan & Pressler, 2009).

This study highlighted the importance of respect and dignity along the CG trajectory and stresses nursing interventions which treat the CG-CR dyad as one, respecting not only the burden of suffering from AHF but also the burden of caregiving. This includes assessment of CG health, social support and the need to increase perceived control by affirming CGs in their role in the in and out-patient setting (Saunders, 2009).

While this study shed some light on caregiver anger this merits more description and focused interventions for all types of CGs living with a chronically ill CR and could be modeled after what is known about anger in caring for the CR with Alzheimer's disease. The waxing and waning CR capacity and competence which specifically describes AHF caregiving was well described in terms of aligning self-determination for CGs and CRs. Cognitive impairment as a perceived vulnerability (Sloan & Pressler, 2009) calls for nursing interventions to support both the CG and CR in finding ways to alleviate, perhaps through energy management, or cope with it. An ethology of office visits as done by Penrod and Baney (2011) to examine CG-CR-HCP interactions could generate insight into how HCPs recognize, assess and incorporate into plans of care the CRs' fluctuating competence along the caregiving trajectory.

HCPs can develop engagement coping skills (Chappell, Reid, & Dow, 2001) which are targeted to CGs' changing needs along the caregiving trajectory (Hupcey, Fenstermacher, Kitko, & Fogg, 2011). Similarly, HCPs need to test if interventions targeted at disengaged coping specifically in the clinical context, such as problem avoidance or wishful thinking can decrease CG anxiety and depression (Garcia-Alberca et al., 2011).

CGs spoke clearly about two specific burdens in AHF caregiving. First, models of outpatient AHF care should focus on minimizing office visits with multiple providers while at the same time increasing HCP availability by telephone at most hours of the day.

This was delivered in the *Presence* case management intervention described earlier, where ARNPs committed to longterm relationships with the CG-CR dyad (Anderson, 2007). ARNPs become the keepers not only of clinical data and knowledge about the dyad, but also the entire illness narrative which allows them to provide therapeutic presence and advocacy. Such an intervention broadens the scope and extends the short-term telephone follow-up provided by most HF programs after hospital discharge, when, as was evident in this study as well, CGs are most vulnerable and vigilant.

Second, CGs need intense support in managing their CRs' dietary restrictions, often for multiple disease conditions. HCPs need to develop interventions which include CGs or even an entire family in dietary teaching, offer practical lessons, for example, reading food packaging labels and guided trips through the grocery store, address social, emotional and cultural issues surrounding food and include the CR's goals for quality of life and adherence. CGs recommended a group setting and utilizing dietitians at local grocery stores which speaks to the finding that social pressure and encouragement from others positively affected adherence (Heo, Lennie, Moser, & Okoli, 2009). This phenomenology suggests that outcomes of improved dietary adherence as reflected in urine sodium concentrations could be sought in perceived control, improved spousal relationship and decreased hospitalizations and ED visits.

The high prevalence and undertreatment of depression was partially explained by CG reluctance to discuss depression and their lack of faith in antidepressants, as well as one HCP's reluctance to add yet another medication to an already extensive medication regimen. Non-pharmacologic strategies to decrease symptoms of depression need further exploration, especially as interventions that target both CG and CR depression. More research is needed to explain the physiologic mechanisms of anxiety in AHF.

HF education needs to address CG and CRs' aversion to the term heart failure. Helping CGs and CRs accept the fact that although they experience symptoms related to fluid overload, the heart is indeed severely weakened, along with sharing the typical illness trajectory of AHF may open doors to conversations about EOL planning, as it did for the participants in this study. More interventions directed at acute breathlessness at home need to be developed and tested, including the use of opioids, CPAP, energy management, and alternative methods such as pursed lip breathing or relaxation strategies.

Loss of night-time sleep is a serious problem for CGs and their CRs. Nursing interventions require a highly individualized approach, incorporating the CR's medication regimen, daily routine, anxiety and depression, physical mobility, need for CPAP, and urinary continence. Urinary incontinence requires a similar individualized approach, taking into account many of the same parameters but also including the stigma attached to incontinence. CGs are interested in learning about personal hygiene products available to help them sleep through the night or go on outings with their CRs.

Personality change in CRs was a most curious finding and merits further inquiry, perhaps even of a phenomenological nature. While this study gave insight into CG perceptions of this change, the CR perception is described in some qualitative studies (Ekman, Ehnfors, & Norberg, 2000; Ekman, Fagerberg, & Lundman, 2002; Ekman, Kjork, & Andersson, 2007; Ekman, Skott, & Norberg, 2001) and could shape nursing interventions to allow CGs to understand their CR better (incorporated into a support group or SCDI session).

This study gave moving insight into the challenges of living with and managing multiple chronic conditions. Nursing interventions, perhaps initiated in the hospital and based on a complete assessment of the illness experience at home, need to help CGs prioritize symptom management not only to clinical parameters but also to their own habits and preferences for quality of life. Adherence needs to be discussed in terms of health outcomes and consequences and with respect to choices CGs and CRs make on a daily basis. Using Tripp-Reimer et al.s image of *inverting the problem* mentioned in the context of dietary management, HCPs can construct a complete picture of the burden of treatment, including SI and adherence, to design treatment plans and interventions that acknowledge the entire illness experience and help CGs and CRs formulate goals of care along the disease and caregiving trajectory.

CGs clearly articulated their ethical intentions in caregiving although they tended to put intentions for their own happiness on hold. They observed their CRs' intentions which were not always directed at adherence and medical stability. There is much evidence that CGs do not always know their CRs' treatment preferences, specifically they tend to opt for less aggressive care than their CRs (Hancock, Clayton et al., 2007b). This study offers one explanation why CGs may believe that their CRs would choose less aggressive care because their actions in daily life reflected a certain inattention to survival at all cost. More research is needed how CRs reconcile non-adherence with implications and preferences for care, and how CGs can be supported to respect these choices while at the same time being empowered to make decisions reflecting their CRs' actual values for quality of life at times when their CRs become incompetent.

Transitions to other settings of care, particularly a NH require much nursing support for the CG, and clearly all participants in this study were considering it a last resort. Outpatient palliative care services are being evaluated (Bekelman et al., 2011) and home healthcare options need to be tested for cost effectiveness compared to NH placement.

The final integration of themes into a timeline revealed palliative information and support needs as identified by Hupcey and colleagues (2011). There were several opportunities for ACP and goals of care discussions which were not optimally met. Nursing interventions can be developed and tested to perform ACP at the time of discharge when relative medical stability has been restored yet the memory of fragility is still fresh. Goals of care need to be reevaluated with each serious hospital admission and should clearly describe implications on care, expectations for the CR and CG, identifying needs to meet these expectations, and support available. HCPs need to be aware of family conversations around the dinner table and invite values and preferences into ACP conversations. HCPs can keep a finger on the pulse of CG intuitions to elicit fears, observations and palliative care needs and revise goals of care accordingly.

Methodological considerations

Phenomenological interviews can be interpreted in different ways to reveal the meaning of the phenomenon under investigation. As stated in Chapter 3, emerging meaning must be the one most probable to explain and understand the text and in this case was carried out from the perspective of a nurse researcher with a clinical background in heart failure nursing. Methods to assure scientific rigor of this study were given in detail along with participant quotes to support development of the themes. Findings from this study cannot be generalized but may be transferred to similar populations within a similar context. Findings in phenomenology always constitute foundation for further reflection within the hermeneutic arc (Ricoeur, 1976).

Limitations of the study

Consistent with the nature of phenomenological inquiry, the sample size was small and homogeneous, consisting of mostly older white partners of spouses with AHF. Participants were recruited from one hospital only and reflect the experience within a limited region in the American Midwest. CRs' illness severity was not verified through clinical data by the investigator but relied on the expertise of the recruiting ARNP. The sample may have been biased according to selection preferences of the ARNP who made occasional comments such as "this CG really needs to talk to someone", "this couple is just not compliant" or, in the case of Elmer, "his wife is worried about him and wants him to talk to you". However, these comments reflected the realities in the CG experience and were more likely to identify those CGs who were in need of interventions as opposed to those who had all their needs met by usual medical and nursing care. Similarly, participants narrated their side of the story and there was no corroboration of what HCPs actually felt they had done or said. Again, this reflects the reality of explaining and understanding within the hermeneutic circle.

Participants were invited to speak openly and given opportunity to reflect deeply about their experiences. This was facilitated by establishing a trusting relationship through several interviews and phone calls. Nevertheless, some may still have found it difficult to fully reveal their innermost feelings in conversation. Two of Chewey's interviews were affected by the presence of her CR and grandchildren. While she called me a "confidante" I was left with the impression that our interviews may have been uncomfortable and adding to her burden of *not* being a caregiver. Elmer had word finding problems related to early dementia and needed some prompting, but his enthusiastic agreement when I had found just the right word was generally affirming of "truth".

Summary of Implications for Education, Practice and Research

The following is a summary of findings from this phenomenological study, as they pertain to the specific domains of education, practice and research in caring for the CG-CR dyad at the end of life with AHF. As discussed in the previous section, some of these findings are already integrated into interdisciplinary interventions, others are new. All findings are grounded in a philosophical framework of friendship with oneself and the other and the need for mutual respect. Just institutions are necessary to grant upon CGs the capacity to act autonomously and to fulfill their ethical intentions and promise toward happiness for themselves and their CRs.

Implications for Education and Teaching

Significant education continues to be needed about interdisciplinary palliative care in advanced heart failure (Goodlin et al., 2004). At some point along the caregiving trajectory HCPs should engage in a conversation with the CG and CR to clarify their respective roles in caregiving and receiving, and assess whether CGs and CRs have the necessary communication skills to meet each others' needs related to self esteem and the ethical intention in these roles. Concerns over being a burden and entering a nursing home bear respectful consideration and mediation. In this cohort of aged AHF patients' and their CGs, it may be necessary to address the stigma of depression through education about the negative effect of depression on cardiac performance. The threatening effect of the term "heart failure" should be validated rather than minimized and lead to meaningful ACP discussions. Recognizing that CGs interpret and manage symptoms of multiple coexisting illnesses, mutual learning is required between CG/CRs and HCPs regarding the priorities of symptoms. As the disease progresses, anticipatory guidance and coaching helps CGs to prepare for, and recognize new symptoms.

According to this study and others, conversations must be tailored to the age of the CG because there may be more anxiety, financial concern and role stress in younger CGs. HCPs caring for CG-CR dyads with AHF need to be skilled in addressing symptom progression, the typical AHF trajectory, the option to deactivate an ICD, and options for palliative or hospice care (Goodlin et al., 2008). If a CG-CR dyad chooses the out-of-hospital DNR status and prefers to die at home or is transferred to long-term care, treatment plans for activity intolerance, breathlessness and sudden death have to clearly reflect a change to dying care.

Implications for Practice

This study validated the need for the four specific interventions described in detail above (SCDI, ACP, PC and support groups). It called for more support with dietary management, specifically with guided tours in a grocery store, a joint cooking class or meal delivery service. CGs wanted interventions to help understand and manage cognitive fluctuations, personality change, and non-pharmaceutical approaches to depression and mild breathlessness at home. Interventions for urinary incontinence and loss of night time sleep must be highly individualized. ARNPs working closely with CG/CR dyads can help couples identify and reinforce pleasurable joint activities and become instrumental in leading support groups at their healthcare institution or in the community.

Out of respect for CGs' time and CRs' activity tolerance, more efforts have to be made to coordinate or even minimize routine clinical visits. On the other hand, CGs appreciate availability of an around-the-clock telephone support line for advice. CGs need to feel welcome and included during clinic visits. In some cases, HCPs may have to model respect for the CG to the CR. HCPs treating the CR/CG dyad as one can assess CG health and social connectivity routinely. Finally, the healthcare industry, as just institution, needs to make home healthcare more affordable and reimbursable.

CGs showed readiness for ACP discussions at various points along the caregiving trajectory but expected HCP guidance. HCPs need to be alert to those points along the disease and caregiving trajectory when goals of care merit review. Any DNR status should be supported by a palliative plan of care transparent and acceptable to the CG/CR.

Implications for Research

The four major interventions of SCDI, ACP, PC and support groups require continued testing for their effectiveness and impact on healthcare utilization. Interventions of joint exercise programs, joint cooking classes, or meal delivery services catering to various dietary restrictions merit testing for outcomes in health-related quality of life or dietary adherence. More evidence is needed for consideration of the application of CPAP prior to a 911 call.

More specifically, we need to know how discussions of symptom progression and a typical disease trajectory, as well as addressing disengaged coping affect CG/CR perceived control, anxiety, depression and willingness to engage in ACP. The question whether CR cognitive status affects CG preferences for care deserves consideration.

Once meaningful ACP was performed by the CR/CG/HCP triad it is necessary to measure whether CR/CGs preferences for care were honored.

Finally, this study identified specific areas for more phenomenological inquiry to understand (1) implications of CR’s cognitive fluctuations on decision making for preferences of care, (2) CRs’ personality changes attributed to an awareness of death being near, (3) the need to retain a purpose in living both as individuals and as a couple, and (4) how CRs reconcile daily choices in illness management and adherence with preferences for care at the end of life.

APPENDIX A: TABLES

Table A-1. The AHF caregiver experience. Quantitative studies.

