Establishing Ties: Descriptions of Meaningful Interactions with Health Care Providers from the Perspectives of Family Caregivers of Persons Diagnosed with Moderate to Advanced Dementia

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ESTABLISHING TIES:
DESCRIPTIONS OF MEANINGFUL INTERACTIONS WITH HEALTH CARE PROVIDERS FROM THE PERSPECTIVES OF FAMILY CAREGIVERS OF PERSONS DIAGNOSED WITH MODERATE TO ADVANCED DEMENTIA

A dissertation
by:
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Submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy
May, 2014
Establishing Ties: Descriptions of Meaningful Interactions with Health Care Providers from the Perspectives of Family Caregivers of Persons Diagnosed with Moderate to Advanced Dementia

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ABSTRACT

Purpose: The purpose of this study was to describe meaningful interactions with health care providers (HCPs) from the perspectives of family caregivers of persons with dementia (PWD). A secondary purpose was to understand ways in which family caregivers obtained needed information for managing uncertainty associated with providing care for a PWD.

Background: Family members of PWD often assume the caregiver role, but lack preparation for the psychological and practical ramifications of caring for someone with a progressive, terminal illness (Alzheimer's Association, 2011a). Lack of preparedness for caregiving impacts well-being and quality of life throughout the caregiving experience (Lilly, Robinson, Holzman & Bottorff, 2012). Meaningful interactions with HCPs have the potential to improve preparedness and alleviate suffering of caregivers, promote caregiver well-being and positively impact treatment provided to PWD.

Methods: Qualitative description was used to obtain rich, straightforward descriptions from perspectives of participants. Congruent with this approach, findings were reported with minimal inference.
**Results:** Positive meaningful interactions with HCPs included interactive dialogue, partnering between HCPs and caregivers, and a sense of being known as individuals with unique needs. Negative meaningful interactions were characterized as lacking one or more of those components. Participants used multiple strategies to obtain information and manage uncertainty associated with caregiving. Efforts to obtain care for PWD were often complicated by challenges of a health care system that was not designed to meet the needs of PWD.

**Conclusions:** HCPs have opportunities to improve interactions, provide support and increase preparedness for family members providing care for PWD. HCP: caregiver partnerships can improve care for PWD and mitigate stressors inherent in the caregiving role. Corrective experiences may change caregivers’ perceptions and provide opportunities for HCPs to intervene, engage and partner with health care consumers. Nurses are particularly well-suited to taking a leadership role in fostering partnerships and helping to design a dementia-ready system to meet the needs of PWD and those who care for them.
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CHAPTER ONE

Overview of the Study

Introduction

Family members of individuals diagnosed with dementia are often asked to take on the role of primary caregiver, yet lack awareness of what the role entails and are unprepared for the psychological and practical ramifications of caring for someone with a progressive, terminal illness (Alzheimer's Association, 2011a; National Institute of Nursing Research, 2011). Caregiving responsibilities, ranging from choice of daily activities to decision-making about treatment and place of residence, gradually increase as the capacity of persons with dementia (PWD) to make informed choices becomes more diminished. Lack of preparedness for caregiving often remains unnoticed until a crisis erupts, highlighting unmet needs of caregivers and the lack of previous systematic assessment of their needs (Spijker, et al., 2011). The stress that accompanies making decisions that affect the life course of another individual is one of the greatest challenges that a caregiver will face (Whitlatch, 2008). Consequences of being unprepared for the scope of tasks that accompany the caregiving role significantly impacts well-being and overall quality of life throughout the caregiving experience (Kiely, Prigerson & Mitchell, 2008; Lilly, Robinson, Holzman & Bottorff, 2012; Shyu, Kuo, Chen & Chen, 2010; Whitlatch, 2008).

Health care providers (HCPs) across a variety of disciplines are in an optimal position to foster preparedness of family caregivers. Unfortunately, however, ineffective communication between HCPs, caregivers and persons with dementia (PWD) and lack of
understanding of caregivers' needs often prevents meaningful interactions from taking place (Mitchell, et al., 2009; Shega, Hougham, Stocking, Deion-Haley & Sachs, 2008; Washington, Meadows, Elliott & Koopman, 2011). Challenges in communication between HCPs, themselves, and between HCP and care recipients are long-standing. The need for improved communication has been highlighted in “Approaching Death: Improving Care at the End of Life,” a report commissioned in 1998 by the Institute of Medicine (IOM) (Field & Cassel, 1998), the Crossing the Quality Chasm report (IOM, 2001) and most recently in the Affordable Care Act passed as part of sweeping health care reform (HCR) (U.S. Congress, 2010). Despite all of these efforts, changes in practice have been slow to materialize. All HCPs, with the advent of new legislation aimed at reforming health care delivery, have an opportunity and responsibility to rethink approaches to care and to address longstanding issues, including communication. Nurses, particularly in light of objectives in the recent Future of Nursing report (IOM, 2010), are especially well-suited to taking on leadership roles aimed at improving communication as changes in health care coordination, organization and delivery continue.

