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INFORMAL FAMILY CAREGIVING AT THE END OF LIFE:
A DISCURSIVE ANALYSIS

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ABSTRACT

Shifts in locations and levels of care and changing demographics have created a high demand for informal family caregivers. The U.S. healthcare system could not sustain the financial or human resources necessary to meet the needs of care recipients who are dying without the assistance of informal family caregivers. End-of-life caregivers pay a price—emotional, social, financial, and physical—throughout the caregiving process. Many factors contribute to the cost of caregiving, such as caregiver distress and burden. Despite the extensive scientific literature on caregiving at the end of life, necessary evidence to inform nursing science in ways that adequately and appropriately support and sustain those healthy informal family caregivers providing end-of-life care remains unknown. No research to date has approached this problem from a linguistic standpoint. This study used discourse-based analysis to examine a qualitative secondary dataset to understand which aspects of self (caregiver) and other (care recipient) are revealed through caregiver discourse and how a caregiver’s perception of self and the care recipient change over time. Principles of discourse analysis were applied to develop an analytic framework and explore the linguistic cues (i.e., grammar, reference, identity, deixis, stance, indexicality and agency) expressed by a caregiver in their role as caregiver. Findings demonstrated the usefulness of a discourse-based analytic method as a new approach in the re-use of large qualitative secondary datasets. In addition, linguistic cues were revealed about how a caregiver perceives self and the care recipient over time. Results established an analytic framework that can be applied to a larger sample of this dataset to more deeply and precisely reveal discursive cues within one End-of-Life Caregiving Trajectory (expected-death) and across all three trajectories (expected-death, unexpected-death and mixed-death). Understanding a caregiver’s discursive cues may give clinicians the ability to better identify subtle yet important expressions of caregivers’ perception of self and others in the caregiving role. Further analysis is
needed to identify how these linguistic patterns can lead to interventions that support informal family caregivers. Timely and appropriate interventions in times of uncertainty can mitigate negative outcomes for the caregiver and care recipient, resulting in a healthy caregiving workforce.
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Chapter 1

Introduction

Background

A nexus of influences has shaped informal family caregiving. The number of adults living with life-limiting chronic conditions has escalated due in large part to advances in life sustaining therapies. Long-term care services are no longer restricted to institutional settings; long-term care is being delivered in the home. In addition, a demographic shift had created a larger segment of the older adult population. Family members are working tirelessly to provide care as illness escalates toward the end of life.

Informal family caregivers provide 75%–90% of the in-home long-term care needed by adults in the United States (Institute of Medicine, 2008; National Alliance for Caregiving & AARP, 2009). In the U.S. approximately 43.5 million informal family caregivers are providing care to someone who is ill, disabled, or aged (National Alliance for Caregiving & AARP, 2015) and 39.8 million unpaid informal family caregivers are providing care for adult family members or friends with chronic conditions (National Alliance for Caregiving & AARP, 2015; Reinhard, Feinberg, Choula, & Houser, 2015). The care provided by these informal family caregivers accounts for 37 billion hours of unpaid care, such as assisting with activities of daily living (ADLs), managing medications, and preparing meals. In 2013, the estimated economic value of informal family caregivers’ unpaid support was $470 billion to $522 billion (Chari, Engberg, Ray, & Mehrotra, 2015; Reinhard et al., 2015). This represents a $20 billion increase from 2009 (Feinberg, Reinhard, Houser, & Choula, 2011).

The demand for family caregivers in the U.S. is expected to increase. A growing number of individuals living with life-limiting conditions (Connor & Bermedo, 2014) are being supported by life-sustaining technologies (i.e., drugs, medical devices, or procedures) (Berlinger,
Jennings, & Wold, 2013; Hart et al., 2015; Oliver, 2016; Skarf & Shwartz, 2017). These factors are compounded by the rapidly increasing older adult population. According to estimates, by the year 2050, the older population (age 65 or older) will reach 20.2% (i.e., approximately 88.5 million people) (Halaweish & Alam, 2015). With one in five Americans over the age of 65 years, the increased prevalence of life-limiting conditions and life-sustaining therapies, and the simultaneous shift in care from institutions to home-based, points to an increased need for informal family caregivers. It has been well-documented that home-based family caregiving has considerable emotional, social, financial, and physical cost for informal family caregivers and may even increase their mortality (Aoun et al., 2015). Sustaining healthy informal family caregivers is critical to supporting the growing demand for care of adults as illness progresses and they approach the EOL.

In this chapter, challenges encountered by informal family caregivers while providing care to dying family members and the lack of resources to adequately support them in this role are discussed. Two conceptual frameworks, Seeking Normal and EOL Caregiving Trajectories, are presented as an interpretative framework for understanding caregiving through the end of life. Research questions are presented and theoretical definitions are defined to clarify those concepts critical to this study. The chapter concludes with a discussion of the significance of this study.

**Statement of the Problem**

Many adults living with illness, disabilities, or chronic/life-limiting conditions require assistance or care to manage everyday life compounded by illness management (National Alliance for Caregiving & AARP, 2015; O’Haire et al., 2011; Penrod, Hupcey, Shipley, Loeb, & Baney 2012a; Waldrop, Kramer, Skretney, Milch, & Finn, 2005). Historically, the term “long-
term care” has been used to refer to services and supports to help frail older adults and younger adults with disabilities maintain their daily lives, typically in institutional settings. The Patient Protection and Affordable Care Act (Patient Protection and Affordable Care Act, P.L. 111-148, as amended) re-defined long-term care services in two ways. First, long-term care delivery systems were re-defined to include both institutionally-based and community-based services. Second, the range of services was expanded to include health care-related services and non-health care services (Harris-Kojetin, Sengupta, Park-Lee, & Valverde, 2013).

Estimates for the amount spent annually on paid long-term care (LTC) services in the United States range from $210.9 billion (O'Shaughnessy, 2011) to $306 billion (Colello, Girvan, Mulvey, & Talaga, 2012; Genworth Financial, 2012; MetLife Mature Market Institute, 2011). Major payers (i.e., Medicare & Medicaid) prefer non-institutional care settings, since home- and community-based LTC services have been shown to be less expensive (Institute of Medicine, 2008; Kaiser Family Foundation, 2012; National Alliance for Caregiving & AARP, 2015). Between the years 1995–2008, a drastic shift from institutionalized to community-based care occurred in expenditures for each of these services. Medicaid spending on LTC community services and home-care services increased from 19% to 42% (Kaiser Family Foundation, 2012). Fortunately, many adults who need LTC services prefer receiving care in a home- or a community-based setting. Because both the payer and patients prefer home- or community-based LTC services, an increase is expected in the number of adults aging and dying in home- or community-based settings in the U.S. (Harris-Kojetin et al., 2013).

Despite the huge investment in LTC by third-party payors, many essential services are provided without cost to insurances or governmental agencies. This assertion is especially salient regarding non-institutional LTC. Unpaid, informal family caregivers provide 75%–90% of the
in-home LTC needed by adults in the United States (Institute of Medicine, 2008; National Alliance for Caregiving & AARP, 2009). An informal family caregiver is “any relative, partner, friend or neighbor who has a significant personal relationship with, and provides a broad range of assistance for, an older person or an adult with a chronic or disabling condition” (Family Caregiver Alliance, 2014, n.p.). Approximately 66 million Americans are unpaid, informal caregivers providing 37 billion hours of unpaid care. The minimum economic value of this care is estimated to be $470 billion additional healthcare dollars (AARP, 2013; National Alliance for Caregiving & AARP, 2015; Reinhard et al., 2015). Without the care provided by informal family caregivers, the cost of LTC in the U.S. would more than double.

Beyond these national trends, the nature of caregiving has shifted. As a result of shorter hospital stays, limited hospital discharge planning, and growth in home-based medical technologies and life-sustaining therapies, informal family caregivers are expected to provide a higher level of care than in the past (Donelan, et al., 2002; National Alliance for Caregiving & AARP, 2015). For example, home care by informal caregivers may include providing wound care, administering parental feedings, and operating medical equipment. As illness progresses and the care recipient progresses toward the end of life, the types of care needed and the challenges faced shift. Necessary changes in care routines range from changing the type/frequency of medications administered to an increased need for physically demanding personal care. Continual and sometimes rapid declines prompt frequent changes in care demands. Coupled with these complex care issues, informal caregivers deal with existential issues surrounding the impending death of their loved one. Informal family caregivers must adapt to these continual and often rapid changes in care demands. Still, caregivers are rarely provided additional training of support to meet these demands, creating stress and burden (Fitzsimons et
Securing paid formal caregiving services to augment the informal caregiver’s role is often difficult and expensive. Many care recipients and their families simply cannot afford this type of care or elect to forego outside services (Rolland, 1987; Tramonti, Barsanti, Bongioanni, Bogliolo, & Rossi, 2014).

Numerous research studies have documented the challenges and demands associated with informal family caregiving through the end of life. Significant personal cost, including emotional, physical, financial, and social strain or burden, have been reported by informal family caregivers providing EOL care (Bee, Barnes, & Luker, 2009; Grande et al., 2009; Kuyper & Wester, 1998; Ohman & Soderberg, 2004; Pinquart & Sorensen, 2003; Stajduhar et al., 2010; Wolff et al., 2009). Some informal family caregivers are not adequately equipped to handle the challenges of caregiving (Pinquart & Sorensen, 2003). Negative outcomes, such as stress, strain, and burden, are strong themes in the informal family caregiver literature (Boter, Rinkel, & de Haan, 2004; Brummett et al., 2006; Northouse, Williams, Given, & McCorkle, 2012; op Reimer, de Hann, Rijnders, Limburg, & van den Bos, 1998; Roth, Perkins, Wadley, Temple, & Haley, 2009; Thommessen et al., 2001). Northouse et al. (2012) asserted that caregiver stress can lead to psychological disturbances, sleep disturbances, changes in the caregivers’ physical health and immune function, and financial well-being. Superimposed on strain and burden is uncertainty throughout the caregiving experience (Greenwood & Mackenzie, 2010; Penrod, 2007).

Insufficient preparation for caregiving duties and the persistent challenges faced by informal family caregivers have been linked to indicators of poor quality of life (Boter et al., 2004; Brummett et al., 2006; Northouse et al., 2012; op Reimer et al., 1998; Roth et al., 2009; Thommessen et al., 2001).
Despite the significant challenges faced during caregiving through the end of life, many informal family caregivers value their role as caregiver and find some reward in the experience. Wolff et al. (2009) reported that 70% of informal family caregivers describe their caregiving experience as making them feel better about themselves and enabling them to appreciate life more. In addition, 76% of informal family caregivers reported feeling “useful” or “needed” in their role as caregiver (Wolff et al., 2009).

An alternative method for understanding caregiver outcomes is to examine informal family caregivers’ perception of the rewards versus burdens of caregiving. In the broader literature (outside of EOL care), the science supports the notion that individual satisfaction increases when expectations are met or exceeded in a given experience (Bell, Kravitz, Thom, Krupat, & Azari, 2002; Bialosky, Bishop, & Cleland, 2010; Calman, 1984; Higginson & Romer, 2000; Janzen et al., 2006; Kravitz, 2001; Mannion et al., 2009; Pager, 2004; Seligman, Wuyek, Geers, Hovory, & Motley, 2009; Thompson & Sunol, 1995; van Dijk, van der Pligt, & Zeelenberg, 1999; Zeelenberg, van Dijk, Manstead, & van der Pligt, 2000). In contrast, when expectations are not met, negative affective and behavioral consequences, including reduced satisfaction, are reported (Bell et al., 2002; Kravitz, 2001; van Dijk et al., 1999; Zeelenberg et. al., 2000). From this perspective, caregivers’ expectations or perceptions of their role represent an important focus for understanding the caregiving experience.

**Purpose of the Study**

The purpose of this study was to demonstrate the utility of discourse analysis to explore caregivers’ perceptions of their role as caregivers, and specifically the expression of self and others in the context of caregiving at the end of life. Discourse analysis involves the systematic examination of patterned uses of discourse (i.e., language, text, and other surrounding semiotic
features of communication) that reveal aspects of the speakers’ or writers’ stances, emotions, feelings, positions, and perceptions. One aspect of discourse analysis uses textual data; that is, textual data can be analyzed to reveal the way in which the perception of reality is presented in words. The textual data selected for this study was a series of 13 interviews provided by one caregiver over one year of caregiving for a terminally ill family member. These data were retrieved from the study entitled *Exploring the Formal/Informal Caregiver Interface across Three Death Trajectories* [NIH/NINR R01NR010127] (Penrod, Hupcey, Baney, & Loeb, 2011b; Penrod et al., 2012a). These serial interviews were exceptionally well-suited to this study of the caregiver’s perception of self in the role of end-of-life caregiving since the likelihood of death was acknowledged (i.e., an expected death trajectory)

**Conceptual Framework**

Two conceptual models set the interpretive frame for this study. First, *Seeking Normal* is a process-oriented model that illustrates the overarching phases of caregiving from pre-diagnosis through bereavement. This framework is general—that is, it is not sensitive to the specific course or duration of phases of caregiving that occur in response to distinctive illness or death trajectories. The second frame of reference, *End-of-Life Caregiving Trajectories*, provides a more detailed description of how the illness/death trajectory influences the course and duration of the phases of the *Seeking Normal* model.

**Seeking Normal**

*Seeking Normal* is a process model that frames the pivotal transitions and phases of caregiving from pre-diagnosis through bereavement. Derived through a grounded theory study, this process-oriented trajectory consists of four phases with three key transitions. The dominant theme of this theory is that across all phases of caregiving, informal family caregivers strive to
re-establish “a steady state, or a sense of pattern” as care demands continually change and even into bereavement (Penrod et al., 2011b, p. 10; Penrod et al., 2012a; Penrod, Baney, Loeb, McGhan, & Shipley, 2012b).

*Sensing a Disruption* describe the period during which the informal family caregiver or the care recipient suspects a health problem. The key transition, *Confirming the Suspicion*, occurs when the suspicion is confirmed and the care recipient receives a diagnosis of a life-threatening or life-limiting condition. At this pivotal point, caregiving progresses into the second phase, *Challenging Normal*. Here, the focus shifts toward treatment and the informal family caregiver tries to maintain a normal life (i.e., life as it was before the diagnosis) while directing the course of care. However, as the condition progresses and care demands escalate, the informal family caregiver reaches the critical transition of *Acknowledging the End of Life*. This transition is marked by an understanding that there is no treatment to cure or to control the advance of the condition. The realization that death from this condition is certain is reached. This acknowledgment of the certainty of death launches the third phase of the trajectory, *Building a New Normal*. In this phase, informal family caregiver assumes a greater responsibility for the care of their dying loved one. During this phase, caregivers provide more active caregiving that is often perceived to be 24 hours a day/7 days a week. The final transition, *Losing Normal*, occurs when the care recipient dies. *Reinventing Normal* describes the final phase in which the caregiver grieves the loss of the care recipient while establishing a new sense of normal without caregiving responsibilities. (Penrod et al., 2011b; Penrod et al., 2012a).

**End-of-Life Caregiving Trajectories**

Building on process-oriented theory, the *End-of-Life Caregiving Trajectories* model examines how these transitions and phases differ in three distinct illness/death trajectories:
expected-death, unexpected-death, and mixed-death (Penrod et al., 2011b). Specifically, this means examining the course and duration of the phases (*Sensing a Disruption, Challenging Normal, Building a New Normal, and Reinventing Normal*) in an illness/death trajectory (Penrod et al., 2012a). Course describes the usual progression of the illness (i.e., symptoms and severity of symptoms, exacerbation periods, episodic fluctuations, and times of stability) and the treatment available for the illness (i.e., aggressive or acute treatment, symptoms management, procedures, or assistive modalities) (Penrod et al., 2012a). Duration describes the time spent within each phase of and throughout the illness trajectory (Penrod et al., 2012a). In each of these trajectories, the duration of *Sensing a Disruption and Reinventing Normal* are similar; however, considerable differences can be seen in the durations of *Building a New Normal and Reinventing Normal*.

The expected-death trajectory describes the course of caregiving when it is clear from diagnosis that the condition is terminal; death is expected (Penrod et al., 2012a). Therefore, Challenging Normal (a treatment-focused phase) is short-lived (Penrod, 2012a). Rather, the caregiver transitions into the phase of *Building a New Normal*, where caregiving is active and the certainty of death is acknowledged. Across a course of progressive decline, treatment focuses on symptom management and promoting quality of life. Amyotrophic lateral sclerosis (ALS) was the illness used to exemplify the expected-death trajectory. The average life expectancy for person diagnosed with ALS is three years; a small percentage of people with ALS have lived up to 10 years with the illness (ALS Association, 2016). This course of illness reveals the prolonged caregiving phase in the trajectory—usually two or more years of active caregiving.

The unexpected death trajectory describes the course faced by those with serious, life-limiting conditions (Penrod et al., 2012a). In these cases, treatment is aimed at managing the
chronic, progressive illness. In this trajectory, the key feature is reiterative cycles of *Challenging Normal* (Penrod et al., 2012a). As the care recipients experience exacerbations that cause periods of aggressive or more acute treatment, the caregiver focuses on treatment acutely. With each exacerbation and recovery, the caregiver continues to focus on treatment within an established pattern of normal life. Often an exacerbation occurs where all effective treatment options have been exhausted and the certainty of death is acknowledged. As a result, the phase of *Building a New Normal* is shortened (Penrod et al., 2011b, Penrod et al., 2012a). In this trajectory, while an early death is statistically probable, it is not certain. Heart Failure (HF) is the illness used to represent the unexpected-death (Penrod, 2012a).

Finally, the mixed-death trajectory presents a course in which early efforts to treat or cure a life-threatening condition ensue. Reiterative cycles of *Challenging Normal* continue until there is a pivotal turn toward end-of-life care as the certainty of death is acknowledged and *Building a New Normal* begins (Penrod et al., 2012b). This transition is sharp, marking a dramatic decline in health. Here the goals of care shift from aggressive, life-saving treatments to EOL care. The duration for Challenging Normal and Building a New Normal can be very similar in duration, unlike the expected-death and unexpected-death trajectory (Penrod, 2012b). Lung Cancer is the illness used to demonstrate the mixed death trajectory.

**Research Questions**

This study addressed the following research questions:

1. How can the principles of discourse analysis be applied to develop an analytic framework that enables further exploration of the linguistic cues expressing caregiver’s perceptions of self and others?
2. Which aspects of self and the care recipient are revealed through the discourse of the caregiver?

a. How does a caregiver’s perception of self change over time?

b. How does a caregiver’s perception of the care recipient change over time?

Theoretical Definitions

Caregiver or informal family caregiver: “an unpaid individual (a spouse, partner, family member, friend, or neighbor) involved in assisting others with activities of daily living and/or medical tasks” (Family Caregiver Alliance, 2012 p. 1)

Care recipient: a person who receives care from an informal family caregiving

Discourse: “the social and cognitive process of putting the world into words, of transforming our perceptions, experiences, emotions, understandings, and desires into a common medium for expression and communication, through language and other semiotic resources” (Strauss & Feiz, 2014, p. 1)

Grammar: “a component of discourse through “which we organize our thinking and express thoughts and ideas in word [nouns, pronouns, verbs, adjectives, adverbs, and prepositions], phrases, or sentences” (Strauss & Feiz, 2014, pp. 14; 18)

Reference: the relationship between words and the things, ideas, entities, states, and people that such words designate” (Straus & Feiz, 2014, p. 99) and can differentiate facets of an individual’s identity

Identity: “refers to the physical and psychological traits and interactional behaviors that characterize who we are as individuals, that distinguish us as unique from others, and that motivate to think, believe and act as we do” (Strauss & Feiz, 2014, p. 293).
Deixis: “the ‘pointing’ function in language” (Freeman, n.d., para 2) or a specific function of a word (usually article or pronoun) whose denotation changes from one discourse to another (Strauss & Feiz, 2014).

Stance: “the speaker’s…feelings, attitudes, perspectives, or position as enacted in discourse … Stance is enacted and created, it is negotiated and renegotiated” (Strauss & Feiz, 2014, p. 103).

Indexicality: “a specific type of meaning expressed through linguistic forms that is not semantic or literal and that is entirely dependent on context” (Strauss & Fiez, 2014, p. 266).

Agency: “the capacity of an individual or group to effect change on some entity, person, experience, state, and so forth” (Strauss & Feiz, 2014, p. 293).

Significance of the Study

This study introduced discourse analysis as an analytic method to extend scientific understanding through secondary analysis of qualitative data. There is no question that qualitative research has produced significant advances in nursing science. Qualitative research requires a significant investment of resources in the production of high-quality datasets that are appropriate for addressing specific research questions. However, at the conclusion of the original study investigation, many high-quality datasets are shelved or archived, leaving rich data unanalyzed. This study examined the utility of discourse analysis to explore caregivers’ perceptions of their role as caregivers, and specifically the expression of self and others in the context of caregiving at the end of life through an analysis of previously collected qualitative data. The application of discourse analysis approaches to a large dataset requires the development of an analytic framework specifying the most relevant components of the discourse. The analytic framework derived in this study will permit continued study of the discourse of end-
of-life caregiving through more extensive exploration of the caregiving experiences in the larger dataset.

**Chapter Summary**

Informal family caregivers are an invaluable resource in the United States. Americans diagnosed with life-limiting conditions are living longer due to advances in life-sustaining therapies. Long-term care has shifted from institutions into the home setting. The need for informal family caregivers is expected to increase and the demands placed on informal family caregivers will be challenging (Buyck et al., 2011; Currow et al., 2011). The purpose of this study was to demonstrate the utility of discourse analysis in exploring caregivers’ perceptions of their role as caregivers, and specifically the expression of self and others in the context of caregiving at the end of life. Understanding the experiences of informal family caregivers is essential to determining strategies to support and protect this valuable resource in the healthcare system. A greater understanding of the caregiving experience will ultimately improve outcomes for all stakeholders: care recipients, informal family caregivers, and the U.S. healthcare system (Bee et al., 2009; Currow et al., 2011; Grande et al., 2009).
Chapter 2

Literature Review

Introduction

In the United States, informal family caregivers serve as an extension of the formal healthcare system and provide an economic value of an estimated $470 billion to $522 billion yearly (Chari et al., 2015; Reinhard, et al., 2015). The economic value of informal family caregiving surpasses the cost of formal home health and nursing home care combined (Arno, Levine, & Memmott, 1999; Feinberg et al., 2011; Institute of Medicine, 2011; National Alliance for Caregiving & AARP, 2015; Office of Disease Prevention and Health Promotion, 2011). Nearly 66 million Americans are informal family caregivers, providing care in 30% of U.S. households (AARP, 2013; National Alliance for Caregiving & AARP, 2015). Informal family caregivers provide care to someone who is ill, disabled, or aged, and devote over 37 billion hours to providing caregiving services (Chari et al., 2015; Feinberg et al., 2011; National Alliance for Caregiving & AARP, 2015). On average, informal family caregivers are in the role for four years (Caregiving in the U.S., 2015), but 24% provide care for over five years. Higher-hour caregivers are twice as likely to have been caregiving for 10 years or more (Caregiving in the U.S., 2015). Caregiving is complex, and informal family caregivers face physical, psychosocial, financial, and existential challenges. Informal family caregivers experience negative health outcomes, strain, and burden due to caregiving (Adelman, Tmanova, Delgado, Dion, & Lachs, 2014; Christakis & Allison, 2006; Garlo, O’Leary, Van Ness, & Fried, 2010; Pressler et al., 2009). Securing and sustaining healthy informal family caregivers is necessary to support the growing demand for care of adults approaching EOL.
This chapter focuses on the scientific literatures on informal family caregivers; challenges of caregiving at the EOL; perspectives of trajectories of caregiving; challenges across EOL Caregiving Trajectories; resources across EOL Caregiving Trajectories; and identity, agency, and caregiving. The informal family caregiver literature indicated shifts in healthcare, broad financial implications, demographics of caregivers, caregiving needs, and the cost to informal family caregivers in their role of caregiver. Caregiving in the EOL literature explained three distinct EOL caregiving trajectories: expected-death, unexpected-death, and mixed-death. Challenges faced and resource availability and usage also were discussed. Finally, an overview is provided of identity and agency in the context of adult caregivers caring for adult care recipients with life-limiting conditions. A summary is presented at the end of the chapter.

**Informal Family Caregivers**

The Informal Family Caregiver is broadly defined as an unpaid family member or friend who provides support or assistance to a person with a chronic or disabling condition (Family Caregiver Alliance, 2006). However, a formal definition of informal family caregiver is “an unpaid individual (a spouse, partner, family member, friend, or neighbor) involved in assisting others with activities of daily living and/or medical tasks” (Family Caregiver Alliance, 2012 p. 1). The support or assistance provided by informal family caregivers goes beyond “customary and normative social support” (Hebert & Schulz, 2006. p. 1174). Informal family caregivers’ commitment, emotional involvement, and understanding of the care recipients’ needs demonstrate that caring is a special way of being, thinking, believing, acting, and growing within the experience of the illness trajectory (Baider, Cooper, & Kaplan De-Nour, 1996; Surbone, Baider, & Balducci, 2011). Although in recent years the healthcare system has acknowledged the
role of informal family caregivers, the significance of their contributions is often under-recognized by the formal healthcare system.