(Author) Country Design Sample	Instruments/analysis	Significant findings
(Nieboer et al., 1998) Netherlands Population-based prospective follow-up N=127 pt/CG dyads (incl. 40 HF dyads)	HADS, (I)ADL, MOS Restriction on CGs' 6 most valued activities due to pt illness	High caregiving tasks and activity restrictions correlate with depression. Depression worsened over time, along with CG's deterioration in phys. health.
(Bull, Hansen, & Gross, 2000)* US Telephone survey N=130	Modified Client Satisfaction Questionnaire, SF-36 and CRA Single-questions re. involvement in DC planning and preparedness to care. Investigator-developed survey to measure continuity of care with strong internal consistency and Cronbach alpha.	Increased involvement in discharge planning → increased satisfaction, feelings of preparedness, and perception of care continuity. Small impact on CG health.
(Westlake, Dracup, Walden, & Fonarow, 1999)* US N=63 pt/spouse dyads	Investigator-developed instrument to measure informational needs. Psychosocial Adjustment to Illness Scale (PAIS) with sexual relations subscale	Confirmed decreased frequency of sexual activity and need for information. Decreased frequency of sexual activity not generally perceived as a problem by the CG.
(Evangelista et al., 2002)* US 103 pt/CG dyads spouses of pts with HF	SF-12 (mental health) Multivariate analysis for age and gender	Pts had lower emotional well-being scores than CGs. CG's emotional well-being affects that of the pt

Table A1. Continued

(Rohrbaugh et al., 2002) US Cross sectional n = 128 male and 49 female HF pts and their spouses.	Psychological distress and marital quality were assessed with Hopkins Symptom Check List	57% of pts and 40% of spouses were distressed. Male CGs were more distressed than female CGs (explained by marital quality). Female CGs were more distressed than their pts. Only the pt's distress reflected the severity of the pt's illness. Partner distress correlated negatively with ratings of marital quality.
(Rohrbaugh, Shoham, Cleary, Berman, & Ewy, 2009) US Mixed methods N= 43 male and 17 female pts and their spouses	Hopkins Symptom Checklist-25 SF-36 Illness severity Home interviews at baseline and 6 months later	The spouse's distress at baseline predicted an unfavorable course of pts' HF symptoms and general health over the next 6 months, independently of the pt's own baseline distress.
(Fried, Bradley, & O'Leary, 2003) US Cross-sectional survey in pts' homes. N=214 pts, CGs and HCPs)	Survey to test agreement about the occurrence of prognosis discussions and pt and CG desire for prognostic information. Sensitive nature of these questions → missing data.	Significant disagreement b/w HCP and pt/CGs. 205 pt/CGs reported no life expectancy discussion & 40% of these did not want discussion. Need to discuss prognosis increased with perceived decreased life expectancy.
(Martensson, Dracup, Canary, & Fridlund, 2003)* Sweden N=48 volunteer men with HF and their spouses	Beck Depression Inventory SF-12 6-minute walk test	Spouse depression and HRQOL did not significantly influence pt depression. Spousal depression was related to husbands' functional status and employment, and their own mental QOL.
(Schwarz & Dunphy, 2003)* US N=75 family CGs to older adults with HF	Perceived Stress Scale Salivary cortisol CES-D, Inventory of Socially Supportive Behaviors Scale	Social support did not moderate the effects of stress on depressive symptoms. (good internal consistency but no correlation with salivary cortisol)

Table A1. Continued

(Dracup et al., 2004)* US Cross-sectional, correlational study. N=69 CGs	SF-36 GH and MH, CAS-F, Caregiver Appraisal. Descriptive statistics, Pearson correlations, and stepwise multiple regression.	Perceived control and older age are associated with emotional well-being. Younger spouses need additional emotional support.
(Fried, Bradley, O'Leary, & Byers, 2005) US N=193 pt/CG dyads.	Investigator-developed instrument: CG/pt communication needs assessment 10-item Zarit BI.	> 30% CGs said communication was difficult and wanted more communication. Increased communication needs associated with increased burden scores.
(Hooley, Butler, & Howlett, 2005) Canada Prospective, descriptive. N=50 pt/CG dyads.	For CGs: Zarit Burden Inventory, Beck Depression II.	CG burden correlated with pt severity of illness and pt/CG depression. Strong correlations and significance.
(Luttik, Jaarsma, Veeger, & van Veldhuisen, 2005)* Netherlands N=38 volunteer couples during hospitalization.	Cantril Ladder of Life to rate QOL during hospitalization, the month prior to hospitalization and as projected 3 years in the future.	CGs have low QOL, it cannot be concluded if this is due to living with HF pt.
(Barnes, Gott, Payne, Parker et al., 2006)* UK Mixed methods, longitudinal (2 yrs) N=213 CGs and 9 focus groups with staff from clinics	Carer Strain Index, SF-36, 5-item GDS, FAMCARE, semi-structured interviews of 16 pt-carer dyads. “Framework” approach for grounded theory.	Depression, older age of CG, multiple comorbidities, spousal status, pt severity of illness affect strain & decreased QOL. Younger spouses have decreased mental health.
(Bakas, Pressler, Johnson, Nauser, & Shaneyfelt, 2006)* US Descriptive design N=21 convenience sample.	Control Attitudes Scale; Oberst Caregiving Burden Scale; Bakas Caregiving Outcomes Scale; SF-36 Mental Health Subscale; SF-36 General Health Subscale. Testing care giving model and conceptual framework.	Decreased CG perceived control over managing heart problems and increased perceived difficulty with tasks was associated with poorer perceived mental health.

Table A1. Continued

(Harkness & Arthur, 2006)* US N=16 pt/CG dyads	Hospital Anxiety & Depression Scale, Caregiver Burden Inventory.	CGs are less depressed but more anxious than pts. (non-significant, pilot study)
(Luttik et al., 2007)* Netherlands cross-sectional design N=357 partners	CRA, LVEF, RAND-36, Dutch Objective Burden Inventory (alpha >.8 for all subscales). Quality of marital relationship measured on Cantril's Ladder.	Pt severity of illness did not contribute to burden but CG emotional health and number of tasks did.
(Saunders, 2008a) US cross-sectional design mixed methods N=50 CGs and 41 pts	CG characteristics and demographic tool designed for this study, CES-D short form, CRA and the NYHA Functional Classification Guide to obtain the CG's perception of pt disease severity, medical records review	Higher levels of burden were found among Caucasian CGs, those caring for other relatives besides the pt, unemployed CGs, and single- versus two-family CGs. 51% of variance in CG burden was accounted for by CG advanced age, higher CG hours, more CG physical health problems, higher levels of CG depressive symptoms, and more pt comorbidities.
(Saunders, 2008b) US N=41 CGs at hospital admission	Face-to-face interviews using instruments Agreement or disagreement on a Likert scale of items associated with CG depressive symptoms, CG appraisal, and perceptions of pt disease severity.	Decreased HRQOL was most strongly associated with lack of finances and impaired CG health.
(Saunders, 2009) US N=50 (adult children and spouses)	Cross-sectional correlational In-home interviews and administration of instruments CES-D, CRA, NYHA classification, QOL Index	Family support, finances, schedule, and health to be associated with decreased HRQL ($p < .01$). CGs who had low self-esteem related to caregiving had decreased HRQL ($p < .01$).
Luttik (2009) Netherlands N=303 CGs of HF pts 304 CGs of healthy elderly	RAND-36, Cantril's Ladder, Dutch Objective Burden Inventory cross-sectional, comparative design	Differences in QOL between partners of people with HF and matched controls were small. HF caregiving was negatively associated with the QOL of female CGs only.

Table A1. Continued

(Ãgren, Evangelista, & Stromberg, 2010) Sweden N=135 (75% female) Descriptive correlational cross sectional	Swedish caregiver burden scale Charlson Comorbidity Index, BDI-II, CAS family versión, Knowledge Questionnaire (RAND), SF-36 physical and mental component scores, and perceived control	CG burden was lower when the mental health of the partner and the physical health of the pt were better and the partner had higher perceived control over the heart disease.
(Chung, Pressler, Dunbar, Lennie, & Moser, 2010) US N=109 mostly spouses	BDI II, CAS-Revised, Duke Activity Status Index, Oberst Caregiving Burden Scale and the Zarit Burden Interview.	27.5% CGs were depressed associated with poorer functional status, lower perceived control, higher perceived caregiving distress; more caregiving difficulty; more time spent in caregiving tasks. CGs functional disability, perceived control and CG burden explained 45% of the variance in depressive symptoms. Pt NYHA class and functional status did not predict CGs' depressive symptoms.
(Hwang, Luttik, Dracup, & Jaarsma, 2010) Netherlands N=338 HF spouse CGs N=1288 CGs of healthy older pts	Dutch Objective Burden Inventory, RAND-36, NYHA classification	Spouses of HF pts were female, older and had poorer self-perceived health. They provided more personal (especially male CGs) and emotional care. Female CGs in general provide more emotional care than males.
Garlo 2010 US N=179 CGs of cáncer, HF (n-47) or COPD pts.	Zarit Burden Inventory over 12 months	At baseline, the median CG burden was 5 and did not rise significantly over time. High burden was associated with CG need for more help with daily tasks and desire for greater communication with the pt

Table A1. Continued

(Trivedi, Piette, Fihn, & Edelman, 2011) US N=23 spouse carers	Cross-sectional descriptive includes correlations. Pilot to test conceptual model CES-D, Zarit Burden Inventory, Dyadic Adjustment Scale, Self-care of Heart Failure Index, Multidimensional Scale of Perceived Social Support	Identified several factors that may mediate outcomes for the pt-spouse dyad and made recommendations for dyadic interventions. Conceptual model considers pt and spouse characteristics which are modified within marital relationship and lead to burden and. disease management outcomes, affecting prognosis.

pt (patient), CG (caregiver), HCP (healthcare provider), HF (heart failure)

* study with communication focus

Table A-2. The caregiver experience. Qualitative studies.

(Author) Country Design Sample	Method/analysis	Significant findings
(Mahoney, 2001)* US Focused ethnography in clinics and homes. N=28 (12 CGs)	Observations, participant observations, demographics, chart reviews & interviews. Thematic analysis.	Process of disruption, incoherence, and reconciling. Reconciling = struggling, participating in partnerships, finding purpose & surrendering.
(Martensson, Dracup, & Fridlund, 2001)* Sweden Critical Incident Technique semi-structured interviews, N=23	Decisive situations in communication and support to self and pt. Interviews conducted to saturation of themes. Good inter-rater reliability between 2 investigators.	Positive decisive situation: spouse experienced involvement with others, was given attention, treated like a person of value & was included in care. Negative: feeling like an outsider, kept at a distance by the patient, socially isolated, received insufficient support from children, friends, and health care professionals.
(Weller Moore, 2002)* US Audio-taped unstructured interviews. N=7 wives of HF pts	Recursive analysis, field logs and analytic memos with peer review and member checking.	Metatheme: surviving chaos. Subthemes: contingency, social isolation, and dissociation of self.
(Brostrom, Stromberg, Dahlstrom, & Fridlund, 2003)* Sweden purposive sample N=25 spouses of HF patients	Critical Incident Technique	Support stimulating situations: receiving help from others. Support inhibiting: anxiety in relation to the disease, limitations as a result of the sleeping habits, dissatisfaction with care related to the sleep situation, and being left to cope alone with the problems.

Table A2. Continued

(Boyd et al., 2004)* UK Serial interviews at 3 monthly intervals N=20 patients, CGs, HCPs	112 interviews tape-recorded and analysed with NVivo and narrative analysis.	Pts/CGs felt unsupported by services, and did not understand condition, treatment aims or prognosis. A palliative care approach was rarely apparent.
(Murray, Kendall, Boyd, Worth, & Benton, 2004)* UK up to 4 sequential semi-structured interviews N=20 HF pt/CG dyads	Taped, transcribed, coded and analysed 149 interviews & fieldnotes, using NVivo and narrative analysis. (also included 20 cancer dyads)	Themes: isolation, hopelessness and loss of confidence. CGs struggled with managing their own spiritual needs and knowing how to help a loved one in spiritual distress.
(Coyne et al., 2001) (Rohrbaugh et al., 2004) (Rohrbaugh, Shoham, & Coyne, 2006) US Volunteer sample. N= 191 pt/spouse dyads.	Interpretation and coding with LIFE technique. Strong, transparent interview & video method and non-parametric statistical analysis.	Predictors of survival: spouse confidence > patient self-efficacy, illness severity >pt self-efficacy. Spouse confidence had over-lapping, co-dominant relationship with useful illness discussions. F/U studies support strong predictive influence on survival.
(Aldred, Gott, & Gariballa, 2005)* UK Focused joint interviews with 10 HF pts/CG dyads	Thematic analysis.	Caregiver burden perceived by pt, not caregiver. Social isolation, lack of professional input, confusion about diagnosis and prognosis.
(Luttik, Blaauwbroek, Dijker, & Jaarsma, 2007)* Netherlands Semi-structured interviews. N=13 partners of HF patients	Content analysis	Main themes: changes in life and relationship; coping, and support. Anxiety interferes in acute phase. Difficult: communication and sexuality.

Table A2. Continued

(McIlfatrick, 2007)* Ireland purposive sample N=24 CGs interviews and focus groups.	thick description taped and transcribed verbatim, grouped into themes →categories →meaning units (Includes cancer, HF etc.)	Difficult: communication and information exchange, co-ordination between services, financial concerns. Important: social and psychological support; choice and information. Disparity between patients with cancer and non-cancer diseases.
(Brannstrom, Ekman, Boman, & Strandberg, 2007a) N=3 (Brannstrom, Ekman, Boman, & Strandberg, 2007b) N=1 Sweden	Hermeneutic phenomenology Narrative interviews	Meanings of being a close relative in home palliative care context: To be on call 24 hours a day is both a comfort and a strain. Metaphor of rollercoaster with palliative care "seat belt"
(Harding et al., 2008) (Selman et al., 2007)* UK cross-sectional N= 20 HF pts N=11 family CGs; 6 palliative care staff; 6 cardiologists	semi-structured interviews constant comparison of emergent themes. 2 coders	Lack of knowledge re. HF disease trajectory, there was no EOL planning. Although pts expected honest discussion of disease implications, clinicians described an unwillingness to disclose poor prognosis. 4 barriers to discussion: disease-; patient-; cardiology-;system-specific.
(Pattenden, Roberts, & Lewin, 2007) UK N= 36 pts and 20 family CGs	Interviews constant comparative analysis	Living with HF was frightening, restrictive and distressing: Communication excluded side effects of medications and social support and was more difficult for those with fewer SES resources.
(Clark et al., 2008) Canada N=30 caregivers	Semi-structured interviews	HF management was a shared and ongoing responsibility between the CG and pt. CGs developed extensive knowledge of HF effects on the patient. Invisible care included monitoring signs of symptom exacerbation, energy boundaries and trying to maintain normalcy.