Identification of specific areas of intervention related to communication have been challenging to identify. It is unclear whether the isolation felt by caregivers and the lack of communication between HCPs and lay caregivers is a function of inappropriate timing, lack of shared understanding or lack of common goals. Regardless, the disconnect between what caregivers need and what HCPs provide creates a situation in which caregivers are left alone to tackle the enormous task of creating a roadmap through
unfamiliar territory (Alzheimer's Association, 2011a). Isolation, confusion, lack of guidance and vulnerability described by family members of PWD, coupled with stress and uncertainty related to decision-making about medications, place of residence and management of symptoms causes distress for both lay and professional caregivers. The schism created departs from the historically accepted fiduciary relationship between HCP and care recipient (Peternelj-Taylor & Young, 2003) and ultimately impacts delivery of care, affecting patient outcomes throughout illness and at the time of death (Oberle & Hughes, 2001; Schulz, et al., 2007).

There is a pressing need to design interventions to effectively prepare caregivers of PWD for the roles they undertake and for the uncertainties and difficult decisions that may arise in future medical crises (Perkins, 2007). Designing such interventions would be premature, however, without a better understanding of what is considered meaningful to family caregivers as they describe interactions with HCPs. Understanding what is meaningful to caregivers will allow HCPs to tailor their interactions to stimulate discussion, foster learning, and support development of skills that meet real, identified needs of caregivers.

**Background and Statement of the Problem**

Over 5 million Americans are currently living with Alzheimer’s disease, a number expected to increase by 40% by the year 2025 (Alzheimer’s Association, 2014). An additional 1.8 million Americans have another form of dementia, and as the population ages, that number, too, is expected to grow (National Institute of Neurological Disorders and Stroke, 2014). The increase in numbers of individuals diagnosed with dementia is a
combination of multiple factors, including earlier diagnosis, the aging of the baby boomer population and changes in technology that result in an ability to keep individuals alive in previously unforeseen circumstances. Etiologies of dementia and specific symptoms experienced by those diagnosed with the syndrome vary; however, the diagnostic category refers to a neurocognitive syndrome characterized by progressive memory impairment and functional decline in conjunction with aphasia, agnosia, apraxia or disturbances in executive functioning (American Psychiatric Association, 2000). The impaired ability of the brain to send or interpret meaningful messages leads eventually to physical problems including impaired swallowing, decreased mobility, limited nutritional intake and a resulting decline in ability of the body to ward off infection. Affected individuals endure an extended trajectory of decline marked by increasing symptom burden, decreasing cognitive ability, decreasing functional status and loss of autonomy to make independent decisions (Mitchell, et al., 2009). In the final stage of the illness, many patients develop multiple infections, behavioral and physical complications, resulting in admissions to acute care hospitals where they are restrained and subjected to invasive treatments such as venipuncture, catheterization and tube feedings (Mitchell, Kiely & Hamel, 2004; Sachs, 2009; Mitchell, et al., 2009; Shega & Tozer, 2009; Volicer, 2005). Many experience continued pain and distress in the final weeks before death (Aminoff & Adunsky, 2004; Shega & Tozer, 2009). Palliative options, those interventions designed to promote comfort, are pursued less frequently for patients with advanced dementia than for their counterparts who have been diagnosed with cancer (National Hospice and Palliative Care Organization, 2013; Sachs, 2009; Shega, et al.,
As cognitive and physical function of a PWD declines, suffering associated with dementia disseminates to include family members, who are often asked to act as caregivers, patient advocates and decision-makers (Schulz, et al., 2007). Those stepping into the caregiver role often incur psychosocial, financial and physical stressors as they struggle to learn new skills, navigate a complex and confusing healthcare system, make decisions about care and integrate caregiving into their day-to-day lives (Alzheimer's Association, 2011a; Lilly, et al., 2012; Pinquart & Sorenson, 2007; Schulz & Sherwood, 2008; Whitlatch, 2008). More than 15 million family members provided unpaid care to PWD in 2013 (Alzheimer's Association, 2014). Of these, more than 60% reported high levels of emotional stress, a third reported symptoms of depression and more than one-half reported financial strain (Alzheimer’s Association, 2014). In addition, many experience physical ramifications associated with being in a state of chronic stress, including an impaired immune response, poor sleep, decreased energy (Family Caregiver Alliance, 2014) and lack of engagement in health promoting activities (Zarit, Femia, Kim & Whitlatch, 2010).

The lengthy trajectory of dementia and relatively long period in which PWD retain the capacity to participate in