**Shift in Healthcare**

Since the 1980s, there has been a shift in the delivery of healthcare into community settings in the United States. These changes rely on care provided by informal family caregivers (Harrington-Meyer & Parker, 2011). Due to the prevalence of life-limiting conditions, the increased longevity of people with certain conditions as a result of life-sustaining therapies, the aging U.S. population, shorter hospital stays, changes in insurance reimbursement, and expanded home health technology, the demand for informal family caregivers is expected to increase by 85% by the year 2030 (Aldrich, 2011). In Pennsylvania, the potential informal family caregiver to potential care recipient ratio was 6:1 in 1990 and 5.8:1 in 2010. In the future, the ratio is expected to continue to decrease to 3.9:1 in 2030 and 3.3:1 by 2050 (Redfoot, Feinberg, & Houser, 2013). Informal family caregivers are and will remain the primary source of long-term care services in the United States (Chari et al., 2015). With the narrowing ratio of potential informal family caregivers to potential care recipients, supporting informal family caregivers is critical. The U.S. does not have the formal services or financial resources to support the needs of care recipients without the use of informal family caregivers.

**Financial Implications**

While the sheer number of informal family caregivers providing care is remarkable, the value and savings to the healthcare system is even more staggering. The most recent cost estimates value informal family caregiving services at $470 billion to $522 billion annually (Chari et al., 2015; Reinhard et al., 2015). Over the last decade, the value of unpaid informal family caregiving has risen significantly. In 2009, the services provided by informal family
Informal family caregivers had an estimated value of $450 billion, which represented an increase of 20% ($375 billion) from 2007 (Feinberg et al., 2011; Gibson & Houser, 2007). In the last eight years, this is a difference of nearly $11 billion per year. According to Coughlin (2010), the value of unpaid informal family caregivers is and will likely continue to be the largest source of LTC services in the U.S (Chari et al., 2015). In fact, Medicare expenditures for LTC cost $446 billion in 2010 (Congressional Budget Office, 2014), which does not include value or cost expenditures for the informal family caregivers. If Medicare had to cover the cost or reimburse for services provided by informal family caregivers, the total cost of LTC would more than double, with an estimate of $968 billion.

Non-licensed individuals (e.g., personal shopper, housekeeper) and licensed healthcare personnel (e.g., direct care workers/nursing assistants, licensed practical nurses, and registered nurses) may provide community-based LTC services. Licensed healthcare personnel can provide services that are within their scope of practice. For instance, direct care workers/nursing assistants provide unskilled care, such as bathing, grooming, and dressing. Licensed practical nurses or registered nurses provide skilled care, such as catheterizations, medication administration, and wound dressing changes. Some of these services are covered by insurances and Medicare; however, many are not and can be very expensive. With the growing need for LTC services, the U.S. healthcare system is taxed in terms of financial and human resources and cannot meet all healthcare needs without the assistance of informal family caregivers.

Thus, informal family caregivers meet a necessary need, providing care in a state and federal healthcare system that is strained both in terms of financial and human resources. Informal family caregivers provide both unskilled and skilled care needs. The level of care that different formal caregivers are permitted to deliver is defined in their respective scopes of
practice (e.g., RN, LPN, or Nursing Assistant). Based on their particular scope of practice, each group of healthcare personnel can replace only a fraction of what the informal family caregivers complete in their role. If paid formal caregivers replaced informal family caregivers, both unskilled (e.g., nursing assistant, direct care worker) and skilled (registered nurse, licensed practical nurse) healthcare personnel would be necessary. The estimated cost of covering unskilled and skilled tasks provided by the informal family caregivers is $221 billion and $642 billion, respectively (Chari et al., 2015). Replacing informal family caregivers with healthcare personnel would cost the healthcare system over $863 billion, which is more than the estimated value of informal family caregivers. This furthers reinforces the important role informal family caregivers play in the U.S. healthcare system.

**Demographics**

Informal family caregivers are balancing multiple roles and responsibilities in addition to caregiving, including paid employment, family life, and social responsibilities (Bialon & Coke, 2012; Clemmer, Ward-Griffin, & Forbes, 2008; Rubin & White-Means, 2009). The time commitment in caring for a dependent individual can be nearly that of an additional full-time job for these informal family caregivers. In general, informal family caregivers spend 24.4 hours each week providing care; however, 23% of informal family caregivers provide 41 or more hours of care a week (Caregiving in the U.S., 2015). Caring for a spouse/partner was even more time-intensive for informal family caregivers, with care-time averaging 44.6 hours a week (Caregiving in the U.S., 2015). Eighty-two percent of informal family caregivers are taking care of one care recipient, while others are providing care to more than one care recipient (Caregiving in the U.S., 2015). Balancing this time commitment with the informal family caregivers’ other responsibilities is not the only factor influencing the role of informal family caregiver.
The informal family caregivers’ gender, age, health, and income are other major factors impacting the role of caregiving. In the United States, the typical informal family caregiver is a 49-year-old married, employed woman caring for her widowed 69-year-old mother who does not live with her (Caregiving in the U.S., 2015; National Alliance for Caregiving & AARP, 2009). However, given the nearly 66 million Americans providing informal caregiving services, informal family caregivers can also be described as diverse and a group which faces varied challenges.

**Gender Differences**

Currently, female informal family caregivers outnumber male informal family caregivers. Approximately 60–65% (21.75 million) of informal family caregivers are women (Caregiving in the U.S., 2015). Not only are these women providing care to a loved one, but 34% provide care to two or more people. More than 37% have children/grandchildren under 18 years old living with them (National Alliance for Caregiving & AARP, 2009). In addition, women who are informal family caregivers are 2.5 times more likely than non-caregivers to live in poverty and five times more likely to receive Supplemental Security Income (National Institute on Aging, 2004).

Males account for a smaller portion of informal family caregivers. Approximately 40–45% of informal family caregivers are males, and they constitute 14.5 million individuals providing care to adult care recipients (Kramer & Thompson, 2002; National Alliance for Caregiving & AARP, 2009). Several authors have suggested that the number of male caregivers is increasing, and with some asserting that the increase is due to a variety of social-demographic factors (e.g., income, recession, changing gender expectations, and longer life expectancies).
Men participate in caregiving, but women still contribute the majority of care (Pinquart & Sorensen, 2006). For example, female caregivers spend more time providing care than men—21.9 hours versus 17.4 hours per week, respectively (National Alliance for Caregiving & AARP, 2009). Male informal family caregivers are less likely to provide direct personal care and more likely to help with finances and other less physically burdensome tasks. Male informal family caregivers also are more likely to arrange care and use paid assistance or formal caregivers (National Alliance for Caregiving & AARP, 2009). Females provide a greater degree of direct care. Of all caregivers, 60% provide assistance with at least one ADL, while only 24% of males helped a care recipient get dressed and 16% assisted with bathing (Caregiving in the U.S., 2015; National Alliance for Caregiving & AARP, 2009; Pinquart & Sorensen, 2006). However, among spousal caregivers age 75 years or older, both genders provide equal amounts of care (McCann et al., 2000). Seventy percent of informal family caregivers caring for a spouse help with at least one ADL (71%), while only 57% of non-spousal caregivers provide direct care (Caregiving in the U.S., 2015). Other studies have shown that 36% of women informal family caregivers handle the most physically difficult caregiving tasks (e.g., bathing, toileting, and dressing) compared with 24% of their male counterparts.

**Caregiving Needs/Demands**

According to the Caregiving in the U.S. study (2015), informal family caregivers indicate that the main reasons the care recipient needs care are old age (14%) and Alzheimer’s dementia (8%). Fifty-nine percent of care recipients have long-term physical conditions and 26% have a memory problem (Caregiving in the U.S., 2015). Fifty-three percent of care recipients have been
hospitalized in the past 12 months (Caregiving in the U.S., 2015). Many informal family caregivers reported having no choice in taking on the role of caregiver (Friedemann & Buckwalter, 2014; Paulson & Bassett, 2015; Steele, 2015). Providing supportive services to informal family caregivers who feel this sense of obligation may help mitigate some of the negative impacts of caregiving.

Fifty-nine percent of informal family caregivers assist with at least one ADL while other informal family caregivers provide assistance with IADLs (Caregiving in the U.S., 2015). The most common ADL requiring assistance was transfers, with 43% of informal family caregivers assisting the care recipient with getting in and out of bed and chairs (Caregiving in the U.S., 2015). Higher-hour caregivers tend to assist with all ADLs (Caregiving in the U.S., 2015). Many of these activities prove challenging for the informal family caregivers. Twenty-five percent acknowledged that assisting with ADLs is “difficult” (Caregiving in the U.S., 2015). The more ADLs with which informal family caregivers assist with, the more likely they were to report “difficulty” (Caregiving in the U.S., 2015). Among those who assist with all six ADLs, 48% of informal family caregivers reported the tasks to be difficult (Caregiving in the U.S., 2015). The ADL reported as most difficult was toileting. Forty percent of informal family caregivers reported that dealing with incontinence and incontinent briefs was difficult, and 33% reported assisting with toileting was difficult (Caregiving in the U.S., 2015). With regard to IADLs, on average, informal family caregivers provide 4.2 out of the 7 activities, with transportation (78%), shopping (grocery and other) (76%), and housework (72%) being the three most often provided by informal family caregivers (Caregiving in the U.S., 2015).

Another caregiving responsibility that falls outside of the ADLs and IADLs is interacting with professionals and agencies (Caregiving in the U.S. 2015). Although this might not be as
physically challenging, these interactions can be time-intensive and psychologically challenging. Sixty-six percent of informal family caregivers monitor the care recipient’s condition and adjust care (Caregiving in the U.S., 2015). Assessing the care recipient and modifying interventions may prove challenging for informal family caregivers, especially those who lack training or confidence. While 63% communicate with healthcare professionals, 50% of informal family caregivers reported needing to advocate for the care recipient (Caregiving in the U.S., 2105). Advocating for care recipients’ needs/wants adds additional strain for informal family caregivers, especially when the informal family caregivers or the care recipient feel their goals have not been met. Fifty-seven percent of informal family caregivers provide complex medical or nursing tasks, such as injections, tube feedings, catheter care, and colostomy care (Caregiving in the U.S., 2015). Despite many lacking the proper education/training to take on these tasks, only 14% of the informal family caregivers who provide these medical or nursing tasks reported these tasks to be difficult (Caregiving in the U.S., 2015). Higher-hour caregivers are more likely to report these tasks as difficult (Caregiving in the U.S., 2015); however, it is unclear if this is due to the increase in hours or simply that the tasks are more difficult. Many are time-consuming, and many informal family caregivers lack the necessary knowledge and skills to perform these tasks confidently. Specifically, 42% of the informal family caregivers assisting with medical/nursing skills reported not having any preparation (Caregiving in the U.S., 2015), while only 14% reported having some type of training. For higher-hour caregivers, 60% of informal family caregivers reported not having any prior preparation. Lack of training can lead to high levels of burden on informal family caregivers. For those who received no previous preparation or training, 62% reported high burden (Caregiving in the U.S., 2015).
In addition to a lack of preparation for providing care to the care recipient, the extent of formal assistance or even the presence of other informal family caregivers willing to assist is limited. Thirty-three percent of informal family caregivers receive no formal or informal assistance with care (Caregiving in the U.S., 2015). Higher-hour- (57%) and spousal- (78%) informal family caregivers are more likely to be the sole caregiver. Only 32% of care recipients get formal assistance, which can range from aides, to housekeepers, to other paid help.

The relationship between informal family caregivers and care recipients can influence the informal family caregiver’s needs and decision to seek additional services (Montgomery & Kosloski, 2000). Spousal-informal family caregivers tend not to identify “self” as caregivers until they have begun to provide direct, hands-on care. As a result, they often fail to seek formal support during the first stages of the informal family caregiver experience. Adult children more often identify themselves as caregivers when the care recipient is disabled. Therefore, they are more likely to seek formal support early (Montgomery & Kosloski, 2000).

Cost of Caregiving

Informal family caregivers can face financial burdens due to the cost of caregiving. Time spent caregiving reduces the number of paid work hours (Cannuscio et al., 2004; Dumont et al., 2009; Koerin, Harrigan, & Secret, 2008; Sawatzky & Fowler-Kerry, 2003). In fact, 69% of informal family caregivers reported having to rearrange their work schedule to meet caregiving responsibilities (Feinberg et al., 2011). Approximately 70% of working informal family caregivers endured work-related difficulties when trying to balance competing demands of caregiving and work (National Alliance for Caregiving & AARP, 2009). In addition, 5% turned down a promotion, 4% chose early retirement, and 37% reduced their work hours or gave up working entirely due to caregiving (Houser & Gibson, 2008). As a result, informal family
caregivers suffer the loss of wages and employer-provided health insurance, as well as other employment benefits, such as retirement and Social Security benefits. The MetLife Mature Market Institute (2011) estimated that 10 million informal family caregivers over 50 years of age forego $3 trillion in lost wages, pensions, retirement, and benefits. In fact, the lower an individual’s income and education level, the more likely that individual is to be a caregiver (Gallup Healthways Wellbeing Survey, 2011). There are even greater financial burdens for female caregivers. Women over the age of 50 years who are caring for their parents lose an estimated $324,044 due to caregiving, compared to men at $283,716. Lost wages for women who leave the workforce early due to caregiving responsibilities experience an estimated loss of $142,693. This results in a $131,351 loss of Social Security benefits and a $50,000 loss in pensions (MetLife Mature Market Institute, 2011).

**Challenges of Caregiving at the End of Life**

While general caregiving presents challenges to and negative outcomes for informal family caregivers, the realization of the inevitable death of the care recipient further intensifies the challenging dynamics of EOL caregiving (Roth et al., 2009). Wallerstedt, Andershed, and Benzein (2014) described three themes and nine patterns for the multiple realities in family caregiving at the end of life. The first theme, becoming a caregiver, is marked by the patterns of having the will, the option, no invitation, and no ability to provide care. The second theme is the challenge of facing death. Three patterns were noted in the theme: having the need for communication and planning, experiencing death as expected or as a surprise, and the impact of loss and grief. The final theme is the meaning of receiving sitting services when the care recipient is actively dying, which leads to the patterns of having to hand over responsibility to another party and experiencing “betrayal” as a result of having limited or no control over the
situation. This study provides insight into the multiple realities of informal family caregivers and the importance of providing support that meets the specific needs of those caregivers (Wallerstedt et al., 2014).

Serious physical, psychosocial, financial, and existential challenges are present throughout the EOL caregiving trajectory, as well as during the dying/bereavement process (Zarit, Reever, & Bach-Peterson, 1980). Challenges are conceptualized as the perception of demands on the informal family caregivers. As challenges emerge, informal family caregivers’ sense of confidence and control shift, creating caregiver distress (Penrod et al., 2012a). Caregiver distress has been examined across the trajectory of caregiving from role acquisition through bereavement (Given et al., 2004; Kurtz, Kurtz, Stommel, Given, & Given, 2002; Nijboer, Tempelaar, Triemstra, van den Bos, & Sanderman, 2001; Northouse, Mood, Templin, Mellon, & George, 2000; Weitzner, Haley, & Chen, 2000; Weitzner, Moody, & McMillan, 1997; Wyatt, Friedman, Given, Given, & Beckrow, 1999). Informal family caregivers may experience negative physical and emotional symptoms referred to as caregiver distress (Yilmaz, Turan, & Gungogar, 2009). Expressions of uncertainty are remarkable indicators of caregiver distress (Given, Given, & Kozachick, 2001; Penrod et al., 2012a).

Penrod (2007) defined uncertainty as “a perception of doubt or not knowing that is brought about by cognitive and pre-cognitive ways of knowing. Doubt may be manifest in the meaning or outcomes of a life experience and is reflected in one’s sense of confidence (reflecting issues of meaning) and control (reflecting issues of outcome)” (p. 664). States of uncertainty are pervasive in the EOL caregiving literature. Uncertainty can be seen in caregiver reports of an inability to plan ahead or plan for the future (Adams, 2006; Burman, 2001; Frankowska & Wiechula, 2011; Galvin, Todres, & Richardson, 2005; Huang & Peng, 2010; Lin, Lin, Lee, &
Uncertainty can stem from a caregiver’s perception of the illness trajectory, prognosis, or care recipient’s health status and the care needed. States of uncertainty are highly individualized and established by the caregiver’s sense of confidence and control. Confidence and control, essential characteristics of uncertainty, create a dynamic flow in uncertainty. Confidence is defined as “sensing an ability to read a situation” (Penrod, 2002, p. 58) and control is the “ability to influence the outcome of the situation” (Penrod, 2002, p. 58). In the caregiving literature, confidence is linked to knowledge, skills, and experience. Control is the sense of influence the caregiver has. As the care recipient’s health/function declines, the caregiver’s sense of control fades (Murray et al., 2010; Penrod, 2011a).

Quality of life is defined as the degree of satisfaction or dissatisfaction with personal, social, and environmental expectations beyond basic human needs (World Health Organization [WHO], 1995). In EOL informal family caregiving, factors contributing to a positive quality of life include general well-being; physical well-being (physical health, physical symptoms); psychological well-being (overall mental health, emotional distress, serenity, mood, social support, social desirability); existential well-being; financial well-being (good financial status); and burden (Arlt et al., 2008; Cohen, Mount, Strobel, & Bui, 1995; Pinquart & Sorensen, 2007; Weitzner, Jacobsen, Wagner Jr, Friedland, & Cox, 1999a; Weitzner, McMillan, & Jacobsen, 1999b). When resources are available, adequate, and employed to manage the challenges of caregiving, informal family caregiver distress is minimized and at times even resolved. However, if challenges are not managed or are left unresolved, the levels of distress continue to override positive aspects of informal family caregivers, and quality of life suffers (Yilmaz et al., 2009) and informal family caregivers are at risk of burnout (Yilmaz et al., 2009).
Factors that can improve informal family caregivers’ quality of life and reduce the risk of burn-out include optimization of the health status of the care recipient, independence from the care recipient, and support (Vellone, Piras, Talucci, & Cohen, 2008). According to Williams, Wang, and Kitchen (2016), the majority of support that EOL informal family caregivers receive comes from informal social support networks such as children, extended family, or close friends/neighbors, rather than formal sources. EOL informal family caregivers who required more support experienced greater negative impacts on their quality of life, employment stability, and advancement, as well as their employment hours (Williams et al., 2016).

**Perspectives of Trajectories of Caregiving**

In order to develop the state of science in EOL caregiving, researchers must document the real-time experiences of informal family caregivers navigating through caregiving at the EOL (Steinhauser et al., 2006). Caregiving trajectory “refers to a course of actions of caregiving and how this course reflects how caregiving is organized, managed, and shaped through time” (Robles-Silva, 2008, p. 359). The caregiving trajectory involves “(a) how the caregiving tasks are performed; (b) determining how activities are adjusted around changes in the ill person’s needs; (c) handling contingencies and crises; and (d) balancing care and demands of the illness” (p. 359). An important facet of the caregiving trajectory is the relationship between the informal family caregiver and the care recipient and the type, number, and frequency of care activities (Robles-Silva, 2008). Robles and Silva (2008) described five phases of the caregiving trajectory: onset, semi-care, care, dying, and termination. Each phase can vary in duration (from no time to months to years) and consist of two key factors: variability and combination.

Depending on the illness trajectory, the initiation or “onset” of the caregiving role may be gradual or very sudden (Cameron & Gignac, 2008; Robles-Silva, 2008) and the informal family
caregiver may not remember when the transition into caregiver occurred, as it was so subtle (Robles-Silva, 2008). Individuals may feel obligated to take on the informal family caregiver or may inherit the role unwillingly because other options have been exhausted or are not available (Stajduhar & Davies, 2005). A systematic review of caregiver reluctance involved 17 articles. General findings revealed that caregiver reluctance as a concept needed further exploration (Burridge, Winch, & Clavarino, 2007). Although research support was limited, this systematic review revealed that a perceived lack of choice was the major indicator of caregiving reluctance (Burridge et al., 2007). In addition, social norms were powerful motivators in accepting the role of caregiver, as women outnumbered males and caring was seen as “women’s work” (Atkin, 1992; Australian Institute of Health & Welfare, 2004; Campbell & Martin-Matthews, 2003).

Robles-Salvo (2008) identified the second phase of caregiving as the semi-care phase, which occurs when the informal family caregiver provides low-intensity caregiving that requires minimal time, such as social support or reminding care recipients of medication times. The care phase is when active caregiving occurs and a caregiving routine needs to be established as the care recipient is dependent on the informal family caregiver. The informal family caregiver is focusing on managing symptoms, supporting the care recipient in their transition to a chronically ill person with life-limiting conditions, and balancing the caregiving while attempting to provide a stable, positive environment for the care recipient. Decision-making may transition from care recipient-decision-making, to care recipient-informal family caregiver shared decision-making, to informal family caregiver decision-making. Through the trials of caregiving, the informal family caregiver has gained knowledge and skills related to the illness and caregiving and, therefore, assessment of symptoms, symptom management, and care skills may improve with time. This stage ends with either the care recipient’s condition improving and the informal
family caregiver providing only intermittent care or the care recipient’s condition worsening and care needs increasing. In the fourth phase, dying, the informal family caregiver withdraws from direct care but continues to make decisions and delegate care to formal caregivers (hospital staff). The informal family caregiver provides comfort care and hopes the care recipient will die to escape further suffering. Termination is the final phase and occurs when the care recipient dies and caregiving is no longer needed (Robles-Silva, 2008).

Other researchers have examined the caregiving trajectory to explore strategies to better support the informal family caregivers in this role and ultimately to enhance outcomes. Northfield and Nebauer (2010) conducted a systematic review of how informal family caregivers of cancer patients cope with the caregiving trajectory. The review included 70 peer-reviewed articles focused on the impact of a cancer diagnosis on families, and resultant caregiver stress and coping across the caregiving trajectory. Their analysis revealed that although many studies focused on the numerous challenges encountered by informal family caregivers caring for someone with cancer, little research had been conducted on the strategies used by informal family caregivers at specific stages along the trajectory to optimize informal family caregiver health or recovery (Northfield & Nebauer, 2010).

Waldrop and Meeker (2011) developed a conceptual model of Crisis Resolution in End-of-Life Care that provides insight into the dynamics that precipitate a crisis specific to caregiving at the EOL. This model was adapted from and expanded on the original framework of crisis theory (Waldrop & Meeker, 2011). In the Crisis Resolution in EOL Care model, with the progression of the illness trajectory comes increased physical, psychological, emotional, and social needs. As a result, a lack of adequate resources may prevent informal family caregivers’ needs from being met, creating disequilibrium and disorganization (Waldrop & Meeker, 2011).
Mahoney, La Rose, and Mahoney (2015) studied informal family caregivers who provide care to dementia patients. Initially, informal family caregivers focused on preserving the dignity of the care recipient by maintaining a usual routine when faced with daily challenges; however, when challenges became persistent and compounding, the informal family caregivers’ focus shifted to preservation of the informal family caregivers’ health and preservation of self (Mahoney et al., 2015). From this research, a “Preservation of Self Model: Care Recipient to Care Giver” was developed (Mahoney et al., 2015). These authors noted that simple training on challenges such as dressing can prevent challenges from escalating to where the caregiving switches focus from care recipient to self-preservation through the trajectory of EOL caregiving.

**End-of-Life Caregiving Trajectories**

In addition to the general understanding of caregiving trajectories, a deeper understanding of distinct death trajectories is warranted. Penrod and colleagues (2011b; 2012a) developed three EOL Caregiving Trajectories that describe caregiving across an expected-death trajectory (illness exemplar: amyotrophic lateral sclerosis); an unexpected-death trajectory (illness exemplar: heart failure); and mixed-death trajectory (illness exemplar: lung cancer).