Table A2. Continued

(Imes, Dougherty, Pyper, & Sullivan, 2011) US N=14	Semi-structured interviews Content analysis	3 main themes included personal experience of caregiving, interaction with HCPs and description of pt experience Identified lack of ICD discussion

pt (patient), CG (caregiver), HCP (healthcare provider), HF (heart failure), ICD (internal cardiac defibrillator)

* study with communication focus

Table A-3. Select studies using Ricoeurian herrmeneutic phenomenology since 2001

Article	Purpose statement	Sample	Interview	Method /steps
(Ahman & Söderberg, 2004)	To elucidate the meaning of district nurses experiences of encounters with people with serious chronic illness and their close relatives in their homes.	purposive, contact mediated by insider N=10 district nurses from 2 med centers.	Interviews with a narrative approach (Mishler) were conducted by the first author. 60-90 minutes 9 interviews in the health care centers 1 at the participant's home at her request.	Meaning units were condensed and abstracted into a formulated meaning. The formulated meanings were then related to each other, and organized into subthemes (8) and themes (3) based on similarities and differences in meaning. (Lindseth –Norberg method)
(Benzein, Norberg, & Saveman, 2001)	To illuminate the meaning of the lived experience of hope in patients with cancer in palliative home care.	N=11 consecutive admissions to pri care, hospital and PC. Mediated by nurses in those services.	Might be demanding but not violating pt integrity. Interview as discourse Narrative. Reflective stories strengthen the credibility of the study.	Lindseth –Norberg method
(Caap-Ahlgren, Lannerheim, & Dehlin, 2002)	To explore women's experiences of living with symptoms related to Parkinson's disease, and symptom-related quality of life.	N=8 women chosen to broadly represent the 38 women of a larger study with regard to age, duration of illness, civil status and dwelling.	Kvale-interviews to deepen and explore the content in order to achieve a broader perspective. 45-60 minutes	2 authors with separate analyses. Lindseth-Norberg method. Lawton's adaptation theory.

Table A3. Continued

(Delmar et al., 2005)	‘What does it mean to learn and to adapt to living with a chronic condition?’	N=18 random consecutive sampling saturation	Emphasizes the role of the researcher in the interview. Conducted by 8 nurses.	Lindseth-Norberg method Empirical data control selection of theory and presentation of findings.
(Delmar et al., 2006)	Focusing on existential values: independence, self-responsibility and self-control combined with relations of dependence.	N=18 (same as above)	interview b/w researcher and informant feeds into dialectic of explaining/understanding. 60-90 minutes	Uses the same transcribed texts as study above. An example of asking a question to the text after themes are identified.
(Donnelly & Wiechula, 2006) Australia	To investigate the lived experience patients have of a tracheostomy tube change. Lit review first, laid out as preconceptions.	N=4 out of 7 approached	Analysis “in stages of sophistication”. 1) Burnard’s (1991) 14-step approach to analysis of an interview. 2) van Manen (1997). 3) Hermeneutic theories of Paul Ricoeur.	Field notes are part of structural analysis. Distanciation as way to bracket. Appropriation: participant’s description first, then literal meaning of the passage then researcher’s metaphorical interpretation.
(Ebbeskog & Ekman, 2001)	To illuminate elderly persons' experiences of living with venous ulcer.	N=15 purposive	45-120 minutes	Lindseth-Norberg method
(Edvardsson, Sandman, & Rasmussen, 2003)	To illuminate meanings of giving touch in nursing care of older patients.	N=12	open-ended interviewing 29-60 minutes	Used NVivo Lindseth –Norberg method

Table A3. Continued

(Edwall, Hellstrom, Ohrn, & Danielson, 2008)	To elucidate the lived experience of regular diabetes nurse specialist check-ups among patients with type 2 diabetes.	N=20 narrative interviews Purposeful consecutive sampling over 6 month period.	35-90 minutes Mishler interviews	Lindseth-Norberg method. Trustworthiness and credibility (Patton).
(Efraimsson, Höglund & Sandman, 2001)	To describe and interpret the meaning of the lived experience of home care nursing, as narrated by pts and CGs.	N= 7 patients and 5 caregivers selected by local district nurses	Unstructured interviews of 45 min.	Lindseth-Norberg method
(Eldh, Ehnfors, & Ekman, 2004)	To explore the meanings of participation and nonparticipation in health care by the lived experience of pts with HF.	N=10 Narrative interviews mediated by clinic nurse. Recruitment was challenging because it paired RNs and pts in telling +/- things about each other	Interviews with preformulated guide, performed by the first author (Innovative because this study counted number of words and the frequency of themes in the interviews but did not draw conclusions upon these findings)	Saturation is pendulation through the hermeneutic circle. Color coding to mark meaning units and themes Validation: separate analyses, comparisons of color codes, discussion and dialogue.
(Eriksson & Svedlund, 2006)	To illuminate the meaning of middle-aged spouse's experiences of living with a chronically ill partner.	N=4 mediated through hospital nurses	Narrative interviews (Mishler) 60 minutes	Lindseth-Norberg method. Strong discussion of limitations and trustworthiness.

Table A3. Continued

(Fagerberg & Kihlgren, 2001)	Longitudinal study to understand how nurses experience the meaning of their identity as nurses, when they are students and nurses 2 years after graduation.	N=27: yearly interviews for 3 years and diaries from clinical placements in the last two years of their education. N=20: follow-up interviews 2 years after graduation.	Exclusion: It was found that one nurse did not narrate stories but gave intellectual descriptions, and she was thus excluded.	Rigor: Co-assessment of every 4th interview. 3 levels of structural analysis: meaning units, ethical intention, and relationship to others. Describes effect on interpretation of co-authors different pre-understandings.
(Forsgarde, Westman, & Jansson, 2002)	To illuminate the meaning of being in problematic situations during the working day in special types of housing.	N=27 staff members with 95 stories	Many told facts and events, not feelings	Lindseth-Norberg method, emphasizes vertical and horizontal integration/hierarchy.
(Fredriksson & Lindstrom, 2002) intervention study	To increase and deepen the understanding of how psychiatric patients in conversations with nurses narrate their experience of suffering.	20 individual caring conversations between eight patients and three psychiatric nurses	Observed and recorded therapeutic sessions	Narrative interpretation compares narrative plots (Wiklund) with Lindseth-Norberg method for their respective implications.
(Haggerstrom, Skovdahl, Flackman, Kihlgren, & Kihlgren, 2004)	To investigate the deeper meaning of work satisfaction and work dissatisfaction at a newly opened nursing home for older residents.	1 Registered Nurse, 16 Enrolled Nurses 3 Nurses' Aides.	Narratives	Experience of work dissatisfaction suggests that their feelings of failing the older residents are connected to their own experiences of feeling betrayed.

Table A3. Continued

(Hellzen & Asplund, 2006b)	Nurses at two group dwellings in Sweden were interviewed about their experiences when caring for people with long-term mental illness.	N=14 volunteers	Narrative interviews The first analysis shows that nurses divided residents into four different typologies or patterns - the good, the disabled, the invisible, and the bad residents, of which the nurses liked the first two and disliked the last two.	Second analysis with Ricoeur questions: 'replenishing one's self-worth and self-esteem' and 'giving up the caring role'. Like/dislike is closely related to whether or not the individual resident confirmed the nurse.
(Hellzen, Asplund, Sandman, & Norberg, 2004)	Nurses at a group dwelling in Sweden were interviewed about their experiences when caring for a person who acts provokingly.	N= 8 volunteers The frequent humiliations could be seen as a symbolic language connected to defilement and 'evil' and therefore as having a deep symbolic meaning for the nurses.	Narrative interviews 3 themes; feelings of being tormented, disrupted and helpless.	These results were interpreted and reflected on from an affliction perspective to see the provoking patient, as he appears to the nurses in order to glimpse the goodness concealed behind the provoking facade.
(Horwitz, Theorell, & Anderberg, 2003)	To find out what thoughts fibromyalgia patients had when they saw themselves moving and speaking on videotape.	N= 8 female volunteers with FMS referred consecutively by their physicians. Performed 3 movement sequences and 2 interviews 6 months apart. 60-90 minutes, to achieve saturation.	The study leader had many years of experience in video self-interpretation technique and phenomenology	Text interpretation of interviews only, not the actual video tape. There was a pattern of paradoxical integration between self image and self awareness. Could become a nursing intervention.

Table A3. Continued

(Lindahl, Sandman, & Rasmussen, 2003)	To illuminate the meanings of being dependent on a ventilator and living at home.	N= 9 participants selected to maximize variation re. medical diagnosis, age, gender and functional status. They could speak in a voice that could be tape-recorded.	5 main themes: experiencing home as safe and comfortable space, experiencing the body as being frail, brave and resilient, striving to live in the present, surrendering oneself to and trusting others, experiencing vent. as burden and a relief.	Meanings indicate that aesthetic and ethical values impact on the lived body, connecting vital force and interdependency, bringing safety and courage into daily life. Nursing implications: must design ventilators that match the living room furniture!
(Lohne, 2008)	To explore experiences of the meaning patients attribute to the substance of hope and the process of hoping during the first 3 to 4 years following a spinal cord injury.	N= 10	3 interviews over 18 months (Kvale conversation) at each interview, reflect on hope for the past, present and future	Focus on increasing distanciation with each level of analysis Describes home environment as part of objective data.
(McGowan, Luker, Creed, & Chew-Graham, 2007) UK	To illuminate living with chronic pelvic pain	N=32 Writers chose to relinquish anonymity and addressed writing to the researcher. They appreciated the opportunity to tell their story.	Written stories about illness trajectory	Patient must be empowered by being met with a “recognizing attitude”.

Table A3. Continued

(Ohman & Soderberg, 2004)	To elucidate the meaning of RN encounters with people with serious chronic illness and their close relatives in their homes.	N= 10 purposive sample	3 themes: being in a close relationship, sharing an understanding and weaving a web of protection.	Lindseth-Norberg method The privilege of the nurse-patient relationship is part of the treatment effect.
(Olsson, Lexell, & Soderberg, 2005)	To elucidate the meaning of fatigue for women with multiple sclerosis.	N= 10 Recruitment was arranged through a hospital rehabilitation clinic in the south of Sweden.	Mishler interviews: Instead of working as an implement to manage in the world the fatigued body has become an enemy of survival.	Lindseth-Norberg method
(Paulson, Norberg, & Söderberg, 2003)	To elucidate the meaning of being a female partner living with a man with fibromyalgic pain.	N= 14 female partners	Mishler narrative 3 themes: struggling to give support and comfort, struggling to keep going on, and experiencing lack of understanding and support.	Lindseth-Norberg method
(Sorlie, Kihlgren, & Kihlgren, 2005)	The registered nurses were interviewed concerning their experience of being in ethically difficult care situations in their work.	N= 5 RNs	Mishler interviews	Lindseth-Norberg method Nurses feel responsibility as they perceive it defined by their patients.
(Spidsberg, 2007)	To describe the maternity care experiences narrated by a sample of lesbian couples.	N= 6 couples snowball sampling	Joint interviews Conditions of vulnerability responsibility and caring were related with the couples' decisions to be open about their sexual identity.	Lindseth-Norberg Couples described genuinely caring situations and being content with less genuine care. In addition to receiving care, they themselves provided care in the encounters.

APPENDIX B: IRB APPROVED FORMS

Approval Memo (IRB issued)

IRB ID #: 201005754

To: Heide Bursch

From: IRB-02 DHHS Registration # IRB00000100,
Univ of Iowa, DHHS Federalwide Assurance # FWA00003007

Re: What does it mean for us? Symptom interpretation and communication as experienced by family caregivers of advanced heart failure patients.

Approval Date: 08/11/10

Next IRB Approval
Due Before: 08/11/11

Type of Application:	**Type of Application Review:**	**Approved for Populations:**
☒ New Project	☐ Full Board:	☐ Children
☐ Continuing Review	Meeting Date: 11/20/08	☐ Prisoners
☐ Modification	☒ Expedited	☐ Pregnant Women, Fetuses, Neonates
	☐ Exempt	

Source of Support: personal funds

This approval has been electronically signed by IRB Chair:

John Wadsworth, PHD
08/11/10 0941

IRB Approval: IRB approval indicates that this project meets the regulatory requirements for the protection of human subjects. IRB approval does not absolve the principal investigator from complying with other institutional, collegiate, or departmental policies or procedures.

Agency Notification: If this is a New Project or Continuing Review application and the project is funded by an external government or non-profit agency, the original HHS 310 form, “Protection of Human Subjects Assurance Identification/IRB Certification/Declaration of Exemption,” has been forwarded to the UI Division of Sponsored Programs, 100 Gilmore Hall, for appropriate action. You will receive a signed copy from Sponsored Programs.

Recruitment/Consent: Your IRB application has been approved for recruitment of subjects not to exceed the number indicated on your application form. If you are using written informed consent, the IRB-approved and stamped Informed Consent Document(s) are attached. Please make copies from the attached "masters" for subjects to sign when agreeing to participate. The original signed Informed Consent Document should be placed in your research files. A copy of the Informed Consent Document should be given to the subject. (A copy of the *signed* Informed Consent Document should be given to the subject if your Consent contains a HIPAA authorization section.) If hospital/clinic patients are being enrolled, a copy of the signed Informed Consent Document should be placed in the subject’s chart, unless a Record of Consent form was approved by the IRB.