Using grounded theory methods, this study explored the experiences of informal family caregivers providing care across multiple life-limiting disease trajectories to reveal the phases and stages of caregiving leading to EOL care (Penrod et al., 2012a). Standard analytic procedures used in grounded theory were applied by the research team. All participants (n=46) provided written informed consent. Data were collected through face-to-face and telephone interviews ranging from 30 to 90 minutes in duration. Initial, monthly, and post-death (up to 13 per participants) interviews were conducted (Penrod et al., 2012a). Interviews were initially unstructured but as theoretical insights emerged, interviews became more focused to explicate
contextual features and dimensions of the model. Data collection and analysis were iterative. Data collection was discontinued when saturation was reached (Penrod et al., 2012a). These strategies resulted in a rich dataset with clean transcripts of the caregivers’ experiences of care at the EOL across multiple life-limiting disease trajectories

**Caregiving in the Expected-Death Trajectory: Amyotrophic Lateral Sclerosis**

Amyotrophic lateral sclerosis (ALS) is a terminal condition that causes a rapid, progressive deterioration and loss of the upper and lower motor neurons that facilitate the movement of body parts. Since there is no specific diagnostic test, diagnosis is sometimes difficult and delayed. Initial symptoms of ALS may include muscle weakness, atrophy, hyperreflexia, dysphagia, or dysarthria. Later stages of ALS are marked by severely limited mobility and respiratory failure, which is the ultimate cause of death (Clarke & Levine, 2011). Progressive paralysis can result in a “locked-in” state in which only residual muscular movement is possible, but mental awareness remains unchanged. The average life expectancy for a person diagnosed with ALS is three years, but the progression of the disease is unpredictable and a small percentage of care recipients have been known to live up to 10 years (ALS Association, 2016). As ALS progresses, so does the informal family caregivers’ level of burden and need to adapt to new responsibilities (Albert & Levine, 2004). Informal family caregivers experience physical, psychosocial, financial, and existential challenges (Aoun, Connors, Priddis, Breen, & Colyer, 2012; Bialon & Coke, 2012; Chio, Gauthier, Calvo, Ghiglione, & Mutani, 2005; Cipolletta, Marchesin & Benini, 2013; Cipolletta & Oprandi, 2014; Clemmer et al., 2008; Hecht et al., 2003; Jenkinson, Fitzpatrick, Swash, Peto, & the ALS-HPS Steering Group, 2000; Oyebode, Smith, & Morrison, 2013; Ray & Street, 2005; Roberto & Jarrott, 2008; Rubin & White-Means 2009). With the diagnosis of ALS, death is inevitable, as there is no cure and
progression of the disease can be rapid. The focus of ALS treatment is never to cure the disease, but rather to provide symptom management and quality of life to the care recipient. The EOL caregiving trajectory of ALS is very different from that of heart failure and lung cancer.

The expected-death trajectory is exemplified by ALS. This trajectory begins with Sensing a Disruption and care recipient symptoms are evident, but no official diagnosis is confirmed (Penrod et al., 2011b; Penrod et al., 2012a). Examples of early symptoms for ALS can include but are not limited to difficulty with ambulation and ADLs, weakness/clumsiness in one or extremities, slurred speech or difficulty swallowing, and muscle cramping (ALS Association, 2016). This trajectory transitions into the next phase when suspicions are confirmed and the diagnosis is received; Challenging Normal begins. Here the caregiver assumes a supportive role while attempting to maintain some sense of normalcy of everyday life. Early discussions and education is designed to anticipate care recipient needs and prepare the caregiver. Challenging Normal is a short-lived phase in expected-death trajectory; the prognosis of this condition is clear and death is expected. After certainty of death is acknowledged, Building a New Normal begins. The majority of time is spent in Building a New Normal, where caregiving is active and the illness has a steady progressive decline. Here the caregiver faces new caregiving demands and changes in routines that create distress. Focus is on symptom management and quality of life. In this phase, care recipients with ALS require total care for ADLS including mobility and toileting and loose their ability to swallow or speak. Conversations and decisions about life-sustaining modalities, such as ventilator and alternative methods for nutrition, often occur during this phase (ALS Association, 2016). The average life expectancy for person diagnosed with ALS is three years; a small percentage of people with ALS have lived up to 10 years with the illness (ALS Association, 2016). This could mean two or more years of active caregiving and living in the
phase of *Building a New Normal* (Penrod, et al., 2011b; Penrod, et al., 2012a). In the last transition, the care recipient dies, leaving the caregiver to *Reinvent Normal*, as he/she works to establish a new routine in life in the absence of the care recipient and the role of caregiver. This phase has an extended bereavement period.

**Caregiving in the Unexpected-Death Trajectory: Heart Failure**

Heart failure (HF) is a chronic, debilitating illness with increasing prevalence in the population in general and particularly in older adults (Quaglietti, Lovett, Hawthorne, Byler, & Atwood, 2002; 2003). Individuals with heart failure are significantly older, experience significantly higher rates of impairment in ADLs, have higher rates of cognitive impairment, and suffer from more severe health instability (Fernandes & Guthrie, 2015). Despite these characteristics, HF patients are less likely to be explicitly diagnosed with a terminal prognosis (less than six months) and therefore lack access to necessary interventions to support the care recipient and informal family caregivers (Fernandes & Guthrie, 2015). When compared to cancer patients, individuals dying with end-stage cardiorespiratory disease are less likely to receive full, and easily understood, information to make them aware that they are dying (Exley, Field, Jones, & Stokes, 2005). Given the instability of and impairments resulting from this disease, HF is one of the most common causes for hospital admissions (Quaglietti et al., 2002; 2003). In fact, HF patients are more likely to die in the hospital (Olshansky et al., 2007). All of these factors contribute to significant healthcare expenses, which are reported to be $32 billion annually (Heidenreich et al., 2011).

HF affects all aspects of the lives of care recipients and informal family caregivers (Aldred, Gott, & Gariballa, 2005). Care recipients have progressively failing health with exacerbation periods, which lead to greater dependence on the informal family caregivers, social
isolation, and family burden for the care recipients and informal family caregivers (Fitzsimons et al., 2007). Important dimensions of care are influenced by the informal family caregiver’s knowledge of the patient's comorbidities, extent of debility, personal values, and goals of care (Friesinger & Butler, 2000). In the role of caregivers for HF, informal family caregivers can be conceptualized as having two identities — “conductors” and “second fiddles” (Lowson et al., 2013, p. 1199). Informal family caregivers take the lead to maintain flexible continuity of care, while taking a back seat to the care recipient’s needs. The extent to which the informal family caregivers neglect themselves determines the negative outcomes experienced by the informal family caregivers (Lowson et al., 2013).

HF was used to illustrate the unexpected-death trajectory, which begins with Sensing a Disruption (Penrod et al., 2011b; Penrod et al., 2012a). Similarly to the other trajectories, symptoms are noted by the care recipient and caregiver. Early symptoms may include dyspnea, especially when lying flat; fatigue; weakness; dependent edema; irregular heart rate/rhythm; persistent cough, and/or activity intolerance (Mayo Clinic, 2017). Upon diagnosis of the illness, suspicions are confirmed and Challenging Normal begins. In these cases, treatment is aimed at managing chronic, progressive conditions that typically limit life. Much of the duration of this trajectory is spent in reiterative cycles of Challenging Normal (Penrod et al., 2012a). With each exacerbation more acute treatment is necessary and although the care recipient recovers, each exacerbation leaves the care recipient more debilitated. These exacerbations may result in multiple acute care stays, procedures, and complicated medication regimens. With each decline, the caregiver establishes a steady but temporary state of normal. In many cases, the caregiver struggles to find a balance between care recipient independence/dependence and questions their functional abilities. Finally, an exacerbation occurs and effective treatments are exhausted. At
this rapid treatment point the caregiver acknowledges that end of life is inevitable and Building a New Normal begins. Building a New Normal is a short and often dramatic phase in the unexpected-death trajectory. The caregiver is often surprised by the certainty of death as the care recipient has recovered from past episodic exacerbations (Penrod et al., 2011b, Penrod et al., 2012a). Finally, when the care recipient dies, the caregiver struggles to Reinvent Normal (Penrod et al., 2011b; Penrod et al., 2012a) The shock of what is perceived as a sudden death causes may cause profound grief, extending the Reinventing Normal phase.

**Caregiving in the Mixed-Death Trajectory: Advanced Lung Cancer**

Lung cancer is a chronic disease with a mixed-death trajectory exemplified by a winding path from diagnosis to aggressive treatment, uncertainty in remission, new recurrence, palliation, and finally death. Lung cancer is the leading (27%) cause of cancer death in both men and women in the United States (Ferlay et al., 2013). Accounting for 1.8 million new lung cancer cases a year, 1.6 million deaths worldwide result from lung cancer (Ferlay et al., 2013). Historically, lung cancer survival rates have been low, and little has changed over the last 50 years (Howlander et al., 2010). Stage of diagnosis is a contributing factor to survival rates, and survival rates decline with age (Howlander et al., 2010).

A lung cancer diagnosis not only affects the quality of life of the care recipient, but significantly impacts informal family caregivers (Girgis & Lambert, 2009; Janda et al., 2008; Kim, Kashy, Spillers, & Evans, 2010; Stenberg, Ruland, & Miaskowski, 2010). Informal family caregivers shoulder a critical role in care delivery to lung cancer care recipients (Aranda & Hayman-White, 2001). As informal family caregivers aim to provide physical and emotional support to the care recipient, physical, psychosocial, financial, and existential challenges are faced (Hudson & Payne, 2009) that directly and indirectly affect the informal family caregivers’
physical, emotional, and financial well-being (Brink, Stones, & Smith, 2012; Cipolletta, Shams, Tonello, & Pruneddu, 2013; Stenberg et al., 2010). Informal family caregivers of lung cancer care recipients continue to express a variety of unmet needs (Girgis et al., 2013; Hwang et al., 2003; Mangan, Taylor, Yabroff, Fleming, & Ingham, 2003; Sharpe, Butow, Smith, McConnell, & Clarke, 2005). One study reported that simply having access to clear, timely information alleviated anxiety, reduced uncertainty, and improved coping strategies of the informal family caregivers (Cain, MacLean, & Sellick, 2004; Rabow, Hauser, & Adams, 2004).

The mixed-death trajectory can be seen in lung cancer. Sensing a Disruption begins when the care recipient and caregiver suspect that something may be wrong (Penrod et al., 2011b; Penrod et al., 2012a). Early symptoms of lung cancer include a persistent and/or productive cough with hemoptysis, shortness of breath, chest pain that worsens with deep breathing, loss of appetite or weight loss, or fatigue or weakness (American Cancer Society, 2016). Once suspicions are confirmed, Challenging Normal presents a course in which early efforts to treat or cure the cancer ensue. Treatment can include any combination of the following: surgery, chemotherapy, radiation therapy, and targeted therapies (Centers for Disease Control and Prevention, 2014). While attempting to maintain some sense of life before the diagnosis, the caregiver balances multiple treatments/procedures and the care demands needed due to treatments. Treatment can include any combination of surgery, chemotherapy, radiation therapy, and targeted therapies (Centers for Disease Control and Prevention, 2014). Reiterative cycles of Challenging Normal continue until there is a pivotal turn and treatment options are exhausted (Penrod et al., 2011b; Penrod et al., 2012a). When certainty of death is acknowledged, the shift toward end-of-life care occurs and Building a New Normal begins (Penrod et al., 2012a). This transition is a drastic, sharp decline; care demands increase. Here the goals of care shift from
aggressive, life-saving treatments to EOL. Management of pain, shortness of breath, and other end of life symptoms need careful attention. The duration for Challenging Normal and Building a New Normal can be very similar in duration, unlike the expected-death and unexpected-death trajectory (Penrod et al., 2011b; Penrod et al., 2012a). When the death of the care recipient occurs, Reinventing Normal begins. Similar to expected-death and unexpected-death, the bereavement period can be prolonged in this trajectory.

Challenges across End-of-Life Caregiving Trajectories

Caregiving can be a rewarding experience; however, informal family caregivers face challenges every day in their roles as caregiver. Challenges can include time management, competing demands, paying for care, or physical or mental stress and strain. Guided by the literature, challenges have been categorized into four types: physical, psychosocial, financial, and existential. Each category is discussed below with particular reference to the challenges faced by caregivers in each of the distinct EOL caregiving trajectories.

Physical Challenges

Physical challenges faced by informal family caregivers are consistently noted in the literature in all three EOL caregiving trajectories. For all three trajectories, informal family caregivers provide physical care (ADLs and IADLs); however, the timing, duration, and intensity of physical care varies among the three EOL caregiving trajectories.

As ALS progresses, the care recipient requires increasing levels of care including physical care (ADLs and IADLs), which may result in physical challenges for informal family caregivers. This expected death EOL caregiving trajectory is marked by a rapid physical decline. Typically, the care recipient’s partner assumes the role of primary caregiver and takes on the physical challenges presented by the disease (Cleary, Kizar, Kalra, & Johnston, 2008; Gauthier
et al., 2007; Goy, Carter, & Ganzini, 2008; Pagnini, 2013). With the continual decline of the care recipient, the physical challenges and the 24-hour-a-day supervision assumed by informal family caregivers are intense. On average, informal family caregivers spend up to 11 hours per day providing care to someone with ALS (Cipolletta & Amicucci, 2015; Gauthier et al., 2007).

Similar to informal family caregiving in ALS, physical challenges perceived by informal family caregivers in the context of heart failure (HF) include providing direct personal care (ADL) and personal assistance (IADLs). Other physical challenges specific to this trajectory include encouraging activity by the care recipient, managing his/her symptoms, supervising adequate nutrition while maintaining sodium/fluid balance, monitoring his/her weight, and maintaining schedule demands (e.g., physician appointments, medication regimen) of both the care recipient and the self (Fernandes & Guthrie, 2015; Molloy, Johnston, & Witham, 2005; Sautter et al., 2014). In addition to the logistics, HF symptoms can be distressing to the care recipient and physically challenging to informal family caregivers. This unexpected death is marked by distressing symptoms or exacerbations that lead to multiple hospitalizations (Aldred et al., 2005; Friesinger & Butler, 2000). Frequent hospitalizations, discharges, and readmissions can add to the physical challenges faced by informal family caregivers.

Informal family caregivers of those with advanced lung cancer also provide assistance with ADLs and typically take on additional family responsibilities to compensate for the declining ability of the care recipient (Girgis & Lambert, 2009). Physical health issues attributed to caregiving for lung cancer care recipients include: pain, poor sleep, and balancing work and caregiving (Lambert, Girgis, Lecathelinais, & Stacey, 2013; Lambert, Jones, Girgis, & Lecathelinais, 2012; Regan et al., 2012). Across this mixed trajectory, caregiver demands shift as multiple attempts at treatment are implemented prior to the pivot toward end-of-life care.
Informal family caregivers of those with advanced lung cancer report considerable physical, psychosocial, financial, and existential challenges for which interventions designed to mitigate these challenges are often ineffective (Candy, Jones, Drake, Leurent, & King, 2011).

**Psychosocial Challenges**

Informal family caregivers described the psychosocial challenges that they encountered as being a “demanding and overwhelming task” (Aoun et al., 2012, p. 845). Expression of concerns, losses, and transitions can be attributed to the psychosocial challenges faced by informal family caregivers. Informal family caregivers expressed concerns surrounding patient safety, social restrictions, informal family caregivers’ tiredness, informal family caregivers’ emotions (anger and frustration), uncertainty about the future, and adequacy of resources (Oyebode et al., 2013). Informal family caregivers’ expressions of loss include the loss of care recipient’s health, care recipient’s identity, hope, and intimacy with partner (Oyebode et al., 2013). Expressions of transitions in roles include role shift from partner to caregiver and adjustments made throughout the illness trajectory, which compound the challenging caregiving experience (Aoun et al., 2012; Oyebode et al., 2013). However, the caregivers also attempted to adjust to the situation by trying to remain strong (inhibit signs of grief), retaining a sense of normality, appreciating the provisions of specialist services, adopting a problem-solving approach, living day to day, and trying to remain positive (Oyebode et al., 2013).

Informal family caregivers expressed an absence of compassion on the part of healthcare professionals. This leads to serious emotional consequences for the caregivers and difficulty in obtaining timely palliative care. Informal family caregivers face challenges such as inability to access services, limited access to information, and lack of awareness of service availability (O’Brien, Whitehead, Murphy, Mitchell, & Jack, 2012). As a result of these barriers, informal
family caregivers may lack faith in the healthcare system. In addition, care recipients with ALS and their caregivers often do not access services in an attempt to retain control and maintain normality within the home (O’Brien et al., 2012).

Communication barriers are a psychosocial challenge that is not necessarily unique to informal family caregivers attending to care recipients with ALS but is more prominent among this group than with other informal family caregivers (Brownlee & Bruening, 2012). According to Brownlee and Bruening (2012), communication between informal family caregivers and care recipients often focuses on physical needs, caregiving issues, and family issues. As the care recipient declines, communication strategies progress through modalities that include natural speech, writing, gestures, and electronic and communication devices. Despite adaptive equipment, communication quality and quantity diminish over time. As communication becomes difficult or nonexistent, informal family caregivers struggle with decision-making based on care recipient wishes, especially when decisions about life-extending treatment (gastrostomy tube insertion and/or mechanical ventilation) versus terminal palliative care are considered (McCluskey, 2007). According to Danel-Brunaud, Laurier, Parent, Moreau, Defebvre, Jacquemin, and Destee (2009), 48% of care recipients with ALS refused to consider EOL treatment options, and only 20% explicitly expressed advance directives, despite being well informed about their disease prognosis. This shifts the burden of decision-making back to the informal family caregivers—yet another challenge faced by the informal family caregivers.

Limited research exists regarding EOL decision-making for care recipients diagnosed with ALS and their informal family caregivers (Seeber, Hijdra, Vermeulen, & Willems, 2012). The available scientific evidence suggests that discussions and resolutions about EOL decision making seemed to be prompted by the occurrence of life-threatening situations directly or
indirectly resulting from the disease itself (Seeber et al., 2012). Some ALS studies have shown that timely discussion of treatment options improved EOL decision-making (Hirano & Yamazaki, 2010). The use of advance directives and collaboration with other related practitioners are recommended to enhance communication associated with psychological challenges (Ushikubo & Okamoto, 2012).

The psychosocial challenges faced by informal family caregivers providing care to care recipients with HF are somewhat different from those of other EOL trajectories. HF is said to alter everyday activities and can be socially isolating for both the informal family caregivers and care recipient (Aldred et al., 2005; Weller Moore, 2002). A disassociation of self is one way the informal family caregivers can survive the madness of HF. The need to be available to the care recipient 24-7 was experienced as both a comfort and a strain (Brannstrom, Ekman, Boman, & Strandberg, 2007). Psychosocial challenges experienced by the informal family caregivers include continual vigilance, lack of control, lack of knowledge, lack of support, and competing demands (e.g., social life, work life, family life). Informal family caregivers acknowledged specific challenges such as interpreting symptoms, managing clinical and emotional manifestations of heart failure, and communicating with the care recipient and healthcare provider (Bursch, 2012). Informal family caregivers felt neglected by the healthcare providers who failed to address the severity of the caregiving experience for HF (Brostrom, Stromberg, Dahlstrom, & Fridlund, 2003).

These challenges further stress the informal family caregivers. Informal family caregivers of care recipients with HF experience high caregiver burden and depressive symptoms (Hooley, Butler, & Howlett, 2005; Martensson, Dracup, Canary, & Fridlung, 2003). Younger informal family caregivers face higher risk for emotional stress and depression (Dracup et al., 2004).
Bursch (2012) explored how informal family caregivers experience self in the role of caregiving for care recipient living with HF. The essence of Bursch’s (2012) findings revealed informal family caregivers’ experience as “being fearfully vigilant, at the mercy of the disease while worrying about that which remains unspoken” (p. 88).

Informal family caregivers of care recipients with LC experience different kinds of psychosocial challenges. In many cases, the informal family caregiver was the coordinator and provider of care at home, excluded from participation in institutional care and lacking the information and support to extend their role with confidence. Care recipients and informal family caregivers manage many aspects of end-of-life care for themselves. Identifying ways to extend their skills and strengthen their voices, particularly in hospital settings, would be welcomed and may reduce unnecessary end-of-life transitions (Hanratty et al., 2014). According to Akechi et al. (2006), adjustment disorders and major depression were the most common psychiatric diagnoses for family members of care recipients with LC (Akechi et al., 2006). In this study, spouses-informal family caregivers accounted for 85% of participants.

**Existential Challenges**

Existential challenges specific to informal family caregivers for care recipients living with ALS were rarely noted in the literature. Brownlee and Bruening (2012) examined communication between informal family caregivers and care recipients with ALS. Not surprisingly, topics of spirituality, as well as death and dying, were the least discussed topics among care recipients and informal family caregivers. Usual communication focused on physical needs, caregiving issues, and family issues (Brownlee & Bruening, 2012).

Existential challenges are more prevalent in informal family caregivers of care recipients with HF given the health instability of the care recipients and understanding of the Unexpected-
Death EOL caregiving trajectory (Fernandes & Guthrie, 2015; Penrod et al., 2011b). Among informal family caregivers of care recipients with HF, concerns about the future of the care recipient were common. One specific existential challenge faced by informal family caregivers of care recipients with HF was uncertainty around prognostication and EOL. Informal family caregivers and healthcare providers disagreed about the extent and clarity of communication around prognostication (Imes, Dougherty, Pyper, & Sullivan, 2011). Healthcare providers reported having a detailed discussion; however, informal family caregivers felt that the conversation never occurred. Some studies have asserted that despite the lack of communication regarding a terminal prognosis, informal family caregivers of care recipients with HF made realistic statements about the limited life expectancy of the care recipient and the inevitability of imminent death (Aldred et al., 2005; Fitzsimons et al., 2007). Another study supported the notion that informal family caregivers and care recipients may not want to openly acknowledge the terminal nature of the condition and expressed fears about further deterioration (Kendall et al., 2015). All informal family caregivers in this study expressed concerns regarding the care recipient’s future, and some expressed feelings of depression, while others reported acceptance of the inevitability of imminent death (Fitzsimons et al., 2007).

For informal family caregivers of care recipients with LC, existential challenges centered on grief and death. Complicated grief symptoms were higher among informal family caregivers with less education, among families with lower prior conflict but higher conflict at the end-of-life, who had family members who had difficulty accepting the illness, and who were caring for patients with greater fear of death. Hospice utilization moderated the effect of fear of death on complicated grief (Kramer, Kavanaugh, Trentham-Dietz, Walsh, & Yonker, 2009).
**Financial Challenges**

Studies specific to financial challenges faced by informal family caregivers providing care to care recipients diagnosed with ALS, HF or LC were lacking. However, the broader literature on informal family caregivers discusses the financial implications of caregiving, such as lost wages (Bialon & Coke, 2012; Clemmer et al., 2008; Gallup Healthways Wellbeing Survey, 2011; MetLife Mature Market Institute, 2011; Rubin & White-Means 2009). Specifically, to informal family caregivers of care recipients with HF, frequent care recipient hospitalization contributes to financial burden (Dracup et al., 2004; Pattenden, Roberts, & Lewin, 2007; Saunders, 2008). According to a group of authors examining informal family caregivers of care recipients with LC, financial challenges were attributed to a reduction in work hours (Lambert et al., 2013; Lambert et al., 2012; Regan et al., 2012). In a study of lung, breast, colorectal, and prostate cancer, lung cancer had the highest expected total cost (Round, Jones, & Morris, 2015).

Although the onset and duration of the types of challenges faced by informal family caregivers vary based on the distinct EOL caregiving trajectory, each type of challenge has the potential to create negative outcomes for informal family caregivers, such as stress, strain or burden. Over time or with increased demands placed on informal family caregivers, the negative outcomes are compounded, leading to poor quality of life. Resources, if appropriate and utilized, may mitigate this caregiver strain.

**Resources across End-of-Life Caregiving Trajectories**

Resources are “…objects, characteristics, conditions, or energies that are valued by the individual…” (Hobfoll, 2001, p. 339) Further, they may also “… serve as a means for attainment of these objects, personal characteristics, conditions, or energies” (Hobfoll, 1989, p. 516).
Resources can be characterized as objective (e.g., equipment or transportation), condition (e.g., personal relationships), personal (e.g., skills), and energy (e.g., knowledge). Resources are an important consideration in caregiving. If resources are available, adequate, and utilized, they can mitigate the challenges faced by caregivers (Harber, Einev-Cohen, & Lang, 2008). Conversely, when resources are inadequate, perceptions of threat will be exaggerated (Harber et al., 2008), creating stress, increased strain, and caregiver burden (Bee et al., 2009; Grande et al., 2009; Kuyper & Wester, 1998; McGhan, 2014; Ohman & Soderberg, 2004; Pinquart & Sorensen, 2003; Stajduhar et al., 2010; Wolff et al., 2009).

Research specific to resource availability is limited; however, the caregiver literature notes that resources for informal family caregivers are expensive and difficult to access (Administration on Aging, 2012; Institute of Medicine, 2008; Kaiser Family Foundation, 2012; National Alliance for Caregiving & AARP, 2009). Funds available for formal caregiving resources, such as respite and home care, are limited, while demand for these resources continues to increase as care shifts from institutionalized settings to community-based/home care. Non-skilled caregiver duties are not a Medicare/Medicaid benefit and therefore an expensive out-of-pocket cost for families dealing with chronically ill and dying care recipients (Administration on Aging, 2012; Institute of Medicine, 2008; Kaiser Family Foundation, 2012; National Alliance for Caregiving & AARP, 2009). In addition to the cost of resources, informal family caregivers reported an inability to access services, limited access to information, and lack of awareness of service availability (O'Brien et al., 2012). These are seen as barriers that decrease the informal family caregivers’ confidence in formal resources/the healthcare system. One study noted that as a result of this lack of faith in the healthcare system, informal family caregivers do not access
services in an attempt to retain control and maintain normality within the home (O’Brien et al., 2012).