Continuing Review: Federal regulations require that the IRB re-approve research projects at intervals appropriate to the degree of risk, but no less than once per year. This process is called “continuing review.” Continuing review for non-exempt research is required to occur as long as the research remains active for long-term follow-up of research subjects, even when the research is permanently closed to enrollment of new subjects and all subjects have completed all research-related interventions and to occur when the remaining research activities are limited to collection of private identifiable information. Your project “expires” at 12:01 AM on the date indicated on the preceding page (“Next IRB Approval Due on or Before”). You must obtain your next IRB approval of this project on or before that expiration date. You are responsible for submitting a Continuing Review application in sufficient time for approval before the expiration date, however the HSO will send a reminder notice approximately 60 and 30 days prior to the expiration date.

Modifications: Any change in this research project or materials must be submitted on a Modification application to the IRB for prior review and approval, except when a change is necessary to eliminate apparent immediate hazards to subjects. The investigator is required to promptly notify the IRB of any changes made without IRB approval to eliminate apparent immediate hazards to subjects using the Modification/Update Form. Modifications requiring the prior review and approval of the IRB include but are not limited to: changing the protocol or study procedures, changing investigators or funding sources, changing the Informed Consent Document, increasing the anticipated total number of subjects from what was originally approved, or adding any new materials (e.g., letters to subjects, ads, questionnaires).

Unanticipated Problems Involving Risks: You must promptly report to the IRB any serious and/or unexpected adverse experience, as defined in the UI Investigator's Guide, and any other unanticipated problems involving risks to subjects or others. The Reportable Events Form (REF) should be used for reporting to the IRB.

Audits/Record-Keeping: Your research records may be audited at any time during or after the implementation of your project. Federal and University policies require that all research records be maintained for a period of three (3) years following the close of the research project. For research that involves drugs or devices seeking FDA approval, the research records must be kept for a period of three years after the FDA has taken final action on the marketing application.

Additional Information: Complete information regarding research involving human subjects at The University of Iowa is available in the "Investigator's Guide to Human Subjects Research." Research investigators are expected to comply with these policies and procedures, and to be familiar with the University's Federalwide Assurance, the Belmont Report, 45CFR46, and other applicable regulations prior to conducting the research. These documents and IRB application and related forms are available on the Human Subjects Office website or are available by calling 335-6564.

Approval Memo for Extension (IRB Issued)

IRB ID #: 201005754

To: Heide Bursch

From: IRB-02 DHHS Registration # IRB00000100,
Univ of Iowa, DHHS Federalwide Assurance # FWA00003007

Re: What does it mean for us? Symptom interpretation and communication as experienced by family caregivers of advanced heart failure patients.

Approval Date: 09/20/11

Next IRB Approval
Due Before: 07/10/12

Type of Application:	**Type of Application Review:**	**Approved for Populations:**
☐ New Project	☐ Full Board:	☐ Children
☐ Continuing Review	Meeting Date:	☐ Prisoners
☒ Modification	☒ Expedited	☐ Pregnant Women, Fetuses, Neonates
	☐ Exempt	

Source of Support: personal funds

This approval has been electronically signed by IRB Chair:
John Wadsworth, PHD
09/20/11 1434

Cash Handling Policy and Procedure

Research subject compensation via cash or equivalent

Purpose: To provide units and individuals with the necessary information and tools to facilitate the establishment of strong cash handling internal controls. University Cash Handling Policies and Procedures apply when research subject compensation is made using cash or its equivalent.

Examples of cash equivalents: currency, coins, money orders, personal checks, gift certificates, gift cards, phone cards, parking passes.

Required Separation of Duties

The cash disbursement process must maintain a clear separation of duties. *It is preferable that an individual have responsibility for only one of the cash handling roles below. However if not feasible, the Obtainer and Disburser may be the same person.*

Obtainer

Purchases cash equivalents or receives cash advance.
Provides proof/receipt of purchase to the Reconciler.
Has access to cash equivalents.
Cash equivalents are to be kept in a secure environment (safe or locking cash box/bag in a locked drawer).

Disburser

Hands out the cash equivalents to the research participants.
Must maintain a journal/log of recipients that will be provided to the Reconciler.
Has access to cash equivalents.
Cash equivalents are to be kept in a secure environment (safe or locking cash box/bag in a locked drawer).

Reconciler

Verifies amount of cash equivalents purchased is reflected on the accounting statements (SA3 or TDS) as part of the monthly review.
Reconciler must have knowledge that research participants on the journal/log are valid.
Must **NOT** have access to cash equivalents.

Required Information

Research Project Name	AHF Caregiver Study
General Ledger WhoKey***	Personally Funded-No Whokey required
Time Period	July 2010-January 2011
Faculty Advisor** (If Applicable)	Howard Butcher
Principal Investigator**	Heide Bursch
Cash Handling Obtainer**	Heide Bursch
Cash Handling Disburser**	Heide Bursch
Cash Handling Reconciler**	Nancy Goldsmith

MEMO TO: Clinical Study Principal Investigator

FROM: Pat Thies

Chair, Mercy and St. Luke's Institutional Review Committees (IRCs)

Thank you for notifying the IRCs of your intent to submit a study for review. In order to facilitate the review process, please submit the information requested below. The format for the information is not important as long as the requested information is included. If the study information has been submitted elsewhere for review, the same material can be submitted to Mercy/St. Luke's IRCs.

Please verify by initialing each item listed below indicating inclusion of those documents in the information submitted to the IRCs. The information submitted includes:

hb______	Study design, including hypothesis and data analysis
hb______	Background
hb______	Hypothesis and proposed method for testing that hypothesis
hb______	Participant selection
hb______	Data collection instruments/forms
hb______	Proposed method of data analysis
N/A____	Relevant information regarding safety and efficacy of drugs and devices, if applicable.
hb______	Proposed informed consent form
hb______	Disclosure of Significant Financial Interest in Research Form

All drug and device studies must be approved by a convened meeting of the IRCs. If your study involves a drug or device, you will be asked to attend the IRC meeting at which your study is reviewed to present your study and to answer questions from the committee members.

If you have any questions, please contact Sherri Hawkins, 369-7200 (Mercy Medical Center) or Gail Stork, 369-8035 (St. Luke's Hospital).

Submitted electronically by heide-bursch@uiowa.edu

Heide Bursch RN, MS, PhD(c)

University of Iowa College of Nursing

Financial Disclosure Form for St. Luke's Hospital IRC

DISCLOSURE OF SIGNIFICANT FINANCIAL INTEREST IN RESEARCH

This form must be completed annually by anyone who performs, participates in, regulates or oversees research conducted under the auspices of the Institutional Review Board of Mercy Medical Center/St. Luke's Hospital. The information must be updated as an individual's circumstances change.

The purpose of this form is to determine whether an individual who performs, participates in, regulates or oversees research conducted at Mercy Medical Center/St. Luke's Hospital, or otherwise accepts the oversight of the Institutional Review Board of Mercy Medical Center/St. Luke's Hospital, has a financial conflict of interest in research, which is defined as follows:

A financial conflict of interest in research exists when the significant financial interest in research of a covered individual may compromise, or have the appearance of compromising, the covered individual's professional judgment in conducting or reporting research. Such a conflict can affect oversight of research, collection, analysis, and interpretation of data, as well as hiring of staff, procurement of materials, sharing of results, choice of protocol, involvement of human participants, and use of statistical methods.

Please complete the following table by making a mark in the appropriate column.

Do (1) you, (2) any member of your immediate family, (3) any foundation or entity controlled or directed by you or any member of your immediate family, or (4) any group practice of which you are a member:

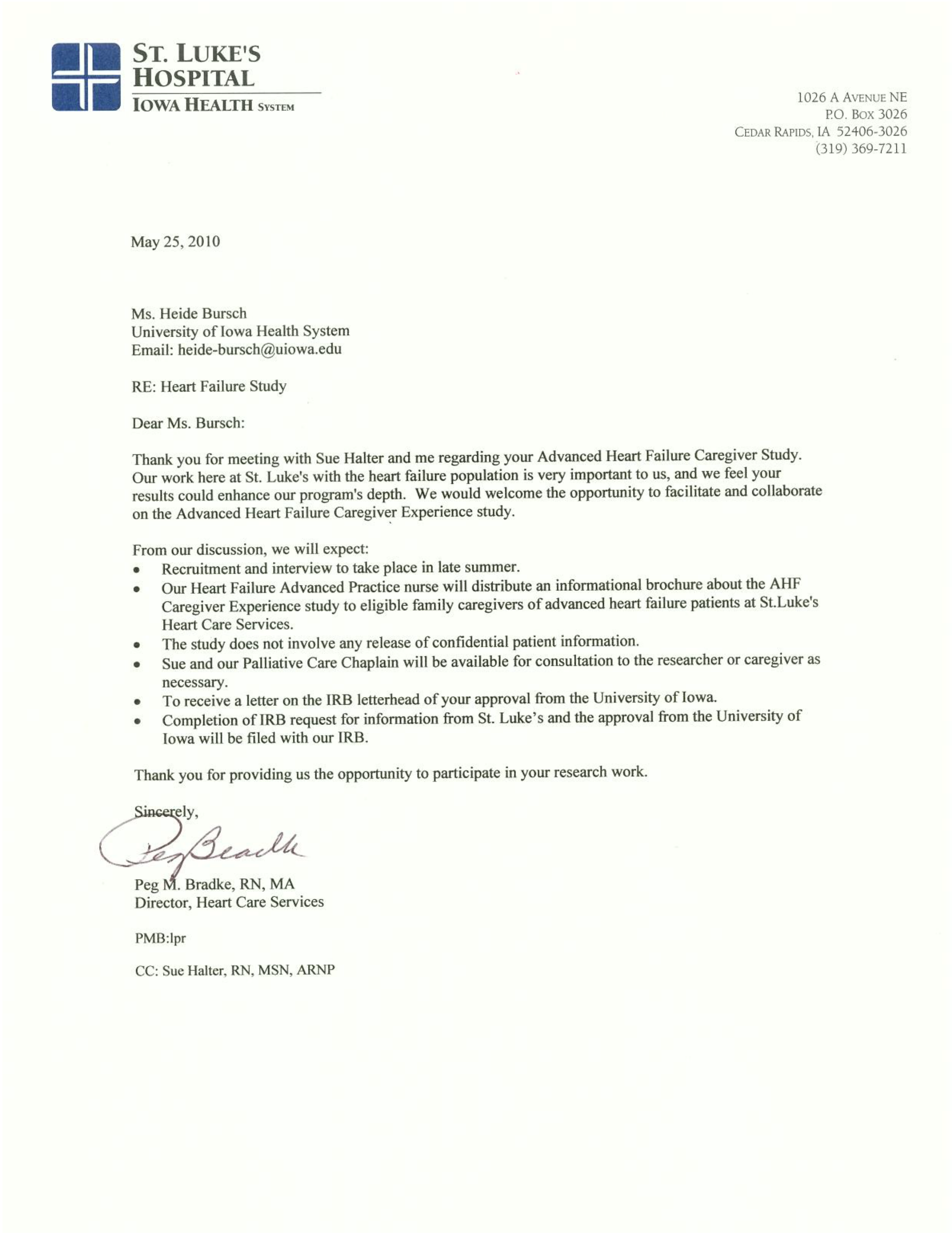
1. Receive or are entitled to consulting fees, honoraria (including honoraria from a third party, if the original source is a financially interested company) gifts or other emoluments, or "in kind" compensation from a financially interested company (or entitlement to the same), whether for consulting, lecturing, travel, service on an advisory board, or for any other purpose not directly related to the reasonable costs of conducting the research (as specified in the research agreement), that in the aggregate have in the prior calendar year exceeded the de minimis amount established in PHS regulation (at present $10,000), or are expected to exceed that amount in the next twelve months?**____ Yes __X No**
2. Have or are entitled to equity interests, including stock options, of any amount in a non-publicly-traded financially interested company?**____ Yes __X No**
3. Receive or are entitled to equity interests in a publicly-traded financially interested company that exceed the defined de minimis amount?**____ Yes _X_ No**
4. Receive royalty income or have the right to receive future royalties under a patent license or copyright, where the research is directly related to the licensed technology or work?**____ Yes __X No**
5. Receive non-royalty payments or entitlements to payments in connection with the research that are not directly related to the reasonable costs of the research (as specified in the research agreement between the sponsor and the institution). This includes any bonus or milestone payments to the investigators in excess of reasonable costs incurred, whether such payments are received from a financially interested company or from the institution on milestone payments tied to the achievement of particular research results?**____ Yes _X_ No**
6. Serve as an officer, director, or in any other fiduciary role for a financially interested company, whether or not remuneration is received for such service?**____ Yes _X_ No**
7. No list of examples of conflict of interest can be complete. Do you have reason to believe that you may have a financial conflict of interest in research that is not covered by items 1-6?**____ Yes __X N**

On a separate sheet, please provide a complete explanation for any item marked "yes".

Name: Heide Bursch Date:5/30/2010

Signature: Electronic submission from heide-bursch@uiowa.edu
Action:

Letter of Support



ST. LUKE'S
HOSPITAL
IOWA HEALTH SYSTEM

1026 A AVENUE NE
P.O. BOX 3026
CEDAR RAPIDS, IA 52406-3026
(319) 369-7211

May 25, 2010

Ms. Heide Bursch
University of Iowa Health System
Email: heide-bursch@uiowa.edu

RE: Heart Failure Study

Dear Ms. Bursch:

Thank you for meeting with Sue Halter and me regarding your Advanced Heart Failure Caregiver Study. Our work here at St. Luke's with the heart failure population is very important to us, and we feel your results could enhance our program's depth. We would welcome the opportunity to facilitate and collaborate on the Advanced Heart Failure Caregiver Experience study.