As with resource availability, research on resource utilization is limited. What has been examined focuses on minimal use or lack of resource utilization (Hong, 2010; Keith, Wacker & Collins, 2009) and negative caregiver outcomes (strain, satisfaction, and physical impairments) (Blyth, Cumming, Brnabic, & Cousins, 2008; Monin & Schulz, 2009; Teipel et al., 2015; Tooth et al., 2008). The National Alliance for Family Caregiving (2015) found that only 9% of informal family caregivers use respite care services and only 11% of informal family caregivers accessed support groups. Those who did utilize these services accessed them late in the caregiving trajectory, limiting the benefit of the service (Hong, 2010). Expanding on this research, McGhan (2014) examined whether informal family caregiver outcomes were moderated by resource utilization and informal family caregivers’ perceptions of resource adequacy. Findings revealed that as the utilization of formal resources (e.g., support groups, respite care) increases, caregiver strain increases (McGhan, 2014). One resource, social support, was found to have a positive relationship with informal family caregiver satisfaction and lower levels of strain (McGhan, 2014). When resources are perceived to be inadequate, caregivers’ perception of threat will be exaggerated (Harber et al., 2008). The escalation of threat induces stress, increased strain, and caregiver burden (Bee et al., 2009; Grande et al., 2009; Kuyper & Wester, 1998; McGhan, 2014; Ohman & Soderberg, 2004; Pinquart & Sorensen, 2003; Stajduhar et al., 2010; Wolff et al., 2009).

Identity, Agency, and Caregiving

In the most general sense, the term caregiving often refers to a parent caring for (parenting) their minor or adult child. In the context of this study, caregiving refers to an adult
person providing care to an adult with a life-limiting condition. Caregiver identity and agency has not been well developed in this context. Identity and agency are described next, followed by a presentation of the limited scientific evidence on both these concepts in relationship to the adult caregiver and adult care recipient.

Identity refers to “the physical and psychological traits and interactional behaviors that characterize who we are as individuals” (Strauss & Feiz, 2014, p. 286). Identity is complex and dynamic and motivates us to think, believe and act in the manner we do. Identity combines our personhood (our individual makeup, personality, likes/dislikes, beliefs, and values) with our outward behaviors (how we want others to perceive us and how others do perceive or recognize us). Some aspects of both individual and social identity can be stable or fixed, while other features remain malleable and shaped by our experiences. In and through discourse we enact, create, and recreate our identities (i.e., members of a family, a profession, a community).

While identity examines who we are and what we do, agency focuses on the capacity of an individual (or group) to effect change. Three aspects of agency can be theorized through different perspectives: human agency as an epistemic issue for the use of narratives in the social sciences; linguistic agency for the analysis of character representations in the storyworld; and agency for narrating in a storied world (author-narrator-audience relationship). For the purpose of this paper, human agency was the focus and will be referred to simply as agency.

Agency is defined as “the capacity of an individual or group to effect change on some entity, person, experience, state, and so forth (Strauss & Feiz, 2014, p. 293) and is essential to the study of self, identity, and personhood. Duranti (2004) described agency “…as the property of those entities (i) that have some degree of control over their own behavior, (ii) whose actions in the world affect other entities’ (and sometimes their own), and (iii) whose actions are the object
of evaluation (e.g., in terms of their responsibility for a given outcome) (p. 453). Agency can be determined by the actions of an individual (or group) as based on consciousness, free will, decision-making, and engagement in both world and self, particularly in narrative self-construction. Agency examines several key features, such as what is an action, who is responsible for that action, and how do we determine whether that action is meaningful.

Agency is reflected in discourse through “grammatical and conceptual meaning of action transitivity, voice, and causation” (Strauss & Feiz, 2014, p. 293). Agency is often associated with responsibility (or blame), action, and cause-effect. Agency is not directional. It is fluid and has degrees of magnitude from highly agentive to non-agentive. In fact, agency can be discursively mitigated with the use of passive voice. The passive voice can avoid placing responsibility on any one individual or group and therefore creating an “agentless passive” (Strauss & Feiz, 2014, p. 295). However, in many cases agency is self-constructed and seen as highly or moderately agentive. Since agency is linked to the change-potential of entities, agency is also associated with the idea of power and control and the degree of that control.

Although several studies have been conducted on agency, identity, and caregiving, many have examined caring for (parenting) minor child(ren). One study reviewed the agentive way by which a sense of ‘self’ emerges in individuals with Alzheimer’s; however, this was from the viewpoint of the care recipient, not the caregiver (Ramanathan, 2009). Although not directly focused on agency, Krieger et al. (2015) examined caregiver language and illness identity in the medical treatment decision-making (specifically cancer treatment) (Krieger et al., 2015). Caregivers either framed the illness as a characteristic of the patient or as part of their relational identity. Caregivers with a patient-level personal identity frame used phrases such as “their body” or “their decision.” Caregivers with a relational identity frame used plural pronouns such
as “we” or “our” when describing the treatment decision. These findings have practical and clinical implications for improving family communication in cases when illness reshapes individual perceptions of the self and relationship roles. Health care providers should pay close attention to determine if patients and their caregivers have similar views of illness identity in the decision-making process. One example that may signal discord between the patient and the caregiver is in situations in which patients discuss treatment decisions using “I” language and caregivers are using “we” language (Krieger et al., 2015).

**Chapter Summary**

In order to understand the discourse of caregiving in end-of-life situations, it is critical to understand the state of the science surrounding caregiving, end-of-life caregiving, trajectories describing caregiving over time, and specific challenges faced by caregivers traversing distinct death trajectories. Identity and agency were described, followed by the current state of the science in relation to caregiving for adults with life-limiting conditions. However, an understanding of discursive expressions of identity and agency in informal family caregivers’ perception of self does not exist. Closing this gap could expand on understanding of the informal family caregivers’ experience and address the question of how informal family caregivers discursively construct their sense of self within the context of EOL caregiving.
Chapter 3

Methodology

Introduction

A series of 13 longitudinal interviews by one end-of-life caregiver participating in the NIH-NINR study entitled *Exploring the Formal/Informal Caregiver Interface across Three Death Trajectories* were analyzed using discourse analysis. Discourse analysis of this qualitative dataset provides an opportunity to extend the scientific evidence regarding the experience of caregiving at the EOL. Discourse analysis of this qualitative dataset was selected as best suited to answering the following research questions:

1. How can the principles of discourse analysis be applied to develop an analytic framework to further explore the linguistic cues expressing caregiver’s perceptions of self and others?

2. Which aspects of self and the care recipient are revealed through the discourse of the caregiver?
   
   a. How does a caregiver’s perception of self change over time?
   
   b. How does a caregiver’s perception of the care recipient change over time?

Secondary Analysis

Secondary analysis involves the use of existing data, collected for the purposes of a prior line of inquiry (Alasuutari, Bickman, & Brannen, 2008; Heaton, 2008). Using secondary analysis, researchers can answer research questions that are distinct from the original study aims. Secondary analysis provides opportunities to maximize the use of data, especially data that may be expensive and time-intensive to collect. This approach can extend the science by answering high-impact research questions while using fewer resources (Smith et al., 2011). Corti (2007)
described the re-analysis of data as an effective approach for developing knowledge, especially when data are focused on vulnerable populations.

Since the mid-1990s, there has been an increased interest in secondary analysis of qualitative data (Alasuutari et al., 2008; Heaton, 2008). Secondary analysis can involve the use of single or multiple datasets, as well as mixed qualitative and quantitative datasets (Alasuutari et al., 2008; Heaton, 2008). Secondary data can be accessed through data archives or informal data-sharing, or by reusing data from one’s own research (Alasuutari et al., 2008; Heaton, 2008). According to Heaton (2008), there are five main types of secondary analyses of qualitative data: supra analysis, supplementary analysis, re-analysis, amplified analysis, and assorted analysis (Alasuutari et al., 2008). Supra analysis transcends the original study work by exploring new theoretical, empirical, or methodological questions (Alasuutari et al., 2008; Coltart, Henwood, & Shirani, 2013; Smith, 2008). Supplementary analysis involves a more in-depth look at an issue not fully addressed in the original study. This approach may focus on a particular theme or issue that emerged from the original study (Alasuutari et al., 2008; Heaton, 2008). Re-analysis focuses on verifying or corroborating the findings from the original study (Alasuutari et al., 2008; Heaton, 2008). The purpose of amplified analysis is to take two or more studies and create an aggregate dataset. The combined dataset is used to compare different populations (Alasuutari et al., 2008; Heaton, 2008). Assorted analysis combines the original study qualitative dataset “with additional primary research and/or documentary analysis of relevant materials” (Alasuutari et al., 2008, p. 511).

The literature on the secondary analysis of qualitative data is not robust. The focus has most often been on how-to topics such as: “how to design secondary studies reusing qualitative data; how to find and select relevant datasets; how to analyze qualitative secondary data; how to
assure and assess the quality of secondary studies; and what to include in reports of such studies” (Heaton, 2004; Heaton, 2008, pp. 512-513; Hinds, Vogel, & Clarke-Steffen, 1997; Thorne, 1994). Thus, there is an urgent need for further research to advance the literature regarding nuances in secondary analyses of qualitative data.

For example, controversy exists around secondary analysis of qualitative data, including epistemological, practical, ethical, and legal problems related to its use. Important considerations when using qualitative secondary data include: 1) compatibility of the data with secondary analysis and the scope for additional in-depth analysis; 2) ethical and appropriate access to data; and 3) reporting the results as secondary analysis (Heaton, 2008). From an epistemological stance, some qualitative researchers have argued that the basic tenets of qualitative inquiry make secondary data analysis difficult as data collected to answer one research question may not be compatible (i.e., be a good “fit”) to answer future questions (Heaton, 2004; Szabo & Strang, 1997; Thorne, 1994). However, other qualitative researchers have debated this point. Corti and Thompson (2004) asserted that secondary data analysis “allows for unexpected topics of investigation…without being directly solicited by the researchers”; therefore, secondary data analysis may provide answers to new questions. Sandelowski (1997) argued that data that could not be used in the original study might be salvaged by applying secondary analyses.

Others have argued that since the researcher performing a secondary analysis was not present at the time of data collection, there is a risk of a lack of understanding of the context in which the data were collected (Corti & Thompson, 2006; Hammersley, 1997; Heaton, 2004; Hinds et al., 1997; Mauthner, Parry, & Backett-Milburn, 1998; Parry and Mauthner, 2005; Thorne, 1994). However, particularly in larger studies, typically one researcher does not collect all the data; mitigating the argument regarding researcher involvement in data collection (Heaton
2004). Other authors have asserted that an increased familiarity with the data over time (i.e.,
deep immersion in the dataset) facilitates the emergence of new perspectives that are ripe for
secondary analyses (Coltart et al., 2013; Heaton, 2008). Consulting with the principal
investigator of the original study is recommended to minimize challenges related to
understanding context and protocol in using qualitative data collection that is subsequently re-
analyzed (Corti & Thompson, 2006; Hinds et al., 1997).

Ethical and legal considerations related to secondary analyses are related to consent and
confidentiality. The secondary researcher must confirm that duly-approved informed consent
procedures were followed. The analysis of de-identified data is preferred to protect
confidentiality. Although this approach meets the requirements for the protection of human
subjects, there has been some debate regarding whether researchers conducting secondary data
analysis should attempt to seek consent from the participants (Alderson, 1998; Corti, Day, &
Backhouse, 2000; Heaton, 2004; Parry & Mauthner, 2004; Richardson & Godfrey, 2003). More
recently, this debate has been quieted since finding participants after the study can be difficult for
the researcher and unwanted by the participant (Heaton, 2008), particularly among vulnerable
participants who have been properly consented for the research.

Description of Original Study

“Exploring the Formal/Informal Caregiver Interface across 3 Death Trajectories”
[NIH/NINR R01NR010127] was the original study in which data were collected and
subsequently re-analyzed using discourse analysis. The original grounded theory study explored
informal family caregiver experiences in providing EOL care from the pre-terminal through the
terminal phases. Key informants (n=46) from three distinct EOL caregiving trajectories—
expected (ALS), unexpected (HF), and mixed (lung cancer)—participated in interviews for up to
one year in the caregiving role (Penrod et al., 2011b; Penrod et al., 2012a; Penrod et al., 2012b). Initial individual face-to-face interviews and subsequent monthly interviews via telephone or face-to-face were conducted with informal family caregivers. During the initial interview, the researchers collected background and demographic information. Following the baseline interview, each participant was interviewed monthly for up to one year. The longitudinal interviews were semi-structured to explore informal family caregivers’ perceptions of their caregiving experience, and to gain insights regarding times of uncertainty and perceptions of the significance of experiences during times of uncertainty. These interviews were loosely structured, that is, lead questions were offered with minimal prompting to gain a full description of each topical area. In instances when the care recipient died during the study, post-death interviews with the informal family caregivers ceased and the case was closed. The full dataset required two years of intensive team effort in data collection. These data provide a wealth of information regarding the perceptions of caregiving (Penrod et al., 2011b), much of which was not explored in the original study.

To date, this dataset has been used in four studies. As part of the original study, Penrod and colleagues (2011b; 2012a; 2012b) examined the experiences of informal family caregivers providing care across three distinct life-limiting disease trajectories and identified the phases and stages of caregiving through EOL. In addition, three EOL caregiving trajectories were described more fully: expected, unexpected, and mixed (Penrod et al., 2011b; Penrod et al., 2012a; Penrod et al., 2012b). An unpublished preliminary analysis conducted by Bachman, Penrod, and Hupcey (2011) revealed strategies informal family caregivers employ to live with situational and existential uncertainty, such as following a routine, seeking support (through persons and faith), finding respite, and engaging in self-education (Bachman et al., 2011). McGhan, Loeb, Baney,
and Penrod (2013) identified themes (e.g., balancing multiple morbidities, feeling overwhelmed and exhausted, dealing with personal health issues, feeling isolated, coordinating care) for older adult spousal caregivers. For dissertation research, Shipley (2012) analyzed ALS cases using Newman’s theory (1999) to document and integrate the life patterns of informal family caregivers providing care to ALS patients.

The purpose of this study was to demonstrate the utility of discourse analysis in exploring caregivers’ perceptions of their role as caregivers, and specifically the expression of self and others. The approach used in this study was unique from that of previous studies; discourse analysis was not applied in the original study. Further the research questions asked were distinct and unique from those for the original study. Applying discourse analysis to the interview text enabled an understanding of how an informal family caregiver expresses perceptions of self (caregiver) and other (care recipients). This study extended the original inquiry regarding EOL caregiving.

**Ethical Considerations**

Data were utilized with the permission of the principal investigator (PI: Penrod). Interview data were cleaned and stripped of identifiers. The resultant de-identified dataset was used in this study. All participants provided written informed consent prior to involvement. The consent form acknowledged protection of confidentiality in publication, indicating that no personally identifying information would be shared (not that data would be reported in the aggregate). While data collection for the original project was closed, the approved research protocol was intact to permit continued analysis of the data (Pennsylvania State University; Continuing Review CR00005691; expiration1/23/18). The researcher conducting the discourse analysis was an approved member of the research team.
Discourse Analysis

According to Strauss and Feiz (2014), discourse is “the social and cognitive process of putting the world into words, of transforming our perceptions, experiences, emotions, understanding, and desires into a common medium for expression and communication…that reflects, creates, shapes, re-creates, and reifies meaning in the lifeworld” (p. 1). Further, “Informed research…should be grounded in a fundamental understanding of language and the linguistic building blocks that combine to create meaningful expressions of experience and perception – all of which enable us to communicate ideas, establish positions, chat, tell stories, convince, dissuade, complain, wield power, exert domination, and rise up against it” (Strauss & Feiz, 2014, p. 9). Discourse analysis (DA) arose from linguistics and semiotics and literally refers to the analysis of texts, written or spoken, in order to gain an understanding of the way that language functions in a given context (J. L. Smith, 2007; Strauss & Feiz, 2014; Wetherell, Taylor, & Yates, 2001). DA is grounded in the philosophy that knowledge and meaning are created through “interaction with multiple discourses” (Starks & Trinidad, 2007, p. 1373). Specifically, DA is shared language, such as words or signs that mediate and construct reality and serve as a “primary means through which they (individuals) enact their identities” (Starks & Trinidad, 2007, p. 1374). Understanding how individuals use language to create and present identities and activities is the primary purpose of discourse analysis (Starks & Trinidad, 2007).

The study of discourse can be seen in several disciplines, including the social sciences (e.g., communications, anthropology), humanities (e.g., literature, media studies), and sciences (e.g., medicine, engineering) (Strauss & Feiz, 2014). However, there has been limited use of this methodology in nursing research—nurse researchers who have employed this method conducted studies that were largely focused on nursing education, nursing as a profession, or nursing
professionalism (J. L. Smith, 2007; Strauss & Feiz, 2014). J. L. Smith (2007) argued that discourse analysis is underutilized in nursing research and goes on to assert that discourse analysis can bring an “added dimension” to understanding nursing problems by offering a systematic way in which language can be analyzed (p. 60).

Discourse provokes individuals to act or react, something language alone cannot do. Experts in discourse analysis provide exhaustive views through which to analyze language and discourse in order to interpret meaning within a given context (Strauss & Feiz, 2014). For the purpose of this study, grammar, reference, deixis, stance, and indexicality were the lenses through which the informal family caregiver’s interviews were analyzed.

**Analytic Components of Discourse**

The analytic components of discourse relevant to this study are discussed below, including grammar, reference, deixis, stance, and indexicality. When analyzing these components of discourse, the word token is used to represent the instances of a particular word or phrase. For instance, in this sentence there are 20 words but there are 3 tokens (or instances) of the word “word(s).” In addition there are 2 tokens of “there” and “are”. This example and the frequency of these instances may not have any meaning, but when examining a dataset to reveal characterization of self or others, these tokens provide a means to assist with analysis.

Grammar captures the conceptual understanding of perceptions and sociocultural expectations. In addition, grammar reflects individual and collective positions on one’s experience. Grammatical meaning is contextual, fluid, and emergent. Word selection and how individuals string words together “reveal much about who we are, how we feel about things, what we think about things, and how strongly they matter to us” (Strauss & Feiz, 2014, p. 17). A speaker’s word selection may be deliberate or unintentional. The organizations and expression of
words, phrases, and sentences create reality. Analyzing words (i.e., nouns, pronouns, verbs, adverbs, adjectives) or phrasing from the individual interviews provides meaning to determine how the informal family caregiver positions self in the role of caregiver.

Reference and deixis are two components that were analyzed in the informal family caregiver’s interviews. Strauss and Feiz (2014) defined reference as “the relationship between words and the things, ideas, entities, states, and people that such words designate” (p. 99). Types of reference terms can create different facets of an individual’s identity. In conjunction with reference, deixis refers to a specific function of a word (usually article or pronoun) whose denotation changes from one discourse to another. For instance, words (and/or phrases) such as “me” or “here” cannot be fully understood without additional contextual information. “Here” in this conversation may refer to a hospital bed, but “here” in another conversation may refer to home (Finch, 2005; Lyons, 1977; Strauss and Feiz, 2014). Deictic expressions require context to provide the speaker and the hearer with a reference. In this study, reference and deixis as components of discourse analysis provided insights into how the informal family caregiver identified the care recipient and self in their role as caregiver.

Through the lenses of reference and deixis, the audience begins to understand the speaker’s attitudes with respect to people, things, and ideas. These attitudes or feelings are referred to as stance. According to Strauss and Feiz (2014), stance is “the speaker’s…feelings, attitudes, perspectives, or position as enacted in discourse...Stance is enacted and created, it is negotiated and renegotiated” (p. 103). Attitudes and feelings may be obvious and represented with strong discursive expressions, or rather may be more subtle with the use of neutral discursive expressions. Using the analytic lenses of reference and deixis, the researcher can uncover a greater understanding of stance.
Indexicality is the central lens through which to view discourse and uses several components—grammar, reference, and deixis—in the analysis. Indexicality refers to “a specific type of meaning expressed through linguistic forms…involves the patterned, context-dependent connection of linguistic forms to meaning” (Strauss & Fiez, 2014, p. 266). Indexicality is not semantic or literal but is entirely context-dependent. Indexicality brings meaning to abstract concepts of “personal and social identity,… agency, power, authority, entitlement, emotion,…resistance, aesthetics, morality, responsibility,…freedom…” (Strauss & Fiez, 2014, p. 266). The intention created through such discursive “interweaving” of what is explicitly said with what is implicitly omitted emerges in patterns. These patterns reveal meaning about an individual’s attitude, beliefs, and feelings.

**Delimitation of the Dataset**

The full dataset (n=46 caregiver cases) was reviewed for compatibility and appropriateness to answer the research questions posed for this study. It was determined that the dataset included deep and rich descriptions of informal family caregivers’ experiences of providing end-of-life care to a dying care recipient across three distinct end-of-life caregiving trajectories (expected, unexpected, and mixed). The sheer volume of available data exceeded that needed for the discourse analysis study.

Processes to delimit the dataset for discourse analysis were guided by Morse’s (2000; 2001) recommendations, including: the scope of the study, the nature of the topic, quality of the data, and study design. In collaboration with the project PI (Penrod) and research team, specific cases from the larger dataset were selected based on the richness of the data and the completeness of the longitudinal interviews. Interview sets consisting of up to 13 interviews per case in each of the three death trajectories were selected for preliminary consideration.
Considering that discourse-based research is often limited to as little as one hour of narratives, further delimitation of the sample was required.

Interview sets for each case were read and reread. A summary of preliminary insights based on this review was presented by the researcher during collaborative meeting with the dissertation committee. As a result of that discussion, it was agreed that one interview set (n=13 interviews) from the expected-death EOL caregiving trajectory would be used in this discourse analysis. The case selected was exceptionally rich in the description of caregiving experiences. In addition, data were collected over a one-year period of caregiving, providing an excellent opportunity to examine change over time. A unique aspect of the selected case is that the caregiver is a male caring for his spouse. For the purpose of discourse analysis, gender of the caregiver was not a constraining concern since data were analyzed to identify linguistic cues of how the caregiver expresses perception of self in the caregiving experience.

**Analytic Approach**

The delimited dataset (n=13 interviews) was read and re-read several times to establish a preliminary coding frame focused on the specific elements of linguistic devices (i.e., grammar, reference, deixis, stance, and indexicality). A coding frame was developed in collaboration with an expert in discourse (Strauss). The data were then coded independently and coded segments were analyzed through multiple lenses of linguistic devices, including grammar, reference, deixis, stance, and indexicality. Coding procedures were refined and verified through regular consultation with the discourse expert (Strauss). Segments of texts were coded independently by Strauss throughout the coding phase in order to verify and refine the coding scheme. This coding process was used to develop categories (e.g., self-characterization, characterizing the care recipient, characterization of the disease/illness, expressions of challenges, expressions of
resources, and transitions in the state of self, care recipient, disease/illness, challenges, and resources). Further evaluation, analysis, and discussion of the categories were conducted through weekly collaborative meetings with committee member (Strauss). From these discussions, categories were then conceptualized into broad themes in collaboration with committee members (Strauss and Penrod). Themes provide a new perspective of the multiple facets of the discursive expression of self and care recipient by informal family caregivers. Expressions of identity, agency, and reference as the caregiver’s sense of confidence and control shifts were analyzed.

**Summary of Analytic Procedures**

Data analysis followed previously reported strategies (Strauss & Feiz, 2014) and was structured as follows:

1. The data, 13 individual caregiver interviews about each caregiver’s perception of the caregiving process, were read/reread to capture the essence of the narrative text. A case study (n=13 interviews) was selected as appropriate for the study.

2. Data were then coded for grammar cues, including first-person singular (e.g., I, me, my), first-person plural (e.g., we, us, our), third-person singular (e.g., he, his, she, her), and third-person plural (e.g., they, them, their). Verbs (action, stative, copular, transitive, and voice) were examined and coded. Adjectives were identified and noted, especially when these were superlatives or exceptional. This analytic process was a foundation and helped determine reference and deixis between the caregiver and others (care recipient, formal caregivers, family) within the community of care.

3. The data were then more closely examined through the lenses of reference and deixis under the assumption that nothing in discourse is neutral. Identification and shifts in these linguistic markers were the first lens applied to better understand the meaning of the discourse.
4. Stance was the next lens applied to the dataset. Stance emerges in the speaker’s choice of one linguistic form over another to express values, beliefs, attitudes, feelings, perspectives, and positions, that is an emotive reaction of what is morally right or wrong or what is normal and what is not. Utterances explicitly voicing perspectives may be an obvious expressions stance and show certainty. However, uncertainty or more moderate perspectives can be seen as instances of hesitations, questioning, silence—what is not said. These can be more subtle utterances, but nonetheless just as informative.

5. Indexicality was used to examine the context-dependent patterns of all of these linguistic expressions and to specifically explore grammar, reference, deixis, and stance. The patterns of these linguistic expressions provide meaning for more abstract concepts such as personal or social identity and agency.

**Chapter Summary**

The derivation of an appropriate and adequate dataset for this study was described. The delimited dataset (n=13 interviews/1 case) provided a robust dataset for discourse analysis. The analytic components selected for use in analysis were best suited to answer the research questions posed in this study. Coding procedures were iterative, with frequent collaborations with experts to verify, refine, and confirm findings.

This study was designed to address two research questions:

1. How can the principles of discourse analysis be applied to develop an analytic framework to further explore the linguistic cues expressing caregivers’ perception of self and others?

2. Which aspects of self and the care recipient are revealed through the discourse of the caregiver?
a. How does a caregiver’s perception of self change over time?

b. How does a caregiver’s perception of the care recipient change over time?

The study has been reported in two manuscripts. Chapter 4, “Discourse analysis: Secondary analysis of qualitative caregiver data” demonstrates the pragmatic utility of DA applied to a qualitative dataset focused on the experiences of a caregiver providing end-of-life care over the course of one year. This manuscript details the derivation of a framework for analyzing the data. Chapter 5, “A discourse analytic view of one caregiver’s voice in end-of-life care”, discusses findings of the micro-level discourse-based analysis and implications for future studies.
Chapter 4

Manuscript 1

Applying discourse analysis to qualitatively derived data:

Secondary analysis of end-of-life caregiving

Introduction

This chapter presents a manuscript submitted to *Nursing Inquiry* in April 2017. The purpose of this article was to demonstrate the pragmatic utility of applying discourse analysis to a qualitative dataset that captured the experiences of informal family caregivers providing care at the end of life. An evaluation of the available dataset, delimitation of the data for secondary analysis of discourse, and the process of the deriving a coding framework for discourse analysis were discussed. Author guidelines are included in Appendix C. *Nursing Inquiry* is an international journal that is peer-reviewed and indexed in PubMed, Proquest, and CINAHL. This journal is easily accessible to nursing scholars.
Applying Discourse Analysis to Qualitatively Derived Data:

Secondary Analysis of End of Life Caregiving

Short Title: Secondary Analysis of Discourse

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Applying Discourse Analysis to Qualitatively Derived Data:

Secondary Analysis of End of Life Caregiving

Discourse analysis (DA) is a set of methods and theories for investigating language and semiotic events in a systematic way that is underutilized in nursing research. Secondary analysis of qualitative data provides an opportunity to maximize the impact of the data and answer high-impact research questions with minimal resources. The purpose of this article is to demonstrate the pragmatic utility of applying discourse analysis to a qualitative dataset that captured the experiences of informal family caregivers providing care at the end of life. Processes for evaluating an available dataset; delimiting an appropriate dataset for discourse analysis; and deriving a coding framework for discourse analysis are discussed. Discourse-based analysis is complex, but has potential implications for advancing nursing research, specifically secondary analysis of qualitative data. As demonstrated in this study in which discourse analysis was applied to qualitatively derived data on end-of-life caregiving, these advances can be achieved by repurposing high-quality qualitative datasets to extend research findings.

KEYWORDS: Discourse analysis, secondary analysis, qualitative, caregiving, end of life
**Introduction**

Secondary analysis of qualitative data maximizes the utility of the data and can provide additional perspectives (J. A. Smith 2007) by answering high-impact research questions that are distinct from those asked in the parent study (Smith et al., 2011). This approach can be especially beneficial to large studies that required a substantial investment of resources during the data collection process (Alasuutari, Bickman, & Brannen, 2008; Heaton, 2008). Discourse analysis (DA) is a set of methods and theories for investigating language and semiotic events in a systematic way. The application of DA to qualitative data is especially relevant in times of limited resources, allowing researchers to extend scientific understanding with fewer resources, and optimizing scientific contributions. The purpose of this article is to demonstrate the pragmatic utility of applying discourse analysis to a qualitative dataset that captured the experiences of informal family caregivers providing care at the end of life. An evaluation of the available dataset, delimitation of the data for a secondary analysis of discourse, and the process of deriving a coding framework for discourse analysis are discussed.

**Discourse and Discourse Analysis**

Discourse signifies written and spoken language and semiotic events; that is, we use words and signs, (i.e., nouns, verbs, adjectives) to label the world in all facets of our communication (Author citation, 2014). Language and discourse are essential features in social science research, especially in data collection and dissemination techniques (Gilbert & Mulkay, 1984). Profession, evaluative judgment, and society may influence a person’s language choice. To illustrate the power of word meaning, nurses may refer to a person undergoing treatment for a medical condition as *patient, client, consumer of care, or care recipient*. The choice of one noun label over another is dependent upon who is speaking/writing and upon context. That same
individual can also be referred to as 5206A (room number/bed), the stroke, a bleeder, or a DNR. Each choice of noun label creates and expresses layers of meaning well beyond the individual word. For example, diagnostic labels or disease-based labels can be detrimental to patient’s self-care and well-being (Ogden & Parkes, 2013). Simply changing the way in which a condition is labelled can influence the way a patient conceptualizes their health care problem, circumstance, and/or interactions with others (Mosher & Danoff-Burg, 2009; Ogden et al., 2003; Tailor & Ogden, 2009; Tayler & Ogden, 2005). The choices that we make in terms of nouns, verbs, adjectives, and other grammatical constructions function as indicators of how we interpret and understand the world and how we communicate perspectives and understandings to others.

The purpose of discourse analysis is to understand how individuals use language and discourse to create meaningful expressions of an experience (Starks & Trinidad, 2007). Experts in DA provide exhaustive views of analytic linguistic lenses through which to analyze language and discourse in order to interpret meaning within a given context (Starks & Trindadi, 2007; Author citation, 2014). Examining components of discourse (i.e., grammar, reference, deixis, stance, and indexicality) provides a unique lens through which a deeper understanding of textual data can be viewed.

**Discourse Analysis Research in Nursing**

Discourse-based research in the nursing literature is largely focused on the profession of nursing (J. L. Smith, 2007). That is, the discourse analyzed in nursing was predominantly of and about nursing education (Celento, 2011; Frederiksen, Lomborg, & Beedholm 2015; Friberg & Lyckhage, 2013; Middleton & Uys, 2009), nurse-patient education (Bergh, Friberg, Persson, & Dahlborg-Lyckhag, 2105; Major & Holmes, 2008; Oresland, Friberg, Maatta & Ohlen, 2015), and the professional interactions (Dilworth et al., 2014; McCabe & Sambrook, 2013; Rees,
Limited attention has been paid to applying DA to better understand patient/family perceptions.

In fact, DA related to experiences of living in varied states of health is quite limited. Recent studies have focused on patient attitudes about cancer (Dryden, Ussher, & Perz, 2014); client empowerment in decision-making (Aasen, Kvangarsnes, & Heggen, 2012); and self-care (Lawn, Delany, Sweet, Battersby, & Skinner, 2014). Jolanki (2012) studied the relationship between professionals and family caregivers, focusing, however, on perceptions of roles, such as authority, expert, ally, incompetent person, or adversaries.

DA studies of informal family caregiving experiences are even more limited. Only one study of informal caregiving (rather than parent-child relationships) was identified. In a study by Hepburn et al. (2002), spousal caregiving relationships were studied to demonstrate that with the exception of wife-caregivers reporting more distress than husband-caregivers, the discourse of the caregiver groups were more similar than dissimilar. Nursing recognizes the significant contributions of informal family caregivers in optimizing the health of those living with advanced debilitating illnesses. Our understanding of caregiving experiences remains underdeveloped. We assert that understanding linguistic cues and discursive patterns used by informal caregivers could be a first step in understanding the dynamic experiences of caregivers, especially those providing care across a trajectory of illness. Ultimately, such understanding could provide insights that may guide tailored, supportive interventions for informal caregivers.

**Secondary Analysis of Qualitative Data**

Results from both original studies and secondary analyses have been critical to nursing research (Jacobson, Hamilton, & Galloway, 1993). A prime advantage of secondary data analysis is that scientific knowledge can be extended without a significant investment of resources in data
collection and minimized burden on participants. Minimization of burden is especially relevant to data that are sensitive or collected during particularly difficult phases of life. Data that were analyzed for the original study are often an untapped resource with the potential to answer other research questions. Using discourse analysis, a researcher has the capacity to re-analyze qualitative data to examine all elements of language, including the written or spoken nonverbal expressions. DA is an effective approach to extending scientific understanding through secondary analysis of qualitative data.

Secondary analyses refer to the reanalysis of data collected for another purpose to answer a unique research question. The ability to identify, locate, and secure a desired database must be considered (Aponte, 2010; Bibb, 2007). Information on many datasets includes insights into the methods used to collect data, including descriptive characteristics of the participant population. Purposeful exploration of the scientific literature is a potential method for secondary datasets. In addition, several countries have established national archives of qualitative datasets, including Finland (Kuula, 2000), Germany (Opitz & Mauer, 2005), Switzerland (Bergman & Eberle, 2004), Denmark (Fink, 2000), Canada, the Netherlands (Mruck, 2000), and Austria (Smioski, 2011). Each country has established criteria and requirements for archiving the data, and efforts continue to establish sound protocols for securing and maintaining valuable data (Smioski, 2011). Ideally, repositories will have the capacity to be searched using terms (e.g., population of interest or methodology) to locate high-quality, appropriate datasets that can be used in subsequent analyses. Continued efforts promote the importance of not only systematically archiving large, high-quality qualitative data, but also encouraging the sharing and continued publication of scientific findings resulting from secondary data analyses of qualitative data (Smioski, 2011).
Rigorous standards for qualitative data collection have been established (Grove, Gray, & Burns, 2014; Morse & Field, 1995; Thorne, 1994). Researchers systematically plan and control the data collection process including IRB approval, targeted population, recruitment strategies, sampling strategies, accessibility, and data collection technique (Hox & Boeije, 2005). Systematically evaluating and describing these aspects of the secondary dataset is essential to ensuring that the original study dataset was collected using rigorous and appropriate procedures (Heaton, 2004; Hinds et al., 1997; Polit & Beck, 2012). Any shortcomings that are uncovered in the evaluation of the dataset and collection procedure should be clearly explicated and the degree to which the issue poses a limitation should be considered carefully. Not all weaknesses are fatal. Ultimately, the researcher conducting the secondary analysis must establish that the available data are suitable to the new inquiry.

A key consideration of the suitability of a dataset for secondary analysis is adequacy. Adequacy is defined as a state of quality and completeness (Morse, Barrett, Mayan, Olson, & Spiers, 2002). Quality of data is related to the breadth and depth of the dataset, that is, data are focused on the phenomenon of interest (breadth) and are rich in description (depth). Completeness implies volume; that is, there are enough high-quality data to build an analytic case. Hinds et al. (1997) recommended evaluating completeness further by examining the condition of the dataset and the accuracy of the transcription. Transcription accuracy can be verified by randomly selecting and comparing transcripts and audio/video files. Transcripts should be free of errors with minimal ambiguous or unintelligible text notations. Data files and related documents that are complete (i.e., without missing/damaged documents) are said to be in good condition.
The rise in interest in qualitative data archiving, sharing, and reanalysis has generated discussion regarding the ethical considerations inherent to this approach, and specifically issues surrounding consent and anonymity (Corti & Thompson, 2006; Corti, van den Eynden, Bishop, & Woollard 2014; Heaton 2004; Smioski 2011). Identifiable data may not be used in secondary analysis without the consent of the participant(s), principal investigator (PI) approval, and IRB oversight. In contrast, it is acceptable to re-analyze de-identified data with permission from the original study PI and institutional review board approval, as long as anonymity is preserved (Corti & Thompson, 2006; Corti et al., 2014). Early debate has focused on whether researchers conducting secondary analysis should attempt to seek consent from the participants even if the data are de-identified (Heaton, 2004). However, seeking the consent of participants who provided original data that were subsequently de-identified prior to secondary analysis has not become usual practice (Corti & Thompson, 2006; Corti et al., 2014; Heaton, 2008; Smioski, 2011). Debates surrounding the secondary analysis of qualitative data continue. As the thoughtful development of qualitative dataset repositories advances, discussions of best practices to protect human subjects must continue (Corti et al., 2014). Clearly, secondary analyses must conform to ethical and legal guidelines to protect the confidentiality and anonymity of human subjects (Corti et al., 2014).

Anonymity is a particular concern in secondary analysis. The depth of qualitative data often captures the context of the participant’s life and experiences and typically generates lengthy narratives with specific detail (Creswell, 2007). Given the nature of rich narrative texts in many qualitative datasets, protecting anonymity is essential in the reporting of secondary analyses (Corti et al., 2014; Thomson, Bzdel, Golden-Biddle, Reay, & Estabrooks, 2005). Linking indirect contextual identifiers risks disclosing the identity of the participant (Morse &
Fields, 1995). Thomson et al., (2005) described foundational approaches to minimize risk of disclosure, including pseudonyms, selective deletion of particular passages, and completely omitting particular interviews if anonymization is not possible. Additional strategies for protecting anonymity or any identification of the participant include masking characteristics of the participants (e.g., demographics, traits) and altering personal identifiers such as specific employment title/field or unique characteristics or anomalies. Such precautions are necessary to protect participants’ identity when reporting findings.

Despite the advantage of secondary analyses of qualitative data, there is a limited literature on how to conduct such analyses with desired levels of precision and rigor. The preliminary discourse in the literature on the re-analysis of qualitative data is looking at “how to” topics on design; identification and selection of datasets; analysis; and reporting (Heaton 2008). Thus, the need for further research and determination of best practices in the secondary analysis of qualitative data remains (Smioski, 2011). In the next section, we describe the evaluation and delimitation of a large qualitative dataset that captured the experiences of informal family caregivers (caregivers) who were providing care at the end of life, in preparation for a secondary analysis of the discourse.

**Evaluating and Delimiting the Dataset**

Data collected under a study entitled *Exploring the Formal/Informal Caregiver Interface across 3 Death Trajectories* [NIH/NINR R01NR010127] were the focus of this exemplar project. Specifically, the data used in this secondary analysis centered on informal caregivers’ experiences in providing end-of-life (EOL) care from pre-terminal through terminal phases of the illness trajectory. Three distinct trajectories leading to the end-of-life were examined: expected death (illness exemplar: amyotrophic lateral sclerosis), unexpected death (illness exemplar: heart
failure), and mixed (illness exemplar: lung cancer). In this arm of the larger study, grounded theory methods were used. Forty-six caregivers participated in the study. Semi-structured interviews included baseline face-to-face interviews followed by longitudinal monthly interviews via telephone or face-to-face. In instances where the care recipient died during the study, a post-death interview was conducted and the case was closed. Total interviews ranged from 7-13 interviews per participant. Each interview was approximately one hour in length and data were collected over a two-year period. The caregiver dataset includes over 400 interviews with 46 caregivers. (For more information on the original study, see Author citation, 2011; Author citation, 2012a; Author citation, 2012b). A de-identified dataset was available once the original research team cleaned all transcripts of identifiers during transcription. The final data provide a wealth of insights into perceptions of caregiving that extend far beyond the purpose of the original study.

Permission to access the data was granted by the PI of the parent study and university-based IRB approval was obtained. First, the data were reviewed to determine if this dataset was compatible and appropriate to answer the following research questions: Which aspects of self and of the care recipient are revealed through the discourse of the caregiver? How do these perceptions change over time? The proposed discourse analysis is unique from the parent and subsequent studies that involved this dataset (Author citation, 2013; Author citation, 2011; Author citation, 2012a). The analysis of discourse has strong potential for high impact on the state of the science. The analytic lens of discourse analysis will reveal subtle yet perceptions of caregiving that have not been explored. Beyond description, we believe that a deeper understanding of linguistic patterns and cues could serve as markers for implementing tailored supportive care of informal caregivers. In particular, examining this dataset through the lens of
agency will provide insights into the caregiver and how the caregiver negotiates, manages, and progresses through the caregiving experience. The caregivers’ discursive expressions of stance, whether strong or subtle, can provide critical linguistic cues that clinicians can use in providing care to both caregiver and care recipient.

An initial evaluation of the quality of the de-identified dataset was examined. The PI of the original study is well credentialed and a recognized expert in qualitative methods, and has a strong record of contributions to the caregiving and end-of-life literature. The stability of the original study research team is evidenced by their number of co-authored publications; clearly, the team responsible for data collection and analysis was qualified and highly collaborative. Consistency in data collection approach was evident. Careful review revealed that transcripts were comprehensive and complete. There were minimal inaudible text notations. There were no missing files; all interviews were transcribed and retrievable. Given these evaluative considerations, the overall quality or condition of the dataset was found to be very good.

The next evaluative consideration examined the epistemological and conceptual stance of the original study. The data were collected using a grounded-theory approach with open-ended, semi-structured interview questions focused on the caregivers’ experiences in providing end-of-life care to dying care recipients (Author citation, 2012b). The theoretical formulation derived in the original study pivots on the basic social process entitled Seeking Normal (Author citation, 2012b). Inherent to this process are conceptual attributes of confidence and control; that is, the balance of confidence and control yielded perceptions of being in steady state (i.e., normal) across varied phases of caregiving.

This theoretical framework was an important consideration in determining the feasibility of the secondary analysis of discourse. Specifically, advancing an understanding of agency
extends the original theory by explicating linguistic patterns and cues indicative of confidence and control that are hallmarks of the derived theory (Author citation, 2011; Author citation 2012a). This evaluation revealed that the research questions, while specific to the analytic technique of discourse analysis, are congruent with theoretical tenets of the parent study (Doolan & Froelicher, 2009; Smith et al., 2011).

Discourse is focused in a language, and language is documented in the available interview transcripts. The goal of a discourse-based study is to uncover systematically meaningful patterns through expressions of speech and writing, and the determination of sufficiency is established on a case-by-case basis with a focus on the research question(s). The appropriate volume of data needed for the analysis varies, but the data must provide a sufficient number of occurrences (of linguistic features) to reveal patterns in the discourse (Wood & Kroger, 2000). Some discourse-based studies have analyzed as little as one hour of narrative text (Potter & Wetherell, 1987).

The available dataset consisted of 400 interviews with 46 caregivers who provided care in distinct end-of-life trajectories. Given the volume of data available, delimitation of the dataset was required.

The primary researcher (first author) read the entire dataset. This review showed that caregiving experiences varied among the three different trajectories. In the next round of delimitation, we focused on trajectory-specific cases. Complete interview sets from three caregivers’ cases (one per trajectory) were selected as exemplars by the original project team. This set of 36 (13, expected-death; 12, unexpected-death; 11, mixed-death) longitudinal interviews was evaluated by the primary researcher to compare and contrast trajectory-specific experiences. An expert in discourse analysis (Author name) also reviewed the trajectory-specific
dataset. This initial analysis of three cases yielded an overwhelming amount of discourse that was not appropriate for establishing a framework for a future analysis of caregiver discourse. All authors collaborated to determine that it was most appropriate to limit the dataset to one trajectory in order to develop a coding framework for discourse analysis. Selection was based on preliminary analysis of the three cases, data richness, and consensus among the authors.

This was a pivotal point in the study design. We decided that data were more than sufficient to permit a thorough analysis of one trajectory followed by refinement of the coding frame (as needed) and comparative analysis of the remaining two trajectories. The team determined that the expected death trajectory case, consisting of 13 interviews focused on caregiving for a spouse with a terminal illness, would be analyzed first. The case selected was exceptionally rich in the description of caregiving experiences. In addition, data were collected over a one-year period of caregiving, providing an excellent opportunity to examine change over time. This delimited dataset was determined to be best suited to the development of a coding framework because it provided data rich in experience and insight. These would provide the best chance of determining patterns in caregivers’ perceptions of the self in the role of caregiving.

Techniques to address threats to caregiver anonymity were framed. Techniques outlined by Corti and Thompson (2006), Corti et al. (2014), and Thomson et al. (2005) were applied. Pseudonyms were used. Demographic characteristics (not relevant to the analysis) were altered. Excerpts used in publication were altered to ensure that the necessary contextual meaning of narratives remained clear. For example, excerpts unique to a particular case and potentially revealing were carefully altered to protect disclosure of identity.
Deriving an Coding Framework for Discourse Analysis

The preliminary analysis of the dataset used during delimitation was critical to the development of a coding framework for discourse analysis. During the iterative reviews, the primary researcher (Author name) systematically read and re-read the dataset several times to establish a preliminary coding frame. All authors reviewed the transcripts and collaborated to develop a final coding frame for this dataset.

The primary researcher (Author name) coded the data independently. Coded segments were analyzed through multiple lenses of linguistic devices, including grammar, reference, deixis, stance, and indexicality. Regular meetings with co-authors were held to review and verify the coding scheme. This coding process was used to develop categories (e.g., self-characterization, characterizing the care recipient, characterization of the disease/illness, expressions of challenges, expressions of resources, and transitions in the state of self, care recipient, disease/illness, challenges, and resources). Further evaluation, analysis, and discussion of the categories were conducted through iterative collaborative meetings. From these discussions, categories were then conceptualized into broad themes.

Preliminary analyses were guided by Positioning Theory (Slocum & van Langenhove, 2003; van Langenhove & Harre, 1999) and the model of caregiving through end-of-life caregiving (Author citation., 2011). The overarching themes, “Who am I,” “Who am I caring for” and “caregiver distress” emerged. While this approach was informative, the team decided to concentrate on the specific elements of linguistic devices (i.e., grammar, reference, deixis, indexicality, stance, and agency). This decision was based on the goal of the study; that is, to identify linguistic cues that could guide supportive interventions.
This code schema was developed after concluding the preliminary analyses. Each linguistic device was analyzed in the following manner:

1. Grammar cues (first-person singular [e.g., I, me, my], first-person plural [e.g., we, us, our], third-person singular [e.g., he, his, she, her], and third-person plural [e.g., they, them, their]; verbs [action, stative, copular, transitive, and voice]; and adjectives [especially when these were superlatives or exceptional] were examined and coded. This foundation helped determine reference and deixis between the caregiver and others (care recipient, formal caregivers, family) within the community of care.

2. Reference and deixis were examined under the assumption that nothing in discourse is neutral and that identification and shifts in these linguistic markers are the first lens that can provide meaning to the discourse.

3. Stance was the next lens applied to the dataset. Stance emerges in the speaker’s choice of one linguistic form over another to express values, beliefs, attitudes, feelings, perspectives, and positions—an emotive reaction of what is morally right or wrong or what is normal and what is not. Utterances explicitly voicing perspectives may be an obvious expressions of stance and show certainty. However, uncertainty or more moderate perspectives can be seen as instances of hesitations, questioning, silence—what is not said. These can be more subtle utterances, but nonetheless just as informative.

4. Indexicality examines the context-dependent patterns of all of these linguistic expressions. For the purpose of this study, we specifically explored grammar, reference, deixis, and stance. The patterns in these linguistics expressions provide meaning on more abstract concepts such as personal or social identity and agency.
The primary researcher re-coded the data independently using the established coding frame, examining self-characterization and characterizing the care recipient. We analyzed a subsample of the coded segments throughout the coding phase, verified, and refined the coding scheme. For example, referent terms of “we” and “I” were coded as shifts in expressions of “I” as an individual to “we” as an individual were noted, indexing the change in agency during times of uncertainty. Referent terms specific to the care recipient were coded as these shifted from “she” and “her” to “my wife” and “wife’s name.” Categories emerged from coded segments, which were conceptualized into broader themes. Iterative cycles of team meetings facilitated discussion, verification, and validation of categories and broader themes.

The conceptual model *Seeking Normal* was used to frame the overarching themes. Data (segments of transcripts) were provided to support such assertions. Themes provided a new perspective on the multiple facets of the discursive expression of self and care recipient by caregivers. Expressions of identity, agency, and reference as the caregiver’s sense of confidence and control shifts were analyzed based on this analysis of discourse. Discourse analysis shed light on the more subtle features of the caregiver’s perceptions of self and the care recipient.

**Discussion**

Advances in nursing science can be achieved by repurposing high-quality qualitative datasets to answer important research questions with a minimal investment in additional resources. Qualitative research is resource-intensive. Consider the investment made by researchers and participants in the process of qualitative data collection in a large study. Given the current constraints on funding, nurse researchers could maximize contributions to science by re-analyzing high-quality datasets. Researchers holding qualitative datasets are often amenable to secondary analyses that would extend their program of research. Internationally, the importance
of secondary data analysis of qualitative data is marked by the development of regulated archives to maintain and secure the data (Smioski, 2011). Formal archiving of qualitative data has the potential to maximize the utility of the data and influence the future of nursing research.

Secondary analysis is particularly beneficial when resources are limited and recruitment of participants is challenging. Recruitment can be most challenging to nurse researchers dealing with sensitive topics, such as end-of-life issues (Gemmill, Williams, Cooke, & Grant, 2012). Caregivers actively providing care to dying loved ones are a vulnerable population. The burden imposed by re-interviewing these participants for multiple studies of related phenomena is not warranted, especially when a complete dataset is available and accessible for further analysis.

Discourse analysis presents a novel approach to extending research findings significantly without imposing undue burden on vulnerable populations. Discourse analysis is the study of language or any significant semiotic event. Qualitative datasets are most often language-based, and therefore are especially amenable to the secondary analysis of that discourse. Discourse analysis unravels perspectives in language to reveal a sense of identity and the relationships between self and others or the flow of events in a given phenomenon of interest. This type of analysis could be very useful in extending or augmenting the original study findings.