From our discussion, we will expect:

- Recruitment and interview to take place in late summer.
- Our Heart Failure Advanced Practice nurse will distribute an informational brochure about the AHF Caregiver Experience study to eligible family caregivers of advanced heart failure patients at St.Luke's Heart Care Services.
- The study does not involve any release of confidential patient information.
- Sue and our Palliative Care Chaplain will be available for consultation to the researcher or caregiver as necessary.
- To receive a letter on the IRB letterhead of your approval from the University of Iowa.
- Completion of IRB request for information from St. Luke's and the approval from the University of Iowa will be filed with our IRB.

Thank you for providing us the opportunity to participate in your research work.

Sincerely,

Peg Bradke

Peg M. Bradke, RN, MA
Director, Heart Care Services

PMB:lpr

CC: Sue Halter, RN, MSN, ARNP

A doctoral student from the College of Nursing at the University of Iowa in Iowa City is currently conducting a research study to learn more about the experience of family members who care for a heart failure patient, like you are. We are assisting in the study by identifying caregivers who may be eligible for her study and providing them with information about the study.

The study goes over 2 months and involves in-person and phone interviews with the researcher.

Would you like to read about this study to see if you are interested in becoming a participant?"

If the caregiver responds positively, she will hand them the information sheet and the consent form, explaining: "This is information about the study and the consent form you would be asked to review and sign if you agree to be in the study. I would encourage you to read it carefully and maybe talk it over with other family members or friends. There is a contact number for you to call the researcher. We ask that you contact her within one week, if you decide that this is something you would like to be a part of. She will go over everything in detail with you and answer any questions you might have.

If you wish, you may let me know that you are interested in the study and I can give your name and contact information to the researcher who will then give you a call.

You should know that the researcher is not connected to your healthcare team here at CRST, and whether you decide to participate or not will not in any way affect the care _________ (name of the patient) receives here.

Thank you for considering this. We want to support caregivers in their experience, and with this study we will learn more about what they need."

Fact Sheet for Potential Participants

RESEARCH STUDY

What does it mean for us?

Symptom interpretation and communication

- as experienced by family caregivers
- of advanced heart failure patients.

INFORMATION SHEET

What is the purpose of this study?

The purpose of this research study is to learn what it is like to be a family caregiver for a care recipient with advanced heart failure. With advancing heart failure, it becomes more difficult for patients to monitor their own symptoms and participate in their own care, so that both patients and healthcare providers rely heavily on you, the family caregiver to help watch over patients. In order to better support family caregivers in the future we would like to learn

- What do heart failure symptoms mean to the family caregiver?
- Where do they find advice and support to help them cope?
- What do they think their role should be in managing care for their care recipient?

Who is eligible to participate?

You may be eligible to participate if you are a caregiver who:

- Is a spouse or significant other of a care recipient age 50 or older who has advanced heart failure
- Lives with the care recipient and identifies him/herself as the primary provider of support with the care recipient's daily needs or visits and is involved with planning care for a care recipient who lives in a care facility.
- Reports to be involved in making treatment choices with or for the patient;
- Accompanies the patient to clinic and hospital visits;
- Speaks English well enough to express his or her feelings and thoughts;
- Is willing to reflect upon and share his/her deepest thoughts and feelings about the meaning and experience of being a caregiver;
- Has access to a telephone for brief weekly check-in phone calls and to contact the primary investigator if needed.

What would I have to do?

You will meet with the researcher three times over a period of 2 months. This can be in any place of your own choosing that is comfortable for you, and private: either your home, or a quiet room at the hospital. You will also receive a phone call once a week at home to make note of your symptom and communication experiences from that week so we can remember to talk about them at the next interview.

What would the meetings involve?

During each interview, you will be invited to reflect and share your thoughts about what it is like to be a caregiver to your care recipient. The interviews will specifically focus on your observations of your care recipient's heart failure symptoms, what these symptoms mean to you or how they make you feel. You will also be asked to describe who you talk to about these symptoms, what others tell you about these symptoms, and what that makes you want to do. Finally, you are asked to reflect about what your role should be and what kind of support you need to secure the best care for your loved one with heart failure now and in the future.

How much time will this require?
Such conversations usually take anywhere from 30- 90 minutes. The weekly phone calls should be less than 10 minutes.

Are there any costs involved for me?
There are no costs associated for you other than your time.

Is compensation offered?
You will receive compensation in appreciation of your time and effort.

Once I begin the study, what if I cannot complete it?
You are NOT obligated to complete the study. Participation is totally voluntary. If you are unable to finish or want to withdraw for any reason, you may do so at any time.

If you would like to find out more information about the study, or to volunteer to participate please contact Heide, the principal investigator within one week.

Heide Bursch RN, MSN, Doctoral Student
Principal Investigator
College of Nursing
University of Iowa
Iowa City, Iowa
319-330-7434
heide-bursch@uiowa.edu

Initial Contact Worksheet

Date of Contact __ __ - __ __ - __ _(all calls were conducted by the primary investigator)
1. Name ____
Address ____
City ____
State _________________ Zip Code ___________________
2. Telephone # (__ __ __) __ __ __ - __ __ __ __

Initial Information

Introduction of caller.
Thank you for expressing interest in participating in the AHF Caregiver Experience study.
Is this a good time to talk about the study?
If this is not a good time to talk, when would be a good time for me to call you back?
Briefly describe the study and overall time commitment.
Have you had a chance to look over the information sheet and the consent form?
Do you have any questions about the study?
Are you still interested in participating in this study? (If they are no longer interested in the study, I thank them for their interest and time)

We now need to review some criteria to see if you are eligible to participate in the study.

Inclusion Criteria:	**Y**	**N**
Do you live with the care recipient?		
Does your care recipient live in a care facility?		
(If CR lives at home) Are you the one who usually helps with the daily needs of your care recipient?		
(If CR lives in a facility) Do you visit your care recipient and are you involved in planning his/her care at the facility?		
Do you take a part in making treatment choices with or for your care recipient?		
When your care recipient is admitted to the hospital, or has a doctor’s appointment, do you come along?		
Do you speak English well enough to express your feelings and thoughts?		
Would you be willing to talk to me about all your feelings, hopes and fears in what it is like to be a caregiver to your care recipient?		
Can you make a telephone call whenever you need to speak to me?		
Can I check in with you on the phone once a week?		
Exclusion Criteria: Do you have a diagnosis of psychiatric illness or major depression?		

Does caregiver meet all criteria for participation in study? Yes _______ No _______

If caregiver meets enrollment criteria and wishes to initiate participation	
First meeting: detailed consent procedure, demographic information, and first interview	
Call back if eligible participant needs more time to think it over	
Information to be obtained after enrollment	
Please choose a name (pseudonym) by which you would like to be known for this study.	
Name and telephone number of a trusted family member or friend	
Best time for weekly phone calls	

Informed Consent

FOR IRB USE ONLY
APPROVED BY: IRB-02
IRB ID #: 201005754
APPROVAL DATE: 08/11/10
EXPIRATION DATE: 08/11/11

INFORMED CONSENT DOCUMENT

Project Title: What does it mean for us? Symptom interpretation and communication as experienced by family caregivers of advanced heart failure patients.

Principal Investigator: Heide Bursch

Research Team Contact: Heide Bursch RN, MSN, PhD Student (319) 330-7434
Howard Butcher APRN-BC, PhD (319) 337-7039

This consent form describes the research study to help you decide if you want to participate. This form provides important information about what you will be asked to do during the study, about the risks and benefits of the study, and about your rights as a research subject.

- If you have any questions about or do not understand something in this form, you should ask the research team for more information.
- You should discuss your participation with anyone you choose such as family or friends.
- Do not agree to participate in this study unless the research team has answered your questions and you decide that you want to be part of this study.

WHAT IS THE PURPOSE OF THIS STUDY?

This is a research study. We are inviting you to participate in this research study because you are the spouse or significant other, and caregiver to a patient who is diagnosed with advanced heart failure.

The purpose of this research study is to learn what it is like to be a family caregiver for a patient with advanced heart failure. As it becomes more difficult for patients to monitor their own symptoms and participate in their own care, both patients and healthcare providers rely heavily on family caregivers to help watch over patients. In order to better support family caregivers in the future we would like to learn

- how do family caregivers makes sense of heart failure symptoms
- where do they find advice and support to help them cope
- what do they think their role should be in managing care for their patient

HOW MANY PEOPLE WILL PARTICIPATE?

Approximately 15 people will take part in this study conducted by investigators from the University of Iowa.

HOW LONG WILL I BE IN THIS STUDY?

If you agree to take part in this study, your involvement will last for approximately 2 months and consists of three interviews ranging from 30-90 minutes each; there will also be weekly telephone check-ins lasting less than 10 minutes.

WHAT WILL HAPPEN DURING THIS STUDY?

You will meet with the researcher (Heide) three times. This can be in any place of your own choosing that is comfortable for you, and private: either your home, or a quiet room at the hospital. Interviews will be scheduled at your convenience and if you should miss an interview, we will reschedule as soon as possible. Heide will also call you once a week at home to ask about your experiences during the week. We will talk about your weekly experiences at the next interview.

First visit

- We will complete a brief form to find out more about you and your caregiving experience. You will be asked to provide your age, gender, and years of schooling completed. We will also ask how long you have acted as a caregiver, about your care recipient's advanced directive or living will, and at how many clinic visits and hospitalizations you have stayed with your care recipient in the last two years. We will ask you to choose a study name which will be used to identify your study information. Finally, we will ask you to name a trusted family member or friend who supports you when you feel sad or overwhelmed. You may skip any questions that you do not wish to answer. Completion of this form should take less than 10 minutes.
- We conduct your first interview. We will ask you about how you became a caregiver for your care recipient, about whom you to talk to about your care recipient's symptoms, and to reflect and share your thoughts about what it is like to be a caregiver to your care recipient. Such a conversation usually takes anywhere from 30- 90 minutes. You may skip any questions during the interview. We will make an audio recording of our discussion.

Second visit

- We will conduct your second interview and ask you to talk about any experiences to do with your care recipient's heart failure since our last visit, especially how you feel about the his/her symptoms and what conversations you had or would have liked to have had to help you make sense of your experience. This will take anywhere from 30-90 minutes. You may skip any questions during the interview. We will make an audio recording of our discussion.

Third visit

- At the third interview, we will review your experiences related to your care recipient's heart failure since the second interview and we will ask you to reflect on your role as caregiver and what your expectations, hopes and fears are for the future. This will take anywhere from 30-90 minutes. You may skip any questions during the interview. We will make an audio recording of our discussion.

Between visits

- We will call you once a week at your convenience, to ask about your feelings, conversations or experiences you had in your role as caregiver during the last week. We will talk about the information collected during the weekly phone calls at the next interview visit. This should take less than 10 minutes each time. You may skip any questions you do not wish to answer.

Audio Recording

One aspect of this study involves making audio recordings of our discussions. We will make a transcription of each discussion so that we have an accurate record of your responses. The recordings will only be available to the researcher on this project and to the transcriptionist. The recordings will be erased at the end of the study.

WHAT ARE THE RISKS OF THIS STUDY?

You may experience one or more of the risks indicated below from being in this study. In addition to these, there may be other unknown risks, or risks that we did not anticipate, associated with being in this study.

As you reflect about being a caregiver to your patient you may experience many emotions. While normal, some of them may be uncomfortable, such as sadness, grief or anger. In the event that any of these emotions become too much for you to handle during the interview or if you have concerns about your responses, we will pause or end the interview. If you experience such feelings in relation to the study at any time, we encourage you to contact the researcher, or a trusted friend or family member. Sue Halter, the ARNP from Heart Care Services can advise you on seeking counseling if needed.

WHAT ARE THE BENEFITS OF THIS STUDY?

We don't know if you will benefit from being in this study. However, we hope that, in the future, other people might benefit from this study because what we learn will tell us how to better support the role of family caregivers of heart failure patients.

WILL IT COST ME ANYTHING TO BE IN THIS STUDY?

You will not have any costs for being in this research study.

WILL I BE PAID FOR PARTICIPATING?

You will receive a $45 gift card to Wal-Mart or Target in the mail after all data collection for the study is completed in appreciation of your willingness to share your experience and time. If there is no Wal- Mart or Target in your area, or if you prefer to shop elsewhere, please inform the researcher and we will obtain a gift card elsewhere. If you withdraw from the study at any time you will receive a $15 gift card for each interview completed. We will mail your gift card to the address you provided. We will mail the gift cards at the end of the study.

WHO IS FUNDING THIS STUDY?

The University and the research team are receiving no payments from other agencies, organizations, or companies to conduct this research study.

WHAT ABOUT CONFIDENTIALITY?

We will keep your participation in this research study confidential to the extent permitted by law. However, it is possible that other people such as those indicated below may become aware of your participation in this study and may inspect and copy records pertaining to this research. Some of these records could contain information that personally identifies you.

- federal government regulatory agencies,
- auditing departments of the University of Iowa, and
- the University of Iowa Institutional Review Board (a committee that reviews and approves research studies)

To help protect your confidentiality, we will ask you to pick an assumed name or pseudonym under which we will store your study information instead of your real name. We will keep all study electronic files in a password protected computer file and all hard copies of the study materials in a locked file cabinet. This consent document and any forms with your identifying information will be stored separately from your study information in a different locked file cabinet and will be accessible to the primary investigator (Heide) only. Your identifying information will be destroyed at the end of the study. If we write a report or article about this study or share the study data set with others, we will do so in such a way that you cannot be directly identified.