For example, in this study we found that shifts, evident in the caregivers’ linguistics and behaviors, indicated a renewed sense of confidence and control and a lessening of uncertainty (and distress) as they transitioned through the trajectory of caregiving. These expressions of shifts in confidence and control are remarkable indicators of uncertainty and caregiver distress (Given, Given, & Kozachick, 2001; Author citation, 2012a). Most importantly, the linguistic cues are identifiable and may prove to be relevant clinical markers of distressed caregivers who would benefit from well-timed interventions to support them in this critical role.
Conclusions

Discourse-based analysis of qualitative secondary data holds great potential for advancing nursing science related to specific phenomena. To promote high-quality secondary analysis, a careful evaluation and delimitation of a dataset was undertaken. Evaluative procedures are critical in establishing the credibility of the data for secondary analyses. The discussion of delimitation demonstrates how serial analyses and decisions direct the selection of an appropriate dataset for discourse analysis. This process is especially valuable to researchers who have access to databases that exceed the volume/quality of data needed for a particular study.

However, discourse analysis can be quite complex. The systematic process of determining which of the varied components of discourse analysis were most appropriate to this study was explicated to demonstrate the need for methodological expertise and flexibility. The derived coding framework meets researchers’ interest in linguistic cues and promotes a better understanding of a caregiver’s perception of self and others in their role as caregiver. The application to one case will enable researchers to refine and extend the analytic framework in preparation for further study. Through these processes, we will begin to unravel the complex experience of caregivers providing end-of-life care to determine if linguistic cues may be relevant to tailored interventions.
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Chapter 5

Manuscript 2:

A Discourse Analytic View of One Caregiver’s Voice in End-of-Life Care

Introduction

This chapter presents a manuscript submitted to *Qualitative Health Research (QHR)* in April 2017. The purpose of this article was to provide a description of the application of discourse analysis to a subset of a larger, qualitative dataset of caregivers who were providing care to dying care recipients. Findings from the study were summarized. Author guidelines are included in Appendix D. *QHR* is an international, peer-reviewed journal that is accessible and indexed in PubMed, ProQuest, and CINAHL.
A Discourse Analytic View of One Caregiver’s Voice in End-of-Life Care

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A Discourse Analytic View of One Caregiver’s Voice in End-of-Life Care

Abstract

Informal family caregivers make a significant contribution to the U.S. health care system and the need for caregivers will likely increase. Gaining deeper insights into the caregiver experience will provide essential knowledge needed to support the future caregiver workforce delivering care. Discourse analysis is a viable approach in analyzing textual caregiver data that focuses on the end-of-life caregiving experience. The purpose of this study was to conduct an in-depth discourse analytic examination of 13 hours of caregiver interview data, which reveal the multiplicity of shifting stances and perceptions of one caregiver in the midst of end-of-life care, specifically with regard to his perceptions of self (caregiver) and other (care recipient). By isolating a specific but limited set of reference terms used throughout the discourse, we gained systematic glimpses into the mind and perceptions of this single caregiver in relation to his role as caregiver for his terminally-ill wife.
Nearly 66 million Americans are unpaid informal family caregivers (caregivers) and make a significant contribution to the U.S. health care system (AARP, 2013; National Alliance for Caregiving & AARP, 2009). Caregivers provide care for adult family members or friends with chronic or life-limiting conditions. As a result of changing demographics (i.e., the graying of America, increases in life-limiting conditions) as well as shifts in the locations (i.e., from institution- to community-based) and level of end-of-life (EOL) care, many caregivers work tirelessly to provide care to family members/friends as the care recipient’s illness progresses and EOL becomes imminent (Halaweish & Alam, 2015). The care provided by caregivers accounts for 37 billion hours of unpaid care, such as assisting with activities of daily living, managing medications, and preparing meals. In 2013, the estimated economic value of informal family caregivers’ unpaid support was $470 billion to $522 billion (Chari, Engberg, Ray, & Mehrotra, 2015; Reinhard, Feinberg, Choula, & Houser, 2015). This is a $20 billion increase from 2009 (Feinberg, Reinhard, Houser, & Choula, 2011).

Although an extensive scientific literature can be found on EOL caregiving, most research has either been quantitatively focused, revealing statistical trends and patterns, or broadly qualitatively focused, revealing general trends and themes within data (Lendon et al., 2015; Morgan, Williams, Trussardi, & Gott, 2016). To date, no research on EOL caregiving has been conducted through a discourse analytic lens that unveils the actual perspectives, feelings, attitudes, and voices of the caregivers as they become immersed in the day-to-day activities of caring for a friend or loved one. A combined macro-micro analysis of caregiver discourse allows the researcher and the nursing community to more accurately “hear” the voices of the individuals involved and to view with more precision and systematicity the multiple ways in which the
caregivers conceptualize self and their roles in the caregiving process, in addition to the ways they conceptualize the care recipients (CRs).

The purpose of this study was to conduct an in-depth discourse analytic examination of 13 hours of caregiver interview data, which reveals the multiplicity of shifting stances and perceptions of one caregiver in the midst of end-of-life care, specifically with regard to his perceptions of self (caregiver) and other (care recipient). The focus of this study was on the types of reference terms used throughout the caregiver interview and narrative data. Specifically, the patterned use of third-person reference terms (‘she’/’her,’ ‘my wife,’ wife’s name) and first-person reference terms (e.g., ‘I’ and ‘we’) to elucidate the more subtle and less obvious manifestations of his perceptions of self as husband/father/caregiver and perceptions of his wife as wife/mother/daughter/CR were analyzed. Through the use of the semiotic lenses of reference and indexicality, this article sheds light on the already established theoretical underpinnings of caregiver discourse, namely Seeking Normal and EOL Caregiving Trajectories (Author citation, 2012b) in the original study (and upon which this secondary data analysis is based).

**Caregiving at the EOL**

An informal family caregiver is “any relative, partner, friend or neighbor who has a significant personal relationship with, and provides a broad range of assistance for, an older person or an adult with a chronic or disabling condition” (Family Caregiver Alliance, 2014, para 6). For the purpose of this article, informal family caregivers are referred to simply as “caregivers.” Numerous research studies have documented the challenges and demands associated with caregiving at the EOL. Caregivers providing EOL care report significant personal cost, including emotional, physical, financial, and social strain or burden (Bee, Barnes, & Luker, 2009; Grande et al., 2009; Kuyper & Wester, 1998; Ohman & Soderberg, 2004;
Pinquart & Sorensen, 2003; Stajduhar et al., 2010; Wolff et al., 2009). Insufficient preparation of and challenges/demands faced by the caregiver have been linked to indicators of poor quality of life, such as sleep disturbance, poor physical health, and poor financial well-being (Boter et al., 2004; Brummett et al., 2006; Northouse, Williams, Given, & McCorkle, 2012; op Reimer, DeHann, Rijnders, Limburg, & van den Bos, 1998; Pinquart & Sorensen, 2003; Roth, Perkins, Wadley, Temple, & Haley, 2009; Thommessen, Wyller, Bautz-Holtzer, & Laake, 2001). Despite poor quality of life indicators, caregivers perceive a value in their role and find some reward in the experience (Vellone, Piras, Talucci, & Cohen, 2008; Wolff et al., 2009); however, caregiver distress continues to override positive quality of life factors, and caregivers experience burnout (Yilmaz, Turan, & Gundogar, 2009). Stress, strain, and burden remain strong influences when considering caregiver outcomes (Boter et al., 2004; Brummett et al., 2006; Northouse et al., 2012; op Reimer et al., 1998; Roth et al., 2009; Thommessen et al., 2001).

Caregiver distress has been examined across the trajectory of caregiving from role acquisition through bereavement (Given et al., 2004; Kurtz, Kurtz, Stommel, Given, & Given, 2002; Nijboer, Tempelaar, Triemstra, van den Bos, & Sanderman, 2001; Northouse, Mood, Templin, Mellon, & Geroge, 2000; Weitzner, Haley, & Chen, 2000; Weitzner, Moody, & McMillan, 1997; Wyatt, Friedman, Given, Given, & Beckrow, 1999). Caregiver distress is defined as negative physical and emotional symptoms experienced by the caregiver (Yilmaz et al., 2009). Despite understanding caregiver distress, interventions to mitigate the challenges/demands faced by caregivers and prevent or minimize caregiver stress, strain, or burden are not well established. Expressions of uncertainty are remarkable indicators of caregiver distress (Given, Given, & Kozachik, 2001; Author citation, 2012a). Examining these caregivers’ expressions or linguistic cues is a logical next step in the caregiver inquiry.
Discourses in Caregiving

To date, there has been limited discourse-based research on caregiving. Studies of caregiving discourse first emerged with child/parent dyads or child/child dyads and sought to understand how language shapes children as they assimilate into a culture, family, or friend group (Corman, 2013; Kendall, 2006; Nwokah, 1987). Research on caregiving of adults with chronic conditions and/or at the EOL is minimal. Hepburn et al. (2002) used coded, open-ended interviews of spousal caregivers sharing their experience of caregiving; findings revealed that despite wife caregivers reporting more distress than husband caregivers, the caregivers interviewed were more similar than dissimilar. Hepburn et al. (2002) established four themes in caregiving discourse: (1) the description of the caregiving situation, (2) caregiver self-care, (3) caregiver needs, and (4) lessons learned from caregiving. Paoletti (2002) provided a discursive analysis in caregiving as “giving help” and a sense of duty, expressed by such comments as, “I must do it (provide care) because he is my husband,” or, “I do it (provide care) because she is my mother.” (p. 810)

Despite these informative studies, none delves deeply into the meaningful patterns of discourse that run through the narratives or responses to interview questions. Nursing science still lacks understanding of effective next strategies to support caregivers providing EOL care. Understanding linguistic cues and discursive patterns could be a first step for healthcare practitioners seeking to more deeply and acutely understand the stances, positions, emotions, memories, hopes, fears, and perceptions of caregivers, especially those in late-stage and EOL caregiving situations with terminally ill patients.
Theoretical Framework

This article is based on a complex interrelated set of theoretical/methodological frameworks. The micro-level theoretical frameworks for the analysis of the discourse involve the semiotic systems of reference and indexicality. Reference can be defined as “the relationship between words and the things, ideas, entities, states, and people that such words designate” (Author citation, 2014, p. 99)—essentially, the network of possible words, labels, and expressions that speakers and writers use to name or refer to the various entities in their discourse (Finch, 2005; Lyons, 1977). Whereas the semiotic system of reference is the more constant, more seemingly objective, and even more finite system of connecting words and meanings to entities and people, indexicality requires context to understand word meaning and paralinguistic meaning. Indexical relationships between words and expressions and the entities or ideas that such expressions are intended to mean are more varied, more variable, and context-dependent (Ochs, 1990, 1996, 2012; Silverstein, 1976, 1996, 2003). Some indexical expressions, such as the personal pronouns ‘I,’ ‘you,’ ‘she,’ ‘we,’ and demonstrative pronouns ‘this’ and ‘that’, are also called “shifters” (Jakobson, 1957, 1995) because the entities that they pick out in discourse constantly shift and change depending upon the situated context. The broader, macro-level theoretical frameworks that this study sought to expand were Seeking Normal (Author citation, 2012a) and EOL Caregiving Trajectory (Author citation, 2011), both of which were established in the original study through a grounded theory analysis. EOL Caregiving Trajectories, superimposed Seeking Normal on the expected-death trajectory, unexpected-death trajectory, and mixed-death trajectory (Author citation, 2011). Little research has been done that focuses specifically on EOL caregiving trajectories. The present study provided a brief introduction to the types of insights a micro-level discourse-based analysis of the larger set of
EOL data from the original study could offer to both practitioners and researchers as we strive to better understand the EOL caregiving process.

**Methods**

**Design**

Discourse analysis (DA) involves the systematic examination of patterned uses of discourse (i.e., language, text, and other surrounding semiotic features of communication) that reveal aspects of the speakers’ or writers’ stances, emotions, feelings, positions, and perceptions. Discourse Analysis was applied to a subset ($n=1$; 13 hours of interview) of a larger qualitative secondary dataset on end-of-life caregiving (Author citation, under review). Applying DA to these data further extends the scientific knowledge and allows them to be examined with a new purpose—specifically, one that seeks to gain a deeper understanding of the intricate emotions, perceptions, and stances of those engaged in the EOL Caregiving Trajectory, specifically the expected-death. Our overarching research questions were:

How can the principles of discourse analysis be applied to develop an analytic framework to further explore the linguistic cues expressing caregiver’s perceptions of self and others?

Which aspects of self and the care recipient are revealed through the discourse of the caregiver?

a. How does a caregiver’s perception of self change over time?

b. How does a caregiver’s perception of the care recipient change over time?

Data were selected and obtained systematically (Author citation, under review) The research questions being asked were distinct from those in the original study and the subsequent secondary data analyses (Author citation, 2013; Author citation, 2011; Author citation, 2012a; Author citation, 2012b). The secondary data were de-identified and obtained with the permission
of the principal investigator. IRB approval was obtained. All identifying information and/or characteristics of the participants were masked to protect the anonymity of the caregiver and care recipient. For the purposes of our discussion, a pseudonym was assigned to the caregiver, Jerry, and the care recipient, Dort. We masked the general details regarding the area where Jerry and Dort reside, in addition to any and all potentially identifying information such as children’s names and ages and the names/affiliations of other individuals involved in their lives that may have emerged in the course of the open-ended interviews. Further, we masked and/or deleted details relating to their local area of residence (e.g., names of schools, shopping malls, grocery stores), in addition to uniquely characteristic manifestations of Dort’s disease or anomalies that could enable identification of the patient, her family, or her place of residence.

**Sample**

The dataset was one case (n=1; 13 one-hour monthly interviews) from the expected-death EOL trajectory that provided the richest, most complete data in terms of robustness of oral discourse and elaboration of interview questions. Narrative transcripts (13) were read and the repertoire of linguistic patterns in Jerry’s discourse that indicated caregiver distress, uncertainty, confidence, and control, influenced by findings from the original study, were identified. A finer-grained analysis of the discourse pointed to additional salient patterns in Jerry’s reference terms (specifically first person and third person). Through collaborative efforts, the expert team from the original study concurred with the preliminary analyses that we proposed. The procedure followed during qualitative dataset selection regarding the use of secondary discourse-based analysis is explained in more detail in Author citation (under review).

Descriptors of the caregiver and care recipient were purposefully vague or masked to ensure anonymity. Jerry was a male caring for his wife, Dort, who had been diagnosed with
amyotrophic lateral sclerosis (ALS; commonly known as Lou Gehrig’s disease), approximately one year before the start of data collection. The couple had been married for over 10 years, and they had children. They lived in a rural location in the Southwestern region of the U.S. Jerry maintained his employment in a blue-collar job throughout Dort’s illness. In addition to Jerry’s care, paid caregivers, neighbors, and the children assisted the caregiver and the care recipient. Dort was middle-aged—from the first interview, it was clear that the she required total assistance with her daily activities. With the exception of her husband and children, Dort’s family did not live geographically close to her.

In these interviews, Jerry recounted his daily routines in caring for Dort and expressed his concerns about his role as caregiver and Dort’s overall health, which declined significantly throughout the course of the study. He responded to interview questions in extended, open-ended narratives in which he described the couple’s past and the details of their marriage, his fears and apprehensions about the future, as well as the various medical treatments that Dort had to undergo and the complex care decisions that needed to be made.

Analysis

We conducted an analysis of Jerry’s oral discourse. The study yielded insights into the interviewee’s perceptions of self as husband/caregiver and his wife as care recipient, as they adapted to the ever-changing EOL caregiving trajectory. Understanding linguistic cues and discursive patterns expressed by the caregiver could be a first step taken by healthcare practitioners who seek to more deeply and acutely understand the stances, positions, emotions, memories, hopes, fears, and perceptions of caregivers, especially those in late stage and EOL caregiving.
Guided initially by the original study and framework of *Seeking Normal* and EOL Caregiving Trajectories, the repertoire of linguistic patterns in Jerry’s discourse that indicated varying degrees of caregiver distress, uncertainty, confidence, and control was identified. Notably, coding included first-person singular/plural reference to self and care recipient as *I, we*; third-person reference to care recipient as *she, her, my wife, wife’s name*; modal expressions as *be able to, can, could, must, have to*; expressions of coping and lifestyle management such as *get/have/lose/out of my control, change, adapt, get used to*; and markers of epistemic uncertainty, e.g., *don’t know, figure out, learn as you go*—all with a view toward plotting and graphing Jerry’s gradient sense of control, agency, distress, confidence, and uncertainty over the course of the 12-month interview trajectory with one interview at the conclusion. A clear decline in Jerry’s stances of confidence, control, and agency was discovered. Over time, these discursive patterns indexed his growing sense of distress and uncertainty, especially as his wife’s condition progressed.

Salient patterns in Jerry’s use of reference terms for self and other, especially the first-person reference ‘I’/’we’ and his use of third-person reference terms to designate his wife, e.g., ‘she/her,’ ‘my wife,’ and ‘Dort,’ was noted. These patterns of *reference* and *indexicality* then became the focus of the present study since such discursive variability was not predicted or anticipated at the outset and proved to be quite revelatory of Jerry’s stances vis-à-vis himself, Dort, and their relationship.

**Results**

In this section, we present our findings with regard to the various ways in which Jerry positioned himself as caregiver and his wife as care recipient/mother in the narratives. Specifics of the framework established to assess the narratives with a particular focus on the expected-
death EOL Caregiving Trajectory, uncertainty, and confidence and control from the dataset were explained by Author citation (under review). We begin with an analysis of reference, specifically concerning third-person reference as Jerry referred to Dort throughout the 13 hours of interviews. We then shift to indexicality, which provides an analytic lens to understand this single caregiver in relation to his perception of self and his terminally ill wife. Patterns using indexical pronouns ‘I’/’me’ (first person singular) and ‘we’/’us’ (first person plural) serve to index a pattern of Jerry, Jerry and Dort as a couple, and intermeshing self with wife/CR, in situations which are actually more skewed as a reference to self (Jerry alone) or care recipient (Dort alone).

**Third person reference ‘she’/’her’/’hers’ vs. ‘Dort’/’Dort’s’**

Our shift to the analysis of reference terms revealed a pattern whereby Jerry only referred to Dort as ‘she’ or ‘her’ throughout the entire first interview, but as time went on Jerry referred to the care recipient as ‘my wife’ or ‘Dort’. As is evident in Table 1, Jerry referred to Dort either by name or as ‘my wife’ only six times in the first three hours of his interviews. Not a single instance (or token) of a specific reference term as her name or as his spouse was evident in the first interview. The second and third interviews contained three instances of ‘my wife’ or ‘Dort,’ respectively. Instead, Jerry systematically and consistently spoke of his wife in very general, objective, and distanced third-person terms, e.g., she, her, hers.

Jerry’s initial narrative provides a clinical and seemingly objective summary and description of his CR and of his responsibilities and tasks as a caregiver. While Jerry expressed his love for his wife (…She’s my number 1 priority. Ain’t nothing else that I care about…6.1, line 147; I live every day to the best of my ability and show her everyday as much as I can that I love her…6.2 line 114-115), he framed her here and throughout the entire initial interview as a once viable, strong, and active individual who was a family member, worker, and member of
society, now transformed into a patient requiring the most basic of care needs: bathing, toileting, feeding.

Excerpts from Interview 6.1 – ‘she’ / ‘her’ (Total tokens of ‘my wife’/’Dort:’ 0)

… she was walking with a cane … She gave her driver’s license up. She had to be let go from work because she was a liability. (lines 24-27)

Then she gets fed. One of the kids will feed her, or I’ll feed her. (line 53)

She did it all. She did it all…housework, laundry, taking care of the kids, making dinner, she did it all. (lines 90-93)

She’s my number 1 priority. Ain’t nothing else that I care about. She’s my number 1 priority. (lines 147-148)

Excerpts from Interview 6.2 – ‘she’ / ‘her’ (Total tokens of ‘my wife’/’Dort:’ 3)

That’s [i.e., outside paid caregiver] been a big help to her and it’s also boosted her spirits up and that gives her another interactive with somebody else. (lines 14-15)

they [i.e., outside paid caregiver(s)] give her a little bit of heck today because she’s not doing her range of motion…very bullheaded. She’s very strong willed. (lines 17-19)

Excerpts from Interview 6.3 – ‘she’ / ‘her’ (Total tokens of ‘my wife’/’Dort:’ 3)

I’m able to take my frustration out on a game from a day of work vs. jumping right in and dealing with the kids and dealing with her. (lines 49-51)

Jerry’s systematic and consistent avoidance of specific reference to his wife in the first 180 minutes of the interviews indexes a psychological/affective distance from his wife and partner, at least in his discourse. However, as indicated in Table 1, in the seventh and twelfth months of the interview process there was a notable shift in Jerry’s manner of referring to Dort. That is, the number of tokens of ‘my wife’/’Dort’ increased sharply from 0 in interview 1, and 3
in interviews 2 and 3, respectively, to 50 and 70 in interviews 6.7 and 6.12, respectively. In contrast with his earlier narratives, Jerry’s patterns of referring to Dort replaced the preponderance of pronouns ‘she,’ ‘her,’ and ‘hers’ to a name and a close familial relationship.

By the seventh interview, Dort’s condition had taken a sharp turn for the worse. Jerry’s narratives were now replete with details concerning the dire situation that his family was facing. Throughout interview 6.7, Jerry talked about the joint EOL decisions that he and Dort had to make, e.g., respirator, intubation. Dort emerges in these narratives with her name, as Jerry’s partner, his wife, and the object of his love, support, respect, and care. The medical care decisions are not and never have been unilateral. Jerry’s life was now being framed as one in union with, in collaboration with, his wife whose medical condition was worsening and who was now more visibly approaching the end of her life.

**Excerpts from Interview 6.7 – ‘my wife’/‘Dort’ (Total tokens: 50)**

*Dort’s* always made a point, if I got to live on a respirator, I don’t want to live. That’s the way we made it known today. Just hearing those words out of her and even me standing up and saying those words myself, puts it back into perspective. Things ain’t forever, I’ve got to face that. I’m telling you, I don’t know what I’m going to do. I just don’t know.

(lines 136-140)

Knowing *Dort*…, if she does decide to go that option, I’ll be behind her 100%, but I know my wife. She’s just going to be, my time card’s up, punch it. I just know that...

(lines 136-139)

Of course, I’m just as bullheaded as *Dort*, so I refused as she has, but yeah, there is probably a point that I could use one. (lines 158-160)

Yes, I’m off work today because of *Dort*, it’s a vacation day. (line 179)
Five months later, by interview 6.12, Dort’s condition had declined even further. In fact, the interview opens with Jerry explaining that he had just gotten off the phone with the physician—he had discussed a procedure necessary to sustain Dort’s life. Jerry referred to Dort almost exclusively as ‘my wife.’

Excerpts from Interview 6.12 – ‘my wife’/’Dort’ (Total tokens: 70)

I mean that’s how I feel about anything anymore with dealing with my wife. I mean I want the best for her no matter what. (lines 54-55)

…anything that the family has to say, in the end it’s my wife’s and my decision. (lines 97-98)

Yeah it involves my wife, it involves us making a decision the best and granted we always said what’s meant to be will be, no matter what. (lines 112-114)

This reference pattern, now isolated in the current study, was not noticed or even considered remarkable in the initial original study, which was designed to investigate broad themes expressed by caregivers providing EOL care.

Indexicality

Also revelatory of Jerry’s perceptions of Dort and himself were his patterns in using indexical pronouns ‘I’/’me’ and ‘we’/’us.’ First-person singular ‘I’ invariably and unambiguously referred to him (unless he was quoting others’ speech). In contrast, first-person plural ‘we’/’us’ variably referred to the family or to Jerry and Dort as equal participants in their marriage. However, throughout Jerry’s interviews, his use of ‘we’/’us’ also served to index a patterned intermeshing of self with wife/CR, in situations actually more skewed as a reference to Dort or more skewed as a reference to himself.
In the first excerpts, in interviews 6.1, 6.9, and 6.12, the pronoun ‘I’ denoted Jerry and only Jerry. Despite the consistency in personal reference term, Jerry’s stance in the three interview excerpts clearly shifted, as noted in the juxtaposition between his expressed sense of control and confidence (6.1) and the lack thereof that had gradually ensued by 6.9 and 6.12. The referent ‘I’ remained the same. His sense of confidence and control had shifted.

Excerpts of first-person singular ‘I’ in Jerry’s narratives: referent = Jerry

Interview 6.1

… if I stand her up… I have to hold her…. I’m able to pick her up… I give her a bath… I take care of that. I do that as much as I can. (lines 10-14)

I don’t use the bed pans, I actually have the actual potty chair, so I’m able to move her… set her down on the pot… (lines 176-177)

Interview 6.9

I lost control. I mean, to me, I think there’s control being taken care of… There’s… but there’s somebody else taking that control. It’s not me no more. (lines 362-366)

Interview 6.12

You know I don’t know, I don’t know how strong I think I am.” (lines 236-237)

Decisions are hard for me. Like they say everybody hates change. Well I hate change totally. (lines 374-375)

Jerry’s use of first-person plural ‘we’/‘us’ referred in an unmarked way to both Jerry and Dort as a couple, with each member framed by the discourse as participating equally in the events that Jerry narrated.