IS BEING IN THIS STUDY VOLUNTARY?

Taking part in this research study is completely voluntary. You may choose not to take part at all. If you decide to be in this study, you may stop participating at any time. If you decide not to be in this study, or if you stop participating at any time, you won't be penalized or lose any benefits for which you otherwise qualify. Your participation or non-participation will not in any way affect your care recipient's care at St. Luke's Hospital or at the doctor's office.

What if I Decide to Drop Out of the Study?

If you decide to leave the study early, we will ask you to notify us by phone.

Will I Receive New Information About the Study while Participating?

If we obtain any new information during this study that might affect your willingness to continue participating in the study, we'll promptly provide you with that information.

Can Someone Else End my Participation in this Study?

Under certain circumstances, the researchers might decide to end your participation in this research study earlier than planned. This might happen because in our judgment it would not be safe for you to continue due to emotional distress.

WHAT IF I HAVE QUESTIONS?

We encourage you to ask questions. If you have any questions about the research study itself, please contact:
Heide Bursch at (319) 330-7434 or Dr. Howard Butcher (advisor) at (319) 335-7039.

If you experience a research-related injury, please contact Heide Bursch at 319 330-7434.

If you have questions, concerns, or complaints about your rights as a research subject or about research related injury, please contact the Human Subjects Office, 105 Hardin Library for the Health Sciences, 600 Newton Rd, The University of Iowa, Iowa City, IA 52242-1098, (319) 335-6564, or e-mail irb@uiowa.edu. General information about being a research subject can be found by clicking "Info for Public" on the Human Subjects Office web site, http://research.uiowa.edu/hso. To offer input about your experiences as a research subject or to speak to someone other than the research staff, call the Human Subjects Office at the number above.

You may also contact Sherri Hawkins, Mercy & St. Luke's Institutional Review Committee at 319 369-4700 with questions about your rights as a research subject.

This Informed Consent Document is not a contract. It is a written explanation of what will happen during the study if you decide to participate. You are not waiving any legal rights by signing this Informed Consent Document. Your signature indicates that this research study has been explained to you, that your questions have been answered, and that you agree to take part in this study. You will receive a copy of this form.

Subject's Name (printed): ____

Do not sign this form if today's date is on or after EXPIRATION DATE: 08/11/11.

______________________________________ ________________

(Signature of Subject) (Date)

Statement of Person Who Obtained Consent

I have discussed the above points with the subject or, where appropriate, with the subject's legally authorized representative. It is my opinion that the subject understands the risks, benefits, and procedures involved with participation in this research study.

______________________________________ ________________

(Signature of Person who Obtained Consent) (Date)

Participant Demographics

Demographic information for ____
(pseudonym)

Age_________

Gender F / M

Years of education completed____________

For how long have you thought of yourself as being in the caregiving role?

There is a document for Advance Directive(AD) or Living Will(LW): YES / NO

Have you had discussions with the care recipient about AD or LW: YES / NO

On approximately how many clinic visits did you accompany your patient in the last 2 years?

Through how many hospitalizations did you accompany your patient in the last 2 years?

Appointment and Interview Schedule

Appointment and interview schedule for ____

(pseudonym)

Purposive sampling strategy of three caregivers for month __________________

Male ☐ Female ☐

☐ Patient is in cardiology care only

☐ Patient is in palliative care

☐ Patient is transitioning to inclusion of palliative care

☐ Other

_____________(date)**First interview questions focus on exploration of the past. They are designed to elicit the caregiver story and get a first snapshot of symptom and communication experience.**

We can start by you telling me what it is like to care for (name of patient). How did you get to be (name's) caregiver?

How does (name's) HF affect your own life? How do you feel about being caregiver for (name)?

What are some of the symptoms of HF that (name) is experiencing?

What is the meaning of (this symptom) to you? How important is (this symptom) to you?

Who do you talk to about (name)'s (symptom)?

How does it make you feel when you talk to (who) about the (symptom)?

What is easy/hard about talking to (who) about this symptom?

Debriefing questions to monitor participant burden after each interview:

Before we end our session, I wonder if you have any questions or concerns for me?

How do you feel about our conversation today?

Script for weekly phone calls which serve to keep track of evolving symptom and communication experience to talk about at the next interview.

How have you been managing as caregiver for (patient's name) this past week?

How do you feel about (patient's name) symptoms this week?

Have you had any conversations about (patient's name) AHF that we should remember to talk about during our next visit?

______________ (date) **The second interview explores evolving situation in the present and focuses on symptom experience.**

Last time you told me about what it is like for you when (name) experiences (symptom). Since then, has there been a change in how you think or feel about (symptom)?

How do you think (symptom) will change in the future? How does that make you feel? What will be easy or difficult about that?

What do you think will happen with (symptom) in the future? What makes you think that? What does this mean to you? How do you feel about this?

What does (this symptom) make you want to do?
Can you tell me what you believe to be your role in the big picture of taking care of (name) as the symptoms of HF go on?
In your mind, what is the best that can happen to (name)? How would that make you feel?
What is the worst that can happen? How would that make you feel?
Was there ever a time when you felt really good about how you handled a symptom? Can you tell me about that?
Is there ever a time when it's difficult for you to know what is the right thing to do? Can you give an example of a time, when it was difficult to know what was the right thing to do? What did that feel like?

________________ (date) **The third interview explores the future, focuses on the communication experience and clarifies the family caregiver's intention towards a desirable outcome for the care recipient.**
Since our last visit, did you have any important conversations with anyone about caring for (name)? Who was that? How did that conversation make you feel? What did that conversation make you want to do?
Did you hear/learn/understand anything new about (symptom)? Who did you talk to? How did that conversation make you feel? What did that conversation make you want to do?
Was there ever a time when you felt really good about a conversation regarding (name's) heart failure? Can you tell me about that?
Was there ever a time when communication did not go so well? Can you tell me about that? How did that feel?
Was there ever a time when you would have liked to talk to a particular person about (name's) HF but for one reason or another you didn't or couldn't? Can you tell me more about that?
Can you tell me what you believe to be your role in the big picture when (name) gets close to dying, and after he/she has died?
How will you manage? What will be easy or difficult about it?
What will be the role of family members and friends, and various healthcare providers when (name) gets close to dying and afterwards?
Is there anything about your own role that you wish could be different? What do you need for things to be different?
Debriefing questions to monitor participant burden:
Before we end our session, I wonder if you have any questions or concerns for me?
How do you feel about our conversation today?

Waiver for Social Security Numbers

From: Johnson, Terry L
Sent: Tuesday, August 30, 2011 10:46 AM
To: Goldsmith, Nancy J
Cc: Housel, Karen L; Thomsen, Linda K; Hand, Linda L; Bursch, Heide C
Subject: RE: Waiver of requirement for Social Security Numbers

Nancy,

Thank you for memorializing our conversation this morning.

I approve your request for an exception to the research subject policy and will not require collection of social security numbers from the participants for the IRB approved $45 gift card payment described below. This waiver does not apply to any additional payments that may be required under this research study.

Please contact me if you have additional questions.

Best Regards,
Terry

THE UNIVERSITY OF IOWA

Adult & Gerontology Nursing
456 Nursing Building
Iowa City, Iowa 52242-1121
319-335-7067 Fax 319-335-7106
www.nursing.uiowa.edu

Iowa Geriatric Education Center
2153 Westlawn
Iowa City, Iowa 52242
geriatric-education@uiowa.edu
www.healthcare.uiowa.edu/igec

October 5, 2011

Thank you for your participation in our study of the Advanced Heart Failure Caregiver Experience.

Your stories and reflections will help us describe what it’s like outside the hospital for someone living with heart failure. Such understanding is necessary for healthcare providers’ efforts to become better partners in caregiving for persons with advanced heart failure and their family members.

In appreciation of your time and willingness to share I am enclosing a gift certificate in the amount of $45 to the business of your choice. I will remember you and our times together and wish you all the best as you continue to care and be a partner to your spouse with heart failure.

Best regards,

Heide Bursch RN, MSN
Doctoral Candidate
University of Iowa College of Nursing
2008-2010 John A. Hartford Foundation BAGNC Scholar
heide-bursch@uiowa.edu

COLLEGE OF NURSING

Invitation to Participate in Follow-up Phonecall

Date

(Personalized Greeting)

We invite you to participate in one final follow-up phone call. The purpose of this phone call is to find out if you have encountered more symptoms of advanced heart failure in your spouse, or have had more conversations about advanced heart failure since our last visit.

I plan to call you on the telephone within this coming week. If you consent to participate in this phone call, I will ask you the following questions:

How have you been managing as caregiver for (patient's name) these past few weeks?
How have you been feeling about your spouse's symptoms these past few weeks?
    Has your spouse experienced any pain from the heart since our last visit?
Have you had any more conversations about end-of-life planning with your spouse or family members or friends, or healthcare providers since our last visit?

This phone conversation should take less than 30 minutes.

If you don't wish to participate in this final follow-up phone call, or don't wish to discuss any one of the questions, you are entirely welcome to call me (319)330-7434 or tell me on the phone right away and we will end our conversation without further questions asked.

All other conditions for this phone call are the same as described on your initial long consent form. I am listing them again below, just in case you want to read them again.

Thank you very much for considering your participation in the final follow-up phone call.

Sincerely,

Heide Bursch MSN, RN
Doctoral Student
University of Iowa College of Nursing

2008-2010 John A. Hartford Foundation BAGNC Scholar
HGNI...Enhancing Nursing Care for Older Adults
heide-bursch@uiowa.edu

We will keep the information you provide confidential, however federal regulatory agencies and the University of Iowa Institutional Review Board (a committee that reviews and approves research studies) may inspect and copy records pertaining to this research. There will be no further audio recordings but I will take some hand-written notes. If we write a report about this study we will do so in such a way that you cannot be identified.

There are no known risks from being in this study, and you will not benefit personally. However we hope that others may benefit in the future from what we learn as a result of this study.

You will not have any additional costs for participating in the final follow-up phone call and there will be no further compensation.

Taking part in the final follow-up phone call is completely voluntary. If you decide not to participate at any time, you won't be penalized or lose any benefits for which you otherwise qualify.

If you have any questions about the final follow-up phone call, please contact Heide at (319)330-7434.

If you experience a research-related injury, please contact: Dr. Howard Butcher (Heide's advisor) at (319)335-7039.

If you have questions about the rights of research subjects, please contact the Human Subjects Office, 105 Hardin Library for the Health Sciences, 600 Newton Rd, The University of Iowa, Iowa City, IA 52242-1098, (319) 335-6564, or e-mail irb@uiowa.edu. To offer input about your experiences as a research subject or to speak to someone other than the research staff, call the Human Subjects Office at the number above.

Script for Final Follow-up Phone Call

Script for final follow-up phone call for ____

(This final phone call is added in order to enhance the longitudinal aspect of the study. The questions are the same as the ones which were asked between visits before. Preliminary findings from the interviews point to two specific issues which merit follow-up: (1) there was a notable absence of chest pain among symptoms observed and (2) all participants were in various stages of conducting end-of-life planning.)

How have you been managing as caregiver for (patient's name) these past few weeks?
How have you been feeling about your spouse's symptoms these past few weeks?
Has your spouse experienced any pain from the heart since our last visit?
Have you had any more conversations about end-of-life planning with your spouse or family members or friends, or healthcare providers since our last visit?

APPENDIX C: CAREGIVER VIGNETTES

Oma

Oma was 75 years old, married to CR for 52 years and completed 11 years of education. She chose her pseudonym after her mother who was an important role model in her life. Oma has thought of herself as caregiver since CR had his heart attack 18 years ago, however, not until the third interview did she remark upon the fact that this was a significantly long time. Oma had the standard hospital Iowa Bar Association combined advance directive and living will which was currently being redone to include all their children in the role of healthcare power of attorney. Oma stated that she and CR had had one or two brief conversations about not wanting to be on “life support”, but the CR really did not care to speak about such things and they had not discussed end-of-life planning with the children. Over the last two years, Oma has accompanied the CR to 5-6 clinic visits each month, and he had been hospitalized four times, including the current hospitalization. “It’s unbelievable how often we go to the doctor’s office”, she says, but the CR also has diabetes, COPD and was most recently diagnosed with myeloma.

I met Oma first in the hospital where her husband was critically ill with an exacerbation of AHF. She told stories of joy and hope, but cried while she was speaking. I soon learned that it was her gift to start out with negatives only to reframe and turn them into statements of hope and optimism. Surprisingly, rather than launching into details of his current situation in ICU, Oma started her story with how the disease had changed the CR even years ago, made him more self-centered, and how her needs had been neglected for a long time now. Oma learned to find respect and esteem in other relationships, with family, friends and healthcare professionals. She had many examples of how his doctors and nurses showed genuine caring for him even while they had to do painful things like running his code or performing risky tests.

In the course of our three interviews, the CR gradually recovered, going through skilled care and then home health care. Oma thoroughly enjoyed contact with all the various providers and felt they brought a sense of lightness and humor into an otherwise ultimately sad situation. Oma knew from conversations with physicians that her CR was at the end of his life, she only hoped to be able to care for him at home as long as possible. She offered the following metaphor to illustrate being a CG to the person with AHF:

> So you live on an edge all the time. You think you're prepared for it but you never are. You never know if this is going to be the last time, because it very easily could be.
>
> So it's like peaks and valleys. Some days you feel everything is going to be alright. You see him doing his therapies and walking with a cane, and what an accomplishment when they didn't even think he was going to make it. You think this is good. But then he'll have a bad day, and he can say things that are hurtful, and then you are down here. And you have to pull yourself back up. It's just ups and downs.
>
> When I'm in the valley I usually call my best friend, because she's been there. And we pull each other up. And there are days when she calls me because she is depressed about losing her husband, so it's like a whole mountain chain of peaks and valleys! I rely on my family too. They call a lot. They're like bridges for those peaks and valleys, so the valleys aren't quite so deep. And the nurses, a lot of times, I need them to put an arm around me and say "hang in there, we're with you".