Excerpts of first-person plural ‘we’/‘us:’ Referents = Jerry and Dort = equal participants
Interview 6.2

We make it a point before we close our eyes every night, even though she’s got this disease, we always made it a point that the last words are I Love You and you get a kiss. (lines 120-122)

Interview 6.8

We stayed at home and enjoyed each other’s company and that’s the way we do things now. That’s us. Why should we let something change us to make us something that we ain’t?… (lines 302-305)

The activities described above are jointly shared and constructed by both participants.

In contrast, Jerry also used ‘we’/’us’ to index a stance of joint participation within an activity, but in reality the activity was being accomplished more by Jerry than by the couple together, as in the following excerpts from 6.1 and 6.4:

Excerpt of first-person plural ‘we’/’us:’ Referents = Jerry and Dort = mostly Jerry

Interview 6.1

a. If we’re taking a shower that night, it usually takes us an hour and a half. If we’re not taking a shower, it usually takes us about an hour… (lines 56-57)

b. She uses the chair and picks herself up. We lean her against the sink and steady her legs and then we’ll set her down on the pot…. (line 78)

In 6.1a, Jerry was the participant who was actually bathing his wife. The activity of shower-taking was not a joint one. He defocused his own agency in giving Dort a shower and instead framed the activity as routine as well as mutually cooperative and mutually participatory. Similarly, in 6.1b, it was Jerry who leaned Dort against the sink and set her down on the commode.
Interview 6.4

She caught her chair and we put a bruise on her leg, and I said look, I’m abusing you.
She said, no, it happens. (lines 79-80)

In 6.4, Jerry recounted a particular accident that resulted in Dort’s leg being visibly bruised. By virtue of his use of ‘we,’ Jerry framed the incident as if Dort might have contributed somehow to the outcome. A few lines later, in the same interview, he shifted his stance and said, “I’m hurting her and she’s not saying nothing. I don’t know if I pull the pad under her the right way or if I pinch her…”

Conversely, as noted in the following excerpts, Jerry also used ‘we’/’us’ to index a sense of shared participation when the reference was skewed toward Dort as the primary participant in the narrated actions.

Excerpts of first-person plural ‘we’/’us:’ Referents = Jerry and Dort = mostly Dort

Interview 6.1

… if we’re going to the bathroom, I don’t use the bed pans, I actually have the actual potty chair, so I’m able to move her. (lines 76-77)

Interview 6.2

I look at other people differently since we’ve come with this disease. (lines 145-146)

Interview 6.11

So we kind of did away with that. I mean the machine is still here but we haven’t used it in probably a good 6 months. We do the nebulizer treatment you know 2 maybe 3 times a day. We’ve never done it more than 3 times a day and it seems like that brings up the mucous pretty good. (lines 156-159)
In the excerpts above, Jerry used ‘we’ to index a jointly achieved activity or state, but in each case, the issues depicted more realistically designated Dort as the primary participant in the activity: using the bathroom/coming with this disease/using the equipment.

‘I,’ ‘we’/’us:’ Referent = Jerry

Finally, in excerpt 6.12, Jerry indexed himself as the ultimate decision maker in the final stages of Dort’s care. His discourse in this narrative was predominantly marked by the first-person singular ‘I’ as agent and experiencer during this extremely painful time in the EOL Care Trajectory. Here, Jerry produced a soliloquy-like spate of talk projecting a hypothetical future for himself, and used one key instance of ‘we,’ when clearly and unambiguously, it was he who was the responsible party.

**Interview 6.12**

You know that’s part of my damned if I do, damned if I don’t kind of thing because in the end you know we don’t put her on a respirator when she does go—dad why didn’t you do something—why didn’t you put mom on a machine—why didn’t you help her – she’d still be here. I got to live with that. I got to live with them possibly at being you know cut me out of their life totally I got to be prepared for that. The other side of the coin is you know I got to be prepared for that even going the other way. I put her on a machine—well if you wouldn’t have put her on the machine she wouldn’t be you know possibly suffering and just laying there being a vegetable. She would be gone and better off. You know can I live with that? You know there’s so many things that I got to feel that I got to be ready to live with no matter how they feel. (lines 98-108)
The study of both reference and indexicality in the EOL Caregiving Trajectory provides one analytic lens through which to view subtle yet powerful aspects of self and other perception. By isolating a specific but limited set of reference terms used throughout the discourse, we have gained systematic glimpses into the mind of this single caregiver in relation to his perception of self and his terminally ill wife.

**Discussion**

Discourse-based analysis of qualitative secondary data has great possibilities for advancing nursing and healthcare research. Reanalyzing a high-quality qualitative dataset to answer new research questions or augment findings from the original study can extend understanding of a given phenomenon with limited use of additional resources. International interest has developed around qualitative secondary datasets (Smioski, 2011). This study explored the application of discourse to a qualitative dataset and developed a framework through which to analyze these data (Author citation, under review).

Discourse analysis is a logical analysis technique for qualitative datasets. DA, the study of language or any significant semiotic event, can offer a unique opportunity to reveal a sense of identity and the relationships between self and others or the flow of events in a given phenomenon of interest (Author citation, 2014). DA remains underutilized when addressing caregiver care provision to adult care recipients (J. L. Smith 2007). This study demonstrated the potential to use DA with qualitative secondary data by establishing a framework and analyzing one case in a larger dataset.

This framework provides direction to efforts to apply DA in order to gain a better understanding of types of linguistic devices used by caregivers to construct agency, express confidence and control throughout the EOL caregiving experience. It was applied to a subset of
caregiver data. Researchers agree that a state of confidence and control is a conceptualization of quality of life (Eastwood, Doering, Roper, & Hays, 2008; Kim & Givens, 2008). Findings offer initial understanding of the linguistic expressions of an EOL caregiver’s perception of self and others in their role as caregiver. Linguistic cues and expressions examined above represent shifts in confidence and control. Expressions of shifts in confidence and control or uncertainty are remarkable indicators of caregiver distress (Given et al., 2001; Author citation, 2012a).

Caregiver distress has been examined across the trajectory of caregiving from role acquisition through bereavement (Given et al., 2004; Kurtz et al, 2002; Nijboer et al., 2001; Northouse et al., 2000; Weitzner et al., 2000; Weitzner et al., 1997; Wyatt et al., 1999). As challenges emerge, caregivers’ sense of confidence and control shift, resulting in caregiver distress (Author citation, 2012a). Challenges are conceptualized as the perception of demands on the caregivers.

When resources are available, adequate, and employed to manage the challenges, informal family caregiver distress is minimized and at times even resolved. However, if challenges are not managed or are left unresolved, the levels of distress continue to override positive aspects of informal family caregivers, and quality of life suffers (Yilmaz et al., 2009).

*Seeking Normal* is a model that frames the ever-changing care demands of informal family caregivers providing EOL care. Informal family caregivers strive to re-establish “a steady state, or a sense of pattern” as care demands continually change (Author citation, 2011, p. 10; Author citation, 2012a). Key transitions (i.e., the diagnosis of a life-limiting condition, acknowledging treatment will no longer cure the condition, death of the care recipient) challenge caregivers’ perception of achieving a “steady state” and predisposes caregivers to distressed states (Author citation, 2012a). Caregivers’ linguistic expressions can be analyzed as they
transition through the End-of-Life Caregiving Trajectory and their role as caregiver (Author citation, 2012a). The conceptual understanding of EOL caregivers’ linguistic expressions can provide nurses with awareness of the experience of EOL caregivers. However, patterns in perceptions of self and other in a clinical setting may be difficult for practitioners to identify without additional evidence. In fact, simply changing the way in which a condition is labelled can influence the way a patient conceptualizes their health care problem, circumstance, and/or interactions with others (Mosher & Danoff-Burg, 2009; Ogden et al., 2003; Tailor & Ogden, 2009; Tayler & Ogden, 2005). If linguistic cues can be assessed by nurses, future interventions may be devised for dealing with issues related to physical, psychosocial, existential and financial challenges faced by informal family caregivers. Understanding how caregivers talk about their experiences and their care recipients will assist in tailoring interventions for caregivers who provide care to dying individuals and promote the need for additional analysis of multiple cases.

Limitations of this study include the small sample size. One of the goals of this type of DA-based work is to uncover meaningful preliminary patterns and design frameworks for further study. The linguistic focus of the study was designed to be narrow to enable the discovery of precise and systematic distributions of target forms within this specific dataset. An analysis of more descriptive markers of caregiver distress, confidence, and control can serve as a next step to complement findings detailed here. Now that a discourse analytic framework has been developed in full for one of the 46 caregiver interviews from the original study, a more global DA-based analysis can be conducted. Additional analysis can be done on cases in other EOL trajectories (unexpected and mixed) to compare themes that emerge. A more in-depth understanding of the experiences surrounding EOL informal caregivers through times of uncertainty during EOL care will be important contributions to science.
This article has provided an in-depth observation of the discursive patterns and systematic meanings of linguistic cues that are not transparent at the surface level. While we set out to investigate the more surface-level issues of caregiver distress, confidence, and control (e.g., modals, expressions of lifestyle management, and coping), we took the analysis in a more microscopic direction in order to initially gain a better understanding of linguistic cues emerging in systematic patterns in this dataset. Additional studies of these and similar datasets can provide deeper insights into such issues as: What underlies caregiver distress? At which specific times in the EOL Caregiving Trajectory does loss of control manifest itself? For what reasons? What does loss of control actually look like? Future analysis of the discourse in EOL Caregiving Trajectories may focus on elements of time (how the past, present, and future are construed by the interviewees), memory, emotions, expressions of challenge, difficulty, hope, and uncertainty in the other datasets from the original study.
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<td>6.2</td>
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<td>6.13</td>
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Author citation, (2013).


Author citation, (2011).

Author citation, (2012a).

Author citation, (2012b).


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Author citation, (2014).


Chapter 6

Conclusion

This chapter provides a brief discussion of the evolution of this project and a summary of key findings. Study strengths and limitations are presented. Then, the implications of this study are presented to frame the future research that is planned to extend this line of research.

Evolution of the Project

This project was conceived under the guidance of the dissertation committee. Experience as a research assistant on Drs. Loeb, Penrod, and Hollenbeak’s qualitatively-driven R01 (Infusing End-of-Life Care Into Complex Organizations: The Prison Study [NIH/NINR R01NR011874-01]) fostered an interest in researching end-of-life issues. As an approved member of Dr. Penrod’s research team examining end-of-life caregiving (Exploring the Formal/Informal Caregiver Interface across 3 Death Trajectories [NIH/NINR R01NR010127]), the richness and depth of the dataset were identified. The team discussed the number of conceptual strands in the data that were untapped; while the data met the needs of the original study, the data were not fully explored. In working with Drs. Strauss and Schrauf, an interest in the study of linguistics emerged. It became evident that discourse analysis provided a method that would extend the findings of Penrod’s original study in a meaningful way. It was determined that a secondary analysis of the end-of-life (EOL) caregiving dataset would be the most appropriate approach for this study. This project was iteratively revised in collaboration with the committee over two years of study. With the committee’s expert guidance, research questions were clarified and refined.

Summary of Findings

Two manuscripts summarizing the methods and findings of this study were developed. The emphasis of the first manuscript (Kitt-Lewis, Penrod, & Strauss, under review) is on the
utility of discourse analysis-based secondary analysis of qualitative datasets and the development of a framework for the application of DA on a subset of a caregiver dataset. The EOL caregiving dataset is referenced as an exemplar of this methodological process article.

The key assertions of this methods-oriented article are that DA is a logical and viable approach for qualitative secondary datasets that could provide new perspectives of a given phenomenon of interest while minimizing the investment of additional resources. DA is the study of language or any significant semiotic event, and qualitative datasets are typically language-based textual data. The article asserts that this analytic approach is amenable to qualitative datasets as it can unravel new perspectives on language within a given framework.

Discourse analysis is underutilized in nursing research. The contribution of this manuscript is to promote DA as a logical choice for repurposing large qualitative datasets. Securing rich, comprehensive qualitative datasets requires a significant investment in resources. Once the researcher analyzes the original study data to meet the study objectives, the data are shelved. In repurposing qualitative data, additional advances in scientific knowledge can be gained without the significant investment required for robust data collection. DA has implications for addressing nursing questions and extending the state of science.

In the second manuscript, the application of the derived coding scheme and findings of the analysis are reported. Data were coded for grammar cues; reference and deixis; stance; and indexicality. The analysis sheds light on the more subtle features of the caregiver’s perceptions of self and the care recipient. The unique contribution of this study is an illustration of the depth of understanding that may be derived through discourse analysis of complex phenomena. The results shed light on the more subtle features of the caregiver’s perceptions of self and other (i.e., wife/care recipient). Specifically, findings with regard to the various ways in which the caregiver
positioned himself as caregiver and his wife as care recipient/mother across a trajectory of caregiving was identified through the narratives. Analytic insights were then integrated with the theoretical frameworks pertaining to caregiving trajectory, uncertainty, and confidence/control. The change over time or trajectory-perspective provides an analytic lens through which to view subtle yet powerful aspects of changing perceptions of self and other. By isolating a specific but limited set of reference terms used throughout the discourse, systematic glimpses into the mind of this single caregiver in relation to his perception of self and his terminally ill wife were described. This study is significant in providing direction when applying DA to understand types of linguistic devices by caregivers to construct agency, express confidence and control throughout the EOL caregiving experience.

**Study Strengths and Limitations**

A primary strength of this project was the forging of new ground in secondary analysis of qualitative data using discourse analysis. This project was ideally situated since the researcher was a member of the original study team and other team members were available for consultation and feedback on the study. This was a definite advantage; however, the lack of such access to project staff would not preclude this type of investigation by other researchers.

Another strength of the study is related to the quality and accessibility of dataset that was analyzed. This was a robust dataset. Data files were of high quality, accessible and complete. There were no missing data; that is, all data files were intact for those participants who engaged in longitudinal interviews. Cases varied by the number of interviews; for example, if the care recipient died, one post-death interview was conducted and the case was closed before the anticipated 12 months of data collection ended. Despite the robust nature of the dataset, it was critical to examine the fit of these data with the new research questions. The description of the
methodical evaluation of the dataset will guide future researchers in considerations of quality that may influence their work.

The approach to discourse analysis used in this study was sophisticated. The project evolved through a series of analyses that shaped the final study. Expertise in discourse analysis and collaborative discussions with other experts were critical. The resultant manuscripts exhibit an appropriate application of key components of discourse analysis.

The primary limitation of this project was its limited scope. However, the derivation of a coding framework through iterative preliminary analyses and the application of that framework to a limited dataset were essential prior to future investigations to build understanding of linguistic cues in greater depth. Examination of the discourse on the other cases and across other caregiving trajectories could provide insights into emergent linguistic patterns that could be quite useful across varied contexts of care in life-limiting or terminal conditions.

**Implications**

Penrod has asserted that linguistic cues may be the most important assessment criteria for triggering phase-specific, time-sensitive interventions for caregivers (Penrod, 2001; 2007). This study has launched deeper examination of that premise and holds promise to serve as a rigorous foundation for clinically applied research. This study demonstrated a shift in perception of self and other in the role of caregiving. Theoretical integration supports the notion that these shifts are related to important transitions in caregiving. Further study will explore the meaning of these shifts in relation to caregiver distress so that nurses and other health care providers may be able to identify distressed caregivers in the discourse of providing care. This line of research extends Penrod’s theoretical work toward interventions, an appropriate progression of the program of research.
Future Studies

The experience of conceptualizing and refining this project were foundational to launching a research career. The resultant manuscripts are important to establishing credibility in the field of discourse analysis, specifically the discourse caregivers providing care at the end of life. As a result of this project, a collaborative partnership was forged with Dr. Strauss, an expert in discourse. This collaboration maximizes exposure in the field of discourse and nursing.

Further studies of caregivers’ discourse in the same large dataset are planned. Over 400 hours of transcripts from 46 caregivers providing end-of-life care in three distinct death trajectories has been made available for continued study. Larger-scale projects will expand this foundational work to enable a deeper understanding of the discourse of caregiving. Comparative analyses of how the death trajectory influences such discourse will be completed. If linguistic patterns are evident, assessment guides may be developed to enhance clinicians’ awareness of cues in order to stimulate supportive interventions, as needed. Thus, the long-term goal of future research is to develop tailored, time-sensitive interventions to support family caregivers through one of life’s most difficult experiences.
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Wolff, J. L., Rand-Giovannetti, E., Palmer, S., Wegener, S., Reider, L., Frey, K., ... & Boult,


APPENDIX A

Institutional Review Board Approval

APPROVAL OF SUBMISSION

Date: February 24, 2016
From: Susie Walmer, IRB Compliance Specialist
To: Janice Penrod

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On 2/24/2016, the IRB approved the above-referenced Continuing Review. This approval is effective through 2/23/2017 inclusive. You must submit a continuing review form with all required explanations for this study at least 45 days before the study’s approval end date. You can submit a continuing review by navigating to the active study and clicking ‘Create Modification / CR’.

If continuing review approval is not granted before 2/23/2017, approval of this study expires on that date.

In conducting this study, you are required to follow the requirements listed in the Investigator Manual (HRP-103), which can be found by navigating to the IRB Library within CATS IRB (http://irb.psu.edu). These requirements include, but are not limited to:

- Documenting consent
- Requesting modification(s)
- Requesting continuing review
- Closing a study
- Reporting new information about a study
- Registering an applicable clinical trial
- Maintaining research records

This correspondence should be maintained with your records.
Date: January 24, 2017

From: Susie Walmer, IRB Compliance Specialist

To: Janice Penrod

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<td>Documents Approved:</td>
<td>• PRAMS 031507EP SUMMARY PROTOCOL (9.1.09), Category: IRB Protocol</td>
</tr>
<tr>
<td>Review Level:</td>
<td>Expedited</td>
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<tr>
<td>IRB Board Meeting Date:</td>
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</table>

On 1/24/2017, the IRB approved the above-referenced Continuing Review. This approval is effective through 1/23/2018 inclusive. You must submit a continuing review form with all required explanations for this study at least 45 days before the study’s approval end date. You can submit a continuing review by navigating to the active study and clicking ‘Create Modification / CR’.

If continuing review approval is not granted before 1/23/2018, approval of this study expires on that date.

In conducting this study, you are required to follow the requirements listed in the Investigator Manual (HRP-103), which can be found by navigating to the IRB Library within CATS IRB (http://irb.psu.edu). These requirements include, but are not limited to:

- Documenting consent
- Requesting modification(s)
- Requesting continuing review
- Closing a study
- Reporting new information about a study
- Registering an applicable clinical trial
- Maintaining research records

This correspondence should be maintained with your records.
APPENDIX B
Institutional Review Board Approval Closed Enrollment

Date:         May 25, 2012
To:           Janice L. Penrod, PhD, RN
From:         Bethann Sherrock, BS, CIP
              IRB Coordinator
              Human Subjects Protection Office

The Human Subjects Protection Office (HSPO) received your April 23, 212 correspondence with
the accompanying documentation regarding the above investigation.

In accordance with Federal guidelines and institutional policy, this issue qualified for review by
a designated Institutional Review Board member.

The deletion of co-investigators Judith Hupcey, Peggy Shipley and Gwen McGhan was noted.

The modification request form indicates that this study is closed to enrollment; therefore, the
revised Summary Explanation of Research and revised Informed Consent Form are no longer
required to be updated for use.

If you have any questions, please phone me in the HSPO (ext. 5687). Thank you very much.

BS\
APPENDIX C
Nursing Inquiry Author Guidelines

Author Guidelines

1. GENERAL

1.1 Overview
Nursing Inquiry is an international peer-reviewed Journal of interest to nurses, health care professionals, social scientists and health policy makers on ideas and issues pertaining to nursing and healthcare. Established as a vehicle for critical reflection and substantive dialogue on topics of emerging interest internationally, it aims to foster debate and dialogue, advance new conceptualizations, and challenge current thought on a wide range of nursing and health phenomena. The Journal publishes original research, discussion papers, review articles and commentaries on topics consistent with its aims and scope (see below).

Authors submitting a manuscript do so on the understanding that the work constitutes original scholarship that has not been published before either as a whole or in part, and is not under consideration for publication elsewhere. Nursing Inquiry requires that authorship and acknowledgement conforms to ethical guidelines for publication and research (details below), and that authors are satisfied that bias was avoided.

1.2 Aims and Scope
Nursing Inquiry aims to stimulate examination of nursing’s current and emerging practices, conditions and contexts within an expanding international community of ideas. The journal aspires to excite thinking and stimulate action toward a preferred future for health and healthcare by encouraging critical reflection and lively debate on matters affecting and influenced by nursing from a range of disciplinary angles, scientific perspectives, analytic approaches, social locations and philosophical positions. Toward this end, the Editor welcomes original research and discussion articles on a wide range of topics. Examples of the kinds of manuscripts that may be considered for publication include the following:

1. Substantive research that draws upon ideas from the humanities or social science perspectives to investigate and interpret nursing and healthcare practices, technologies and trends.
2. Substantive research that uses methodological innovation within empirical investigation to shed new light on health phenomena.
3. International or comparative perspectives on health, health care delivery, human health resources, health promotion or health planning from a global perspective.
4. Policy analysis that critically examines controversial or timely matters such as evolving health labour workforce, transitions in service delivery systems, or trends in health funding patterns.
5. Advancement of methodological approaches and frameworks to enrich and extend the capacity of nursing and healthcare inquiry.
6. Ethical inquiry that illuminates or challenges the assumptions underlying the everyday practices and policies affecting nursing and healthcare.
7. Philosophical inquiries that stimulate thought, deconstruct ideologies or challenge conformities related to the nature and expression of nursing and healthcare.
8. Historical research that revisits the assumptions upon which professional narratives have been built.
9. Critical integrative reviews of the current state of scientific and/or non-scientific knowledge in relation to conceptualization, practice, delivery or planning of health systems.
10. Discussion or opinion papers providing critical commentary on current trends, policies or practices in nursing.

Authors uncertain as to the fit between their ideas in progress and the journal's aims and scope are invited to send a letter of inquiry to NINedoffice@wiley.com

To submit a manuscript, please follow the instructions below.

2. MANUSCRIPT FORMAT AND STRUCTURE

2.1. Format
As of March, 2016, Nursing Inquiry’s format, structure and language use generally follow those set out in the 6th edition of the Publication Manual of the American Psychological Association (APA). However, given the international aims and scope of Nursing Inquiry, and the diversity of manuscripts it publishes, a few exceptions and variations apply, as set out below.

Language: The language of the publication is English. Authors for whom English is a non-dominant language should consider having their manuscript professionally edited by an English speaking person before submission to make sure the English is of sufficiently high quality to allow for rigorous review of the ideas. Visit our site to learn about the options. Please note that using the Wiley English Language Editing Service does not guarantee that your paper will be accepted by this journal.

Spelling: Spelling may follow either British, USA or Australian conventions, but must be consistent throughout the manuscript. Occasional foreign words used in the text may be identified through the use of italics and, if necessary, include English translation following in square brackets.

Manuscripts should be consistent throughout in presentation and style.

Word Limits: Original Articles and Reviews are normally between 5000 and 6000 words, not including tables, figures and references. Invited Commentaries tend to be shorter pieces, often of a more discursive or polemic nature, and usually range from 1000 to 3000 words. Authors submitting papers beyond the normal word limits are advised to provide a compelling justification in their cover letter of the need for additional space.

2.2 Structure
All manuscripts submitted to Nursing Inquiry should include: title page, abstract and keywords, text, acknowledgements, references, figure legends, figures and tables. Please do not number your pages, as the uploaded manuscripts will be automatically paginated upon submission. The author(s) name(s) should not appear on the manuscript itself and any identifiable references or information should also be deleted from the main document. Layout should be double-spaced.

Title Page: The title page should contain the category of the article, the title and word length of the paper (with and without references and tables etc). The title should be short and informative and may contain the major keywords. A short title (up to 40 characters including spaces) should also be provided. The title page document should include correspondence details of the author(s) as well as any acknowledgements or conflict of information as may be required (Nursing Inquiry does not normally publish conflict of interest statements). Material in the title page will not be available to blind reviewers.

Abstract and Keywords: All full manuscript submissions must include an unstructured abstract of 150-200 words, which describes the intent of the paper, generally its aims, approach and main conclusions. The abstract should be an original synopsis of the manuscript, not a duplication of material in the main text. It should not contain subheadings, abbreviations or references. Up to eight (8) key words (chosen from the CINAHL thesaurus, if possible) should also be provided. Authors are encouraged to be strategic in selecting keywords that will optimize search access.

Manuscript Style: Nursing Inquiry manuscripts focus on the development of ideas, not merely the presentation of technical information. Therefore the narrative flow of the ideas is a priority. Avoid or minimize the use of bullet points or numbered lists. Ensure that your paper ends with a thoughtful narrative conclusion regarding what can be learned from the ideas you are working with.

Headings/ Subheadings: Nursing Inquiry does not use a standardized research reporting style, and encourages the creative use of headings and subheadings to effectively showcase the ideas contained in your manuscript. Depending on whether the Original Article or Review paper is based on a study report or is a discursive consideration of an idea, you are encouraged to structure your manuscript according to the logical flow of the main arguments you are making in presenting the work to your audience. Please structure your arguments such that they build toward your concluding remarks, which should be presented in narrative form rather than a list.