She hoped he would die in his sleep, preferably at home, but she was comfortable with the prospect of maybe having to withdraw life support at the hospital if need be. At our follow-up phone call I learned that her CR had died 2 months after our last interview, one day before their 53rd anniversary. They had just gotten into the car to go to the doctor when he collapsed. Although they had the AD with requests for no heroic efforts, Oma reflexively called 911 so that the medics re-established a heartbeat and he was transferred to the hospital where the physician again asked her permission to stop life support and CR died a second time. The next day the flowers arrived that he had ordered for her to celebrate the anniversary. Looking back at pictures now she wondered how he could get to looking so bad without her noticing it. He had become more depressed because he was losing his sight, and was feeling more and more like a burden. And she admits to having been exhausted and sleepless, from helping him go to the bathroom at night frequently. “He just pulled through so many times before,” she sighed. She wonders if she let him go gamble one too many times, maybe he caught something at the casino. “But it made him so happy”. Now she comes home to an empty house. There is no one to talk to. Yet again, she derives comfort from the greater community, children and friends. Since his death she has traveled to Alaska and Las Vegas, the dreams she had written off as unrealistic before. Could CR have died at home, without the 911 response? Oma said: “I knew he was really dead this time, I just didn’t know what else to do. And then they took me away, so I wouldn’t have to watch the CPR. In my mind, he died at home, just the way he wanted it.”

Elmer

Elmer was a special case. He had been extremely involved in his wife’s care over the years. However, in the process of our study he was being diagnosed with Alzheimer’s disease. Elmer had no trouble with the screening and consent procedure, and was able to answer my questions to test understanding of the informed consent. He generally had good recall of our meetings although he sometimes lost his train of thought in the middle of a sentence and I had to help him find just the right words at times. We met at their farm and his wife retreated to the bedroom to give us privacy at the kitchen counter.

Elmer was a 74 y/o retired farmer who completed high school plus one year community college. He chose his pseudonym after his father whom he greatly admired. Elmer had been married for 52 years and considered himself to be CR’s caregiver all these years because she had brittle diabetes with a history of “passing out just like that” . Elmer first heard the word heart failure about one year ago. He did not care for the term "heart failure", because it implied impending death and he did not see her anywhere near death.

They updated their AD as a family one week ago at the attorney's office, covering both estate and healthcare POA. He was going to share HCA for CR with his sons.

Elmer took CR to a doctor's office at least once a month and says that there have been so many (6-8) hospitalizations in the last two years, he has lost count. CR also has DM, arthritis, fibromyalgia, depression, obesity and neuropathies.

During the first interview Elmer described a lifetime of caring: it was overwhelming at first, but he had no choice and he got used to it. Now he was having to do things he never expected to have to do, and wondered if other men had to do the same. Their major problems were finding a diet for CR that had restrictions for weightloss, diabetes, heart disease and kidney disease. They also felt it demanding to manage all the medications and doctor visits. However, the greatest inconvenience of everyday life was her incontinence from frequent infections and the diuretics. The second interview took place after Elmer was officially diagnosed with dementia. He freely expressed his anger, grief, and feelings of betrayal but he said he didn't want to show too much of his feelings to CR, because it would add to her stress and provoke an exacerbation. He spoke about facing his own aging and mortality. More than ever he needed CR "to be the head of the organization". Again, he expressed despair over dietary and incontinence issues. At the last interview he seemed to have reconciled with his diagnosis and the associated driving restrictions. However, CR's incontinence continued to be the bane of his existence. Elmer and CR were planning a trip to Arizona in a camper with a large bathroom and accompanied by his son and daughter-in-law. This trip was going to bring the seriousness of her incontinence out into the open: "She doesn't want anyone to know that she has this problem. And up till now they'd heard about the problem a little bit. So they will learn more about it." At the follow-up phone call, Elmer reported that the trip went so well, they will try it again this winter, this time with an even bigger bathroom. CR was still tired most of the time, and her blood pressure was low which was being regulated with frequent clinic visits but had not required hospitalization. CR had fallen on her nightly sprint to the bathroom four times in the recent weeks and had given up on CPAP. Each time she fell, Elmer had to call his son to help pick her back up again. She had received a scooter to increase her mobility and Elmer wanted me to pass on that it truly was covered by Medicare! There had not been anymore ACP. Elmer summarized his caretaking with a comparison to farming: “I try not to be impressive; I just want to be me. To take things as they come, take care of them. I tried to do an excellent job farming, and I think I did. I guess I just take it as something normal. Just something that has to be done.” Being a caregiver made him a helpful human being, and always tired, he smiled. It’s not what they had in mind for their golden years, but it’s what they had to do. And they felt blessed by friends and family.

Elmer had many comments about communication with HCPs. He resented their role as gatekeepers to getting medication, and their general inaccessibility. He did not appreciate having to see so many specialists. He also felt that his doctor just did not understand the extent of CR’s suffering: “He is a fine young man, I trust him with most anything. But he’s missed the point somewhere and doesn’t understand how un-handy this situation is. He doesn’t appreciate how much this affects our life, and how unbearable it is.” Elmer seemed well aware of the ambiguity in the doctor’s prognosis statement: “She’d live to be 100 the doctors say. So heart wise we are in good shape. Unless it changes over night or something.”

Elmer thought CR would eventually die from hypoglycemia. Looking back on his years of caregiving, when he had to repeatedly save her from hypoglycemia, he wondered if he could continue to do so. “I don’t know, if she’s low and runs out of sugar cubes and I’m not here, maybe we’ll have a bad scene, like the movie “Steel Magnolias”… she went low when she was at the hair dresser. That is exactly how they act.” Elmer had many stories about other peoples’ deaths and wanted for CR to die at home, with hospice. He trusted that CR would let him know when enough was enough. He'd been told several times that she almost died which was scary because he was not aware of it at the time. He plans to advocate, be with and protect her when the time comes.

The Count

TC was a 62 year old retired construction worker who had completed high school education. The pseudonym he chose reminded him of his working days, when it was his nickname among his peers. He has been married to CR for 41 years. He said he has been her caregiver off and on ever since they married; helping her through various surgeries and the onset of DM. Heart failure was diagnosed 4 or 5 years ago. There were no advance directives and they have not had conversations about her wishes for care at the end of life. Over the last two years he has accompanied her to at least 25 clinic appointments and two or three hospitalizations.

TC suffered from obesity, COPD, HTN and DM himself. He cried easily during our conversations, which he said was not at all like him. In interview #1, TC described the situation leading up to her first hospitalization for heart failure some time ago. He did not know how seriously ill she was and there was a delay in calling the ambulance. Then she was hospitalized for a fall in the middle of the night, without symptoms of HF. Her most recent hospitalization was for SOB and weight gain which they found during a routine clinic visit for her diabetes. While he did not consider this admission an emergency he was scared nevertheless, because he remembered the intensity of care required the last time and how close she had come to dying without him realizing it. TC described CR's other health problems to be arthritis, obesity, DM and renal insufficiency. There was quite a bit of syndrome X in her family, with CR's parents and one sister deceased, and both brothers and one remaining sister suffering from it worse than CR. In interview #2 the CR had improved some. TC had been able to get away on a four-hour hunting excursion which improved his mood. He also had conversations with his children and friends about his fears for the CR and the need for advance care planning (ACP). However, there was a delay in getting the papers from the hospital. Upon his request, I spent some time explaining AHF and the effect of some of CR's medications on heart performance. At interview #3 the CR was hospitalized again. TC felt pleased with how he had recognized tell-tale signs immediately and admitted her to the hospital in a timely manner. The family had also developed a telephone tree to notify close friends and family and elicit their support. However, the ACP papers were not signed in all the ten months I had contact with TC and there was no further follow-up from the hospital.

Overall, TC was satisfied with communication with HCPs, he emphasized the fact that they spoke at a level he could understand. He drew some reassurance from what he heard doctors say over the months: while she had weak kidneys, she had a strong heart; her lungs were clear; she got a clean bill of health and could do anything she wanted; some exacerbations were unavoidable; she could live a long time; she could live to be 80 years old.

TC offered the following metaphor for being CG:

> "Being a caregiver for CR from day to day is just like the ball on the paddle that is attached by a string. It bounces back and forth, long and short or whatever… And you have to keep catching it with the paddle. It seems to me that the heart failure is always there and it will come back to you, you just don't know how or when. We're trying to fight the good and the evil at the same time. It's a tight war, actually. It's a damned-if-I-do, damned-if-I-don't situation. A rock and a hard place. We don't know what to do."

At our final follow-up phone call eight months after our last interview, the CR was still doing apparently well although she had stopped doing physical therapy due to knee pain and she still was not comfortable wearing the CPAP machine consistently. Both her brother and sister were currently seriously ill and hospitalized. There had been no more hospitalizations and only two clinic visits for her. Her blood sugars were under control and again she was told that “her heart was really good and looking the way it should.” TC said that the ball on the string wasn’t coming back quite as forcefully, and the string was getting longer. He wished it would break, but he understood that it wouldn’t. “I have to live with it, it’s never going away; it doesn’t bother me. My job is to support and love and care.” They were looking forward to the birth of a new grandchild in a couple of months.

Chewey

Chewey was a 58y/o elementary school art teacher who had completed 18 years of education. CR, a healthcare professional, was her second husband. They had known each for seven years before they were married eight years ago. Chewey emphatically denied being a caregiver; she preferred to see herself in the role of partner and wife. Even though she felt involved in CR’s healthcare decision making she did not know if there was an advance directive or if she even should be HCA for him. She tried to have ACP conversations with CR but she has not found him receptive to such talks. All together, she had only been to three clinic visits with him because he was still very much in charge of his own care. In the last two years she has been with him through three hospitalizations. CR also has diabetes; respiratory allergies sometimes mask his AHF-related respiratory symptoms.

We visited at her home. CR was present in the background, watching TV and interrupting our conversation occasionally with unrelated issues. Sometimes Chewey asked him a question to verify her own thoughts. However, she kept her voice low in order not to be overheard as we talked.

She began with her story about his first hospitalization for HF. It seemed like an emergency to her because he passed out during a coughing fit, while they were vacationing in Florida. He refused any emergency care at the time, even delayed it until they returned to Iowa. Chewey spoke a great deal about years of wanting to protect him and keep him safe which was in contrast with his self-direction and determination to manage his own symptoms without her help. Chewey experienced more anxiety than any of the other CGs, much of it tied into the fact that she saw his physical and financial state as one combined illness. Because she felt the financial aspect was the most modifiable factor in their lives, she wished for him to be financially secure. Her biggest concern was his diet but since she didn't cook, she had little influence on what he ate. Chewey was grieving the loss of activities they used to share. As they did less together, he and his illness began to feel like invaders of her own home:

> "It's like intruding. Because when I bought this house it was going to be my place and that is it. We dated for seven years because I was determined not to get married again. But he convinced me. I worry tremendously about the financial end of it, the unknown that I can get almost sick over."

CR was still entirely autonomous in dealing with his AHF, and Chewey resented the few tasks that he delegated to her. This is how she felt after he pushed himself through another physically rough day at the office against her advice:

> "He came home and threw up again. It's kind of an ongoing problem for him. When he suffers like that it makes me want to run away. I don't know that I handle it very well. I am not at all a nurse; I'm not good at cleaning up after people. When he threw up all over the sink and the bathtub he never cleans up his own so I usually have to do it; and it takes me a little bit. And I feel bad for him, but then I'm angry at him for having to do this when I'd like to be doing something else and not cleaning up that sort of thing. I get anxious when bad things happen to the house. It's kind of my sanctuary."

Chewey described communication with HCPs and her CR. She still had only a vague understanding of AHF and was critical of the conflicting opinions of all the specialists involved in CR's care. : "I would like to know if this could be something that is the beginning of something, if it could lead to more serious congestive heart failure or cardiac arrest, or whatever." After observing an interaction at the hospital, she wondered if his HCPs really knew: "The two doctors, the intern and the cardiologist disagreed; then a third cardio came in and disagreed with both of them. So it got to be pretty complex and you start to wonder if anyone knows what is going on." When she accompanied him to clinic visits or was present at bedside consultations she generally felt excluded from the conversations:

> "I am just trying to figure out what they are doing. When a doctor comes in they will talk directly to him. And sometimes when he is confused about something they will ask 'did you have such and such this morning' and I will know that he did or didn't and I will correct his answers. They will look at me like: I'm not asking you, I am asking him."

However, she noticed much improved communication during the last hospitalization, at least with the nursing staff: "They had a wipe board where everything was written down: The nurses, when he was checked last, all of his vitals. We all knew what was going on. Made me feel like I was part of the team." When Chewey described conversations about his health with CR, she had to reverse her metaphor of the intruder:

> "He doesn't like to talk about his health. If I try and discuss something with him he gets very agitated; starts pacing and stomping around, growly. It makes me feel like I am the intruder. Makes me feel very much like the intruder. I'll say 'I just want to clarify with you what you think is going to happen, what you want to see happen, what you are working towards." And he'll just say 'I hope I get everyone paid off.'

Chewey offered two metaphors for being a partner to CR with AHF. First she described having to walk a very narrow path:

> "So I worry about keeping him in that narrow path that he can travel between the diabetes and the sugar, and now the salt. Right now, I think we are on this narrow path because he can't veer one way or the other. He has to be very careful of what he eats. It is treacherous.
>
> I'm not real sure about my role. I just see myself as walking behind him holding onto his belt and hoping that he doesn't fall. I don't know that I am as helpful as I would like to be, because I just can't be. My jobs takes about everything I've got, and my daughter needs me, and he needs me, my parents are getting older and are still on the farm. So I feel like he has to carry a lot of this burden by himself. I think we both need a stay-at-home wife. We need a Hazel or an aunt Bee. Someone with a machete paving the way!
>
> I see HCPs as the people who hover around him and are able to give him the expertise that he needs. They are the ones who

> monitor, analyze, diagnose, and prescribe. And I try to listen to all of it, so I have a picture of what it is that he needs, and what I can do to help prevent further problems. They're not so much hovering around me; I am just trying to figure out what they are doing."

The next metaphor is much less earth-bound: "He is like the space shuttle, so finely tuned. If anything gets out of order it all goes out of whack." She goes on to explain how each time CR flies off into outer space with an exacerbation he comes back a changed man. Each time it takes something away from him.

Lee

Lee was an 87 year old female with 11 years of education who has been in the caregiver role for 18 months. She has been married to CR for 70 years. CR (83) was recently discharged from the hospital directly to a nursing facility. Lee expected him to die soon. They had an advanced directive which stated that he did not want a feeding tube. They had had numerous conversations about dying in general, because many years ago Lee had a life-after-death experience which affected him profoundly. Lee shared the role of HCA for CR with her granddaughter. In the past two years, Lee has accompanied CR to clinic visits at least monthly, and there were two hospitalizations and numerous ER- admissions. Both Lee and her spouse have ICDs. Lee chose her pseudonym to be the name of their daughter who was murdered as a young woman.

We visited at the NH, in CR's private room. He was restless and SOB, but by now unable to verbalize his distress. The sound of our voices seemed to calm him. Lee appeared younger than her stated age; she was immaculately dressed and wore make-up. Her youthful appearance helped her sell [brand of beauty] products to this day. She was anxious to begin; it was as if she had saved up all the stories of a lifetime for this moment. She launched into the story of his life-after-death experience, before we ever reviewed consent or gathered her demographic information. Unfortunately this story did not get recorded.

CR’s decline became most evident around the time he had an ICD placed 18 months ago. More recently his cognitive function declined but it was unclear if this was related to AHF or dementia. During his most recent hospitalization he suffered aspiration pneumonia. Lee admitted that she had fed him while he was in a recumbent position even though she had been warned not to do so. Apparently this caused some conflict with HCPs who labeled it non-compliant behavior. Lee described a conflicted discharge from the hospital to the NH: First there was an unexpected discussion of his terminal status led by the palliative care specialist who Lee had never met before. Then he was supposed to be discharged the next day but no arrangements had been made. Home health care did not seem to be an option: “I was told that if I didn’t have $60 an hour for 24 hours a day there would be no way that you could care for him at home.” Lee couldn’t recall if hospice care was mentioned at the hospital: “I don’t think they did. I wouldn’t want to be positive about that because I was in a state of mind from the sudden discharge.”

Fortunately Lee’s granddaughter flew in from North Carolina, toured several homes and was able to secure a place for CR for the next day. Then it turned out that the hospital had CR categorized as receiving one-on-one care which delayed the NH transfer for three days during which time Lee felt abandoned by hospital HCPs: “Once they saw that they couldn’t help him he was out on the street. They didn’t really care where he went. In fact, we had three more days that we didn’t see anybody except an occasional nurse.” At the NH, CR did receive a private room but was challenged to physical rehabilitation activities. Because she had promised CR never to “put him in a NH”, Lee was relieved: “I knew he didn’t know he was in a nursing home. He thought he was in a health club, and I just let him believe that because he was happy.”

The rest of the story comes from the bereavement interview Lee invited me to do five days after CR’s death. CR’s activity tolerance rapidly declined and he stopped eating. His weight gain and edema remained undetected for several days until Lee pointed it out and insisted on communicating with his cardiologist about it. There was a flurry of communications and the afternoon of the same day, CR was finally transferred to his own home with hospice care. Again, the suddenness and scope of all the activity was very traumatic for Lee. Thankfully, her granddaughter flew back emergently and there were family members and friends to support Lee in the next few hours. As soon as CR was settled in the hospice bed in his own living room "he just seemed to relax. You just can't believe how he was so serene and everything and wanted to just hold the hand all the time, so I just sat there." CR received two doses of morphine during the next 16 hours, then early morning the next day Lee told me with tears in her eyes:

> "I was with him and he wanted to kiss me. He did. Three times he wanted to kiss. Then he said one more. Then he squeezed my hand and said he loved me and just—gone. Instantly, never moved. I figured he'd move or shake. But he was just so sweet and he just looked so perfect. He didn't have any worry looking on his face or anything like he did over at the NH."

Lee went on to describe the meaningful funeral service conducted by her granddaughter who was a minister, and how she derived comfort from her strong faith and the constant visits and cards of friends and family. The acute stress of circumstances surrounding CR's death resulted in an auto accident Lee sustained during the transfer on the way home from the NH, and a six- hour observational admission to the ER to rule out a blood clot in her leg immediately after he was pronounced dead. Lee called me six months later, to let me know that she was continuing to do well with frequent family visits and active engagement in community affairs. Remembering CR's stories of being-after-death she didn't really miss him because he was still present in her mind. They were still talking she told me, only half in jest!

Lee's was an experience of miscommunication overall. These are some of the things she heard: While she was told clearly by a physician at the hospital that "he didn't have much longer" in a conversation that felt more like between friends than doctor-patient, the sudden discharge where she "didn't understand but thought I had to do these things" left her feeling abandoned by her familiar HCPs and created an adversarial relationship that carried over into the NH environment. CR was not professionally treated like a dying patient. "You couldn't tell if they thought he was going to live or die. They didn't talk to us in any terms. The nurses were just more or less dutiful." Lee who was accepting of his imminent death was not able to advocate for him the way she wanted to. Lee did not offer a metaphor but if I were to visualize her in a picture, it would be the image of an old woman clinging to the hand of an old man tossed about in a hostile sea of system and organizational disorder but finding eventual peace and safety in a story of their own construction.

Librarian

Librarian was an 81 year old white female with 17 years of education. She chose her pseudonym according to her profession of 25 years. She'd been married to CR (84) for 58 years. She has thought of herself in the caregiver role for the past 18 months. CR was diagnosed with heart disease 25 years ago when he had a myocardial infarction and received coronary bypass grafts, followed some time later with an aortic valve replacement. He has since experienced a stroke and developed DM and lymphoma. He was diagnosed with Alzheimer's disease 2 years ago, at the same time when a pacemaker was placed. The standard AD and LW was completed, requesting that there be no resuscitation. There was no discussion about disabling the ICD at any time. Their son was HCA but Librarian pointed out that more discussion with him was necessary because he did not share their values and beliefs about end-of-life preferences. Librarian has accompanied CR to monthly clinic visits for his AHF, more than 24 in the past two years. CR was hospitalized two months before our interview and they had VNA assistance for a while at home.

We visited in the kitchen of their condominium. Throughout our time together, Librarian was preparing for a move to assisted living in a nearby complex. "My main purpose is selfish, but I feel like if I'm not well or something, there's somebody there to care for him." CR was becoming more difficult to care for mostly because of his dementia. Librarian astutely pointed out that at least she didn't have to worry about him wandering off with the Alzheimer's disease, because he would be too weak and tired from the heart failure to be able to do it! She received emotional support from her three children none of which lived close.

While Librarian recognized and appreciated the symptoms of AHF she was much more affected by CR's expressions of Alzheimer's disease. As a couple they had lived busy fulfilling, but separate lives. Now all of a sudden they were very much tied to each other. Librarian got angry about some of his behaviors at times, for example his excessive scratching of a rash, and the fact that he refused to adhere to a toileting intervention designed to prevent incontinence. But she saw the anger as a healthy outlet for her own sanity: "So if I get angry and yell at him, that's okay, he doesn't remember a half-hour later anyway. I guess it doesn't matter. It's a relief for me." After "yelling" at CR she felt "sad, or, I don't know, guilty. And I find myself having to take those pills for heartburn and stuff more than I usually do so I figure my stomach is getting disturbed." Librarian described other anxiety-related physical symptoms which she ascribed to being caregiver to CR; she has not been able to address these with either the CR's or her own physician. "I went for a checkup and told her how things were going. She just glossed it over. She was more interested in my cholesterol count than anything else. I kind of was disappointed that she didn't listen." She felt fully engaged in making healthcare decisions for CR: "CR's doctor talks to me, especially now; he talks to both of us, but it may be directed at me except that CR is there to listen to it. I'm the one that asks the questions." More than the other participants, Librarian described feeling lonely and isolated as caregiver for her CR. But she was also most effective in ACP. By the third interview she had had another discussion with her son who was going to act as HCA: "I told him how we felt. We do not want to have the resuscitate. He said then, he would advocate for our wishes and not his own. If he was going to be on the list after me, he had to agree to that."

Librarian's communication experiences were rather one-sided. While she said she loved to talk, she rarely actually spoke of herself, except in this interview situation which she took very seriously, keeping a journal between visits and taking notes during our conversations. Self-disclosure in that setting led her to seek a support group for caregivers of patients with Alzheimer's disease. She described herself as a private and independent person who did not want to burden others with her own problems, especially family members. Librarian had many questions about Alzheimer's disease and AHF. She didn't know that Alzheimer's disease was a terminal disease and wanted to know the most likely manner of death with both Alzheimer's disease and AHF. She then decided: "I worry that this heart problem will take him. Actually, I think it would be better for him if it would. I don't want to have that happen, but I think the possibility exists."

This last information comes from the final follow-up call. CR died from sudden cardiac death shortly after moving into the assisted living facility. Librarian had gotten an OOH-DNR status on file for him at the ALF. CR died on the sunny outside patio the morning after he had an extended visit with his family and had held his new granddaughter for the first time. Librarian tells that he was carried into the office and an ambulance was called, but after the nurse verified his DNR status they cancelled the call and were never charged for it. Her memories of the event were peaceful, framed by the family visit and the photo taken of CR smiling and holding his baby granddaughter just the day before. Librarian moved back into her old condo after CR's death, was planning to spend Thanksgiving with her daughters in N. and then spend the winter in Florida where she and CR had gone for many years and where friends were waiting for her.

Smiley

Smiley was a 78 years old female. She had 14 years of education and had worked in industrial and clerical jobs. She picked her pseudonym because this is what people called her at work. She had been married twice: divorced her first husband and cared four years for her second husband before he passed away from cancer in hospice care. She had been living with her current partner for 8 years and had been his caregiver for the past five and half years. They had not married for financial reasons and she considered herself financially dependent on him. He was diabetic. The CR also has had kidney and lung cancer which had been treated with a nephrectomy and lung resection respectively, followed by chemo therapy several years ago. She felt that this compounded his exertional SOB. CR generally went to his doctor visits by himself, only recently, for approximately ten visits in the past two years, has she started to accompany him because there has been confusion about his medication management. He did not welcome her into the conversations however. In the past two years, John has had four or five hospital stays and additional ER visits, generally for SOB or issues related to diabetes. While Smiley considered herself involved in healthcare decisions and instrumental in his caregiving she did not want to be HCA for him, thinking that was a task best left to his daughter. After having to make end-of-life decisions with her second husband she said : "I hope I never have to make a decision for anyone except for myself, in that case." After his last hospitalization they were prompted to pursue ACP: "In the hospital they give you all these pamphlets and everything. So we both had to write into someplace in Des Moines—to send us a copy. In fact, I don't think we've gotten that yet." These papers were never completed throughout the study period.

Smiley and I met at a local diner to get the kind of freedom to talk that Smiley wanted. Much of her description of being a caregiver to CR added the caveat that she had to protect herself and her own health (atrial fibrillation) against the stress caused by CR's sometimes belligerent and verbally abusive communication style.

> "It's hard to talk to CR because he's probably the most self-centered person I've ever known. His whole world is about CR. If CR wants it, that's what he gets. If somebody else does, he could care less. Whenever I try to talk to him, like he has an appointment, maybe he forgot, or the time's different, then he gets upset. Well, he likes to use swear words. So, it's my fault that he forgot an appointment or whatever. Sometimes I get frustrated because I'd go to doctor appointments with him, and I sit there and listen so I know what's going on. Then I have a question, and he looks at me like, keep your mouth shut or you're not coming back, this kind of thing. I don't know, sometimes it is frustrating."

She was clear about keeping certain boundaries, for example in trying to help him figure out his list of medications: "I tried to help him going by their list. 'No, you don't know what you're talking about.' So I just left him. If he's going to get sick, you're going to get sick, but at least you're not going to make me sick." Smiley had many questions about AHF and atrial fibrillation as well as medication management for either. She embraced all of CRs life style modifications for own atrial fibrillation and hypertension. Like Chewey she spoke about having to respect the CR's personal autonomy when negotiating shared care. Like Oma and Elmer she gave examples of how she could make continued productivity possible for her CR, for example by doing part of the yard work. Smiley saw herself as somewhat of an ally to HCPs in encouraging CR's adherence, although she had to be circumspect in her communication with CR about it. She was able to convince him to attend a heart seminar at the hospital, used AHA resources for cooking and organized the transfer of medical information to a hospital in Texas where they plan to spend the winter.

At the follow-up phone call two and a half months later, they had had 8-10 doctor's visits but no hospitalizations. Smiley was cautiously planning another winter in Texas with CR. However, he had developed more kidney trouble, and Smiley herself was suffering from severe arthritis in her neck. Smiley offered the following metaphor for being a caregiver to CR: "Being a caregiver for CR., with him it's like going from a sunny day into a storm, I guess. Yeah, because he gets angry, too, and so then there's all that turbulence, and you don't know how bad a storm it is."

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