Main Document: The main document you submit for consideration should not include acknowledgements, conflict of interest, or author contributions information.

Optimizing Your Abstract for Search Engines
Many students and researchers looking for information online will use search engines such as Google, Yahoo or similar. By optimizing your article for search engines, you will increase the chance of someone finding it. This in turn will make it more likely to be viewed and/or cited in another work. We have compiled these guidelines to enable you to maximize the web-friendliness of the most public part of your article.
Acknowledgements: Acknowledgements should be brief and formal. Relevant sources of financial and key logistical support must be referenced. Where individuals are named as having contributed to the work, authors are expected to have obtained their prior permission. Authors must clear the copyright of material they wish to reproduce from other sources and this should normally be acknowledged. A copy of any documentation granting permission to reproduce material must be enclosed with the final version of the manuscript. Acknowledgements may be included either in the title page document or prepared as a separate file submitted as a ‘Supplementary File not for Review’.

2.3 References
In text citations
Citations in the body of the text identify the author and date of publication, with full details of the source in the list of references. Refer to APA referencing style (6th edn) for specific format requirements.
Personal communications should rarely be necessary as a reference source. Exceptions could include essential factual information that is unavailable through published sources. Secondary citations should also be avoided unless primary sources are clearly unavailable.
Although in-text citation does not normally include author first names, where appropriate, such as in a historic account, author first names may be included as part of the narrative account.
Footnotes are permissible but are to be used sparingly.
Reference list
Full references are listed in alphabetical order at the conclusion of the manuscript using APA 6th edition formatting requirements.
Journal
Book
Chapter from a Book
Unpublished paper presented at a meeting
Unpublished thesis
Electronic reference
For publications available in Early View (prior to publication) format, please record publication date as “in press” rather than assigning a year. This is important as the publication date may change, compromising future search capacity.
We recommend the use of a tool such as Reference Manager for reference management and formatting. Reference Manager reference styles can be searched for here www.refman.com/support/rmstyles.asp
It is the author’s responsibility to carefully review all in-text and reference list information for accuracy, completeness, and consistency with formatting requirements prior to submission.

2.4. Tables, Figures and Figure Legends
Tables: Tables should be self-contained and complement, but not duplicate, information in the text. Tables should be numbered consecutively and have self-explanatory titles.
Figures: Figures must be of high-quality reproductive art or in electronic form ready for reproduction. Figures should each be on a separate page, be numbered consecutively and have self-explanatory titles. They should be sized to fit within the column (80 mm) or full text (170 mm) width. Written permission to publish must be obtained from any
subjects recognisable in photographs and for any copyright material. Please see http://authorservices.wiley.com/bauthor/illustration.asp.

Preparation of Electronic Figures for Publication

Although low quality images are adequate for review purposes, print publication requires high quality images to prevent the final product being blurred or fuzzy. Submit EPS (line art) or TIFF (halftone/photographs) files only. MS PowerPoint and Word Graphics are unsuitable for printed pictures. Do not use pixel-oriented programs. Scans (TIFF only) should have a resolution of at least 300 dpi (halftone) or 600 to 1200 dpi (line drawings) in relation to the reproduction size (see below). EPS files should be saved with fonts embedded (and with a TIFF preview if possible). For scanned images, the scanning resolution (at final image size) should be as follows to ensure good reproduction: line art: >600 dpi; halftones (including gel photographs): >300 dpi; figures containing both halftone and line images: >600 dpi.

Further information can be obtained at Wiley-Blackwell Publishing's guidelines for figures: http://authorservices.wiley.com/bauthor/illustration.asp

Check your electronic artwork before submitting it: http://authorservices.wiley.com/bauthor/eachecklist.asp

Permissions: If all or parts of previously published illustrations are used, permission must be obtained from the copyright holder concerned. It is the author's responsibility to obtain these in writing and provide copies to the Publisher.

Colour Charges: Nursing Inquiry is published in an online only format, there is no cost to authors for the publication of colour images.

To read PDF files, you must have Acrobat Reader installed on your computer. If you do not have this program, this is available as a free download from the following web address: http://www.adobe.com/products/acrobat/readstep2.html

Figure Legends: In the full-text online edition of the journal, figure legends must be truncated in abbreviated links to the full screen version. Therefore, the first 100 characters of any legend should inform the reader of key aspects of the figure.

3. SUBMISSION OF MANUSCRIPTS

Manuscripts should be submitted electronically via the online submission site. The use of an online submission and peer review site enables immediate distribution of manuscripts and consequently speeds up the review process. It also allows authors to track the status of their own manuscripts. Complete instructions for submitting a paper are available below and on the site; a user ID and password can be obtained on the first visit. Support can be contacted by phone (1 434 817 2040 ext. 167) or at http://mcv3support.custhelp.com. If you cannot submit online or have a general query, please contact the Editorial Office via e-mail at NINedoffice@wiley.com

3.1. Getting Started

Launch your web browser (supported browsers include Internet Explorer 6 or higher, Netscape 7.0, 7.1, or 7.2, Safari 1.2.4, or Firefox 1.0.4) and go to the journal's online Submission Site: http://mc.manuscriptcentral.com/nin.

Log-in or click the 'Create Account' option if you are a first-time user.

If you are creating a new account.

- After clicking on 'Create Account', enter your name and e-mail information and click 'Next'. Your e-mail information is very important.
- Enter your institution and address information as appropriate, and then click 'Next'.
- Enter a user ID and password of your choice (we recommend using your e-mail address as your user ID), and then select your area of expertise. Click 'Finish'.

If you have an account, but have forgotten your log in details, go to Password Help on the journals online submission system http://mc.manuscriptcentral.com/nin and enter your e-mail address. The system will send you an automatic user ID and a new temporary password.

Log in and select 'Author Center'

3.2. Submitting Your Manuscript

After you have logged in, click the 'Submit a Manuscript' link in the menu bar.

Enter data and answer questions as appropriate. You may copy and paste directly from your manuscript and you may upload your pre-prepared covering letter.

Click the 'Next' button on each screen to save your work and advance to the next screen.

You are required to upload your files.

- Click on the 'Browse' button and locate the file on your computer.
- Select the designation of each file in the drop-down menu next to the Browse button.
- When you have selected all files you wish to upload, click the 'Upload Files' button.

Review your submission (in HTML and PDF format) before sending to the Journal. Click the 'Submit' button when you are finished reviewing.

3.3. Manuscript Files Accepted
Manuscripts should be uploaded as Word documents or Rich Text Format (.rft) files (not write-protected) only plus separate figure files. GIF, JPEG, PICT or Bitmap files are acceptable for submission, but only high-resolution TIF or EPS files are suitable for printing. The files will be automatically converted to HTML and PDF on upload and will be used for the review process. The main document text file must contain the manuscript; abstract; references; tables and figures legends, but no imbedded figures, these should be uploaded as separate files. Figure tags should be included in the file. Manuscripts should be formatted as described in the Author Guidelines below.

*Update (25 May 2012): Please note that we now accept .doc and .docx files.

3.4. Blinded Review
Manuscripts submitted to Nursing Inquiry will normally be reviewed by at least two experts in the field. Nursing Inquiry uses double-blinded review. The names of the reviewers will thus not be disclosed to the author submitting a paper and the name(s) of the author(s) will not be disclosed to the reviewers.
To allow double-blinded review, please submit (upload) your main manuscript and title page as separate files. Please format your main manuscript in such a manner that your identity is concealed, such as replacing the name in a citation to your prior work with "[author]".
Please upload:
Your manuscript without title page under the file designation 'main document'
Figure files under the file designation 'figures'
The title page, Acknowledgements and Conflict of Interest Statement where applicable, should be uploaded under the file designation 'title page'
All documents uploaded under the file designation 'title page' will not be viewable in the HTML and PDF format you are asked to review at the end of the submission process. The files viewable in the HTML and PDF format are the files available to the reviewer in the review process.

3.5. Suspension of Submission Mid-way in the Submission Process
You may suspend a submission at any phase before clicking the 'Submit' button and save it to submit later. The manuscript can then be located under 'Unsubmitted Manuscripts' and you can click on 'Continue Submission' to continue your submission when you choose to.

3.6. E-mail Confirmation of Submission
After submission you will receive an e-mail to confirm receipt of your manuscript. If you do not receive the confirmation e-mail after 24 hours, please check your e-mail address carefully in the system. If the e-mail address is correct please contact your IT department. The error may be caused by spam filtering software on your e-mail server. Also, the e-mails should be received if the IT department adds our e-mail server (uranus.scholarone.com) to their whitelist.

3.7. Manuscript Status
You can access Manuscript Central any time to check your Author Center for the status of your manuscript. The Journal will inform you by e-mail once a decision has been made.

3.8. Submission of Revised Manuscripts
Revised manuscripts must be uploaded with 6 months of authors being notified of either the need for revision and reconsideration or for conditional acceptance pending satisfactory revision. Failure to do so will necessitate that the manuscript is submitted as a new submission, subject to further review. Locate your manuscript under 'Manuscripts with Decisions' and click on 'Submit a Revision' to submit your revised manuscript. Please remember to delete any old files uploaded when you upload your revised manuscript. Please also remember to upload your manuscript document separate from your title page.
3.9. Supporting Information
Nursing Inquiry is able to host online Supporting information. Such material must be important ancillary information that is relevant to the parent article but which does not appear in the printed edition of the Journal. Supporting information will be published as submitted and will not be corrected or checked for scientific content, typographical errors or functionality. Supporting information should be submitted to ScholarOne Manuscripts as ‘Supplementary materials for review’.

3.10. Appeal of Decision
The decision on a paper is final and cannot be appealed.

4. ETHICAL GUIDELINES
Nursing Inquiry endorses the International Committee of Medical Journal Editors (ICMJE)’s Uniform Requirements for Manuscripts, which can be found at http://www.icmje.org/ and adheres to the below ethical guidelines for publication and research.

4.1 Authorship and Acknowledgements
Authorship: Authors submitting a paper do so on the understanding that the manuscript has been read and approved by all authors and that all authors agree to the submission of the manuscript to the Journal. ALL named authors must have made an active contribution to the conception and design and/or analysis and interpretation of the data and/or the drafting of the paper and ALL must have critically reviewed its content and have approved the final version submitted for publication. Participation solely in the acquisition of funding or the collection of data does not justify authorship and, except in the case of complex large-scale or multi-centre research, the number of authors should not exceed six.

Nursing Inquiry adheres to the ICMJE authorship criteria, based on 1) substantial contributions to conception and design of, or acquisition of data or analysis and interpretation of data, 2) drafting the article or revising it critically for important intellectual content and 3) final approval of the version to be published. Authors must meet all three conditions.

It is a requirement that all authors have appropriate accreditation upon submission of the manuscript. Contributors who do not qualify as authors should be mentioned under Acknowledgements.

Acknowledgements: Acknowledgements should be brief and must include reference to relevant sources of financial and logistical support. Acknowledgements should be prepared as a separate file submitted as a ‘Supplementary File not for Review’.

4.2. Permissions
If all or parts of previously published illustrations or other materials subject to copyright are used, permission must be obtained from the copyright holder concerned. It is the author’s responsibility to obtain any required permission in writing and provide copies to the Publishers.

5. AFTER ACCEPTANCE
Upon acceptance of a paper for publication, the manuscript will be forwarded to the Production Editor who is responsible for the production of the journal.

5.1. Copyright
If your paper is accepted, the author identified as the formal corresponding author for the paper will receive an email prompting them to login into Author Services; where via the Wiley Author Licensing Service (WALS) they will be able to complete the license agreement on behalf of all authors on the paper.

For authors signing the copyright transfer agreement
If the OnlineOpen option is not selected the corresponding author will be presented with the copyright transfer agreement (CTA) to sign. The terms and conditions of the CTA can be previewed in the samples associated with the Copyright FAQs below:
CTA Terms and Conditions http://authorservices.wiley.com/bauthor/faqs_copyright.asp

For authors choosing OnlineOpen
If the OnlineOpen option is selected the corresponding author will have a choice of the following Creative Commons License Open Access Agreements (OAA):
• Creative Commons Attribution License OAA
• Creative Commons Attribution Non-Commercial License OAA
• Creative Commons Attribution Non-Commercial -NoDerivs License OAA

To preview the terms and conditions of these open access agreements please visit the Copyright FAQs hosted on Wiley Author Services http://authorservices.wiley.com/bauthor/faqs_copyright.asp and visit http://www.wileyopenaccess.com/details/content/12f25db4c87/Copyright--License.html. See the OnlineOpen section below for more information.

If you select the OnlineOpen option and your research is funded by The Wellcome Trust and members of the Research Councils UK (RCUK) you will be given the opportunity to publish your article under a CC-BY license supporting you in complying with Wellcome Trust and Research Councils UK requirements. For more information on this policy and the Journal’s compliant self-archiving policy please visit: http://www.wiley.com/go/funderstatement.

5.2. OnlineOpen

OnlineOpen is available to authors of primary research articles who wish to make their article available to non-subscribers on publication, or whose funding agency requires grantees to archive the final version of their article.

With OnlineOpen, the author, the author's funding agency, or the author's institution pays a fee to ensure that the article is made available to non-subscribers upon publication via Wiley Online Library, as well as deposited in the funding agency's preferred archive.

To preview the terms and conditions of these open access agreements please visit the Copyright FAQs hosted on Wiley Author Services http://authorservices.wiley.com/bauthor/faqs_copyright.asp and visit http://www.wileyopenaccess.com/details/content/12f25db4c87/Copyright--License.html. All OnlineOpen articles are treated in the same way as any other article. They go through the journal's standard peer-review process and will be accepted or rejected based on their own merit.

5.3. Proof Corrections

The corresponding author will receive an e-mail alert containing a link to a website. A working e-mail address must therefore be provided for the corresponding author. The proof can be downloaded as a PDF (portable document format) file from this site.

Acrobat Reader will be required in order to read this file. This software can be downloaded (free of charge) from the following website: www.adobe.com/products/acrobat/readstep2.html. This will enable the file to be opened, read on screen, and printed out in order for any corrections to be added. Further instructions will be sent with the proof. Hard copy proofs will be posted if no e-mail address is available; in your absence, please arrange for a colleague to access your e-mail to retrieve the proofs.

Proofs should be returned to bpcorrections@sps.co.in within a week of receipt. If further time is required, authors are requested to notify the Production Editor (nin@wiley.com).

Major changes will not be entertained and authors may be charged for excessive amendments at this stage. Excessive changes made by the author in the proofs, excluding typesetting errors, will be charged separately. Other than in exceptional circumstances, all illustrations are retained by the publisher. Please note that the author is responsible for all statements made in their work, including changes made by the copy editor.

5.4 Author Services

Online production tracking is available for your article through Wiley-Blackwell's Author Services. Author Services enables authors to track their article - once it has been accepted - through the production process to publication online and in print. Authors can check the status of their articles online and choose to receive automated e-mails at key stages of production. The author will receive an e-mail with a unique link that enables them to register and have their article automatically added to the system. Please ensure that a complete e-mail address is provided when submitting the manuscript. Visit http://authorservices.wiley.com/bauthor/ for more details on online production tracking and for a wealth of resources including FAQs and tips on article preparation, submission and more.

5.5. Early View

All papers which have been fully copy-edited and peer reviewed are published online prior to the print edition of the journal publishing. Authors may sign up for e alerts in Author Services http://authorservices.wiley.com to be informed when a new issue of this journal is published online.
5.6. Author Material Archive Policy
Please note that unless specifically requested, Wiley-Blackwell Publishing will dispose of all hardcopy or electronic material submitted two months after publication. If you require the return of any material submitted, please inform the editorial office or production editor as soon as possible.

5.7. ELocators
This journal now uses eLocators. For more information, please visit the Author Services eLocator page here.

5.8. PDF offprint
Free access to the final PDF offprint of your article will be available via Author Services only http://authorservices.wiley.com. Please therefore sign up for Author Services if you would like to access your article PDF offprint and enjoy the many other benefits the service offers.

5.9. Note to NIH Grantees
Pursuant to NIH mandate, Wiley-Blackwell will post the accepted version of contributions authored by NIH grant-holders to PubMed Central upon acceptance. This accepted version will be made publicly available 12 months after publication. For further information, see www.wiley.com/go/nihmandate
APPENDIX D

Qualitative Health Research Author Guidelines

Author Guidelines: Qualitative Health Research (QHR)

1. Article Types
   1.1 What type of articles will QHR accept?
2. Editorial Policies
   2.1 Peer review policy
   2.2 Authorship
   2.3 Acknowledgements
   2.4 Funding
   2.5 Declaration of conflicting interests
   2.6 Research ethics and patient consent
   2.7 Clinical trials
   2.8 Reporting guidelines
   2.9 Data
3. Publishing Policies
   3.1 Publication ethics
   3.2 Contributor’s publishing agreement
   3.3 Open access and author archiving
   3.4 Permissions
4. Preparing your Manuscript
   4.1 Article format
   4.2 Word processing formats
   4.3 Artwork, figures and other graphics
   4.4 Supplementary material
   4.5 Journal layout
   4.6 Reference style
   4.7 English language editing services
   4.8 Review Criteria
5. Submitting your Manuscript
   5.1 How to submit your manuscript
   5.2 Title, keywords and abstracts
   5.3 Corresponding author contact details
6. On Acceptance and Publication
   6.1 Fees
   6.2 SAGE Production
   6.3 Access to your published article
   6.4 Online First publication
   6.5 Open Access and SAGE Choice
7. Additional information

Please read the guidelines below then visit the Journal’s submission site http://mc.manuscriptcentral.com/qhr to upload your manuscript. Please note that manuscripts not conforming to these guidelines may be returned. Only manuscripts of sufficient quality that meet the aims and scope of QHR will be reviewed. As part of the submission process you will be required to warrant that you are submitting your original work, that you have the rights in the work, that you are submitting the work for first publication in the Journal and that it is not being considered for publication elsewhere and has not already been published.
elsewhere, and that you have obtained and can supply all necessary permissions for the reproduction of any copyright works not owned by you.

1. Article types
Each issue of QHR provides readers with a wealth of information — book reviews, commentaries on conceptual, theoretical, methodological and ethical issues pertaining to qualitative inquiry as well as articles covering research, theory and methods.

1.1 What types of articles will QHR accept?
QHR asks authors to make their own decision regarding the fit of their article to the journal. Do not send query letters regarding article fit.

- Read the Mission Statement on main QHR webpage.
- Search the QHR journal for articles that address your topic. Do we publish in your area of expertise?
- Ask these questions: Does it make a meaningful and strong contribution to qualitative health research literature? Is it original? Relevant? In depth? Insightful? Significant? Is it useful to reader and/or practitioner?
- Note the sections: General articles, critical reviews, articles addressing qualitative methods, commentaries on conceptual, theoretical, methodological, and ethical issues pertaining to qualitative inquiry.
- QHR accepts qualitative methods and qualitatively-driven mixed-methods, qualitative meta-analyses, and articles addressing all qualitative methods.
- QHR is a multi-disciplinary journal and accepts articles written from a variety of perspectives including: cross-cultural health, family medicine, health psychology, health social work, medical anthropology, medical sociology, nursing, pediatric health, physical education, public health, and rehabilitation.
- Articles in QHR provide an array of timely topics such as: experiencing illness, giving care, institutionalization, substance abuse, food, feeding and nutrition, living with disabilities, milestones and maturation, monitoring health, and children’s perspectives on health and illness.

Look Out for These Regular Special Features
Pearls, Pith and Provocation: This section fosters debate about significant issues, enhances communication of methodological advances and encourages the discussion of provocative ideas.

Book Review Section: Qualitative Health Research includes a book review section helping readers determine which publications will be most useful to them in practice, teaching and research.

Mixed Methods: This section includes qualitatively-driven mixed-methods research, and qualitative contributions to quantitative research.

Advancing Qualitative Methods: Qualitative inquiry that has used qualitative methods in an innovative way.

Evidence of Practice: Theoretical or empirical articles addressing research integration and the translation of qualitatively derived insights into clinical decision-making and health service policy planning.

Ethics: Quandaries or issues that are particular to qualitative inquiry are discussed.

Teaching Matters: Articles that promote and discuss issues related to the teaching of qualitative methods and methodology

2. Editorial policies

2.1 Peer review policy
QHR strongly endorses the value and importance of peer review in scholarly journals publishing. All papers submitted to the journal will be subject to comment and external review. All manuscripts are initially reviewed by the Editors and only those papers that meet the scientific and editorial standards of the journal, and fit within the aims and scope of the journal, will be sent for outside review.

QHR adheres to a rigorous double-blind reviewing policy in which the identity of both the reviewer and author are always concealed from both parties. Ensure your manuscript does not contain any author identifying information. Please refer to the editorial on blinding found in the Nov 2014 issue: http://qhr.sagepub.com/content/24/11/1467.full.

QHR maintains a transparent review system, meaning that all reviews, once received, are then forwarded to the author(s) as well as to ALL reviewers.

Peer review takes an average of 6–8 weeks, depending on reviewer response.
2.2 Authorship
Papers should only be submitted for consideration once consent is given by all contributing authors. Those submitting papers should carefully check that all those whose work contributed to the paper are acknowledged as contributing authors.
The list of authors should include all those who can legitimately claim authorship. This is all authors who:
(i) Made a substantial contribution to the concept and design, acquisition of data or analysis and interpretation of data,
(ii) Drafted the article or revised it critically for important intellectual content, (iii) Approved the version to be published.
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<tr>
<td>2. <strong>Theoretical orientation and evaluation:</strong> Is it theoretically clear and coherent? Is there logical progression throughout?</td>
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<tr>
<td>3. <strong>Methodological assessment:</strong> Appropriate to question and/or aims? Approach logically articulated? Clarity in design and presentation? Data adequacy and appropriateness? Evidence of rigor?</td>
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<tr>
<td>6. <strong>Data analysis and findings:</strong> Does the analysis of data reflect depth and coherence? In-depth descriptive and interpretive dimensions? Creative and insightful analysis? Linked with theory?</td>
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</table>
7. Discussion: Results linked to literature? Contribution of research clear? Relevant to practice/discipline?

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Vanessa Shannon, Managing Editor, vshannon@qhr.com
Vita  
Erin Kitt-Lewis

<table>
<thead>
<tr>
<th>Home Address</th>
<th>Office Address</th>
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<tbody>
<tr>
<td>912 Franklin Street</td>
<td>College of Nursing</td>
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<td>Roaring Spring, PA 16673</td>
<td>The Pennsylvania State University</td>
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<tr>
<td>(814) 327-0081</td>
<td>205E Nursing Sciences Building</td>
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<tr>
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<td>University Park, PA</td>
</tr>
<tr>
<td>(814) 867-2393</td>
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**EDUCATION**

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<td>University Park, PA</td>
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<tr>
<td>Doctoral Program, Nursing</td>
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<tr>
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<tr>
<td><strong>The Pennsylvania State University</strong></td>
<td>May 2005</td>
</tr>
<tr>
<td>Master of Science, Nursing</td>
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<td>Specialty Areas: Community Health</td>
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<td><strong>University of Pittsburgh</strong></td>
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<td><strong>The Pennsylvania State University</strong></td>
<td>University Park, PA</td>
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<tr>
<td>Bachelor of Science, Nursing</td>
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**SCHOLARSHIPS**

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<tr>
<td>National Centers for Gerontological Nursing Excellence</td>
<td>July 2012- August 2014</td>
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<tr>
<td>2012-2014 Patricia G. Archbold Scholar, $100,000</td>
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**CERTIFICATIONS**

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<tr>
<td>The Certificate for Online Teaching, The Pennsylvania State University</td>
<td>June 2014</td>
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<tr>
<td>Geriatric Nursing Education</td>
<td>May 2013</td>
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<tr>
<td>American Association for Long-term Care Nursing:</td>
<td></td>
</tr>
<tr>
<td>Culture Change Nurse Coordinator</td>
<td>December 2012</td>
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<tr>
<td>Staff Development Specialist</td>
<td>December 2012</td>
</tr>
<tr>
<td>School Nurse Certificate</td>
<td>May 1999</td>
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**TRAINING**

Course in College Teaching in Nursing, Schreyer Institute for Teaching Excellence, July 2016
Education in Palliative and End-of-Life Care (EPEC), Self-study On-line, December 2012.
End-of-Life Nursing Education Consortium (ELNEC), Attendee, University of Pennsylvania School of Nursing, Philadelphia, PA; March 5-6, 2012.

**ACADEMIC EXPERIENCE**

<table>
<thead>
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<td><strong>The Pennsylvania State University, College of Nursing</strong></td>
<td>University Park, PA</td>
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<tr>
<td>Nursing Instructor</td>
<td>July 2014- present</td>
</tr>
<tr>
<td>Research Assistant</td>
<td>January 2011- June 2014</td>
</tr>
<tr>
<td>Teaching Assistant</td>
<td>May 2013-August 2013</td>
</tr>
<tr>
<td>Nursing Instructor</td>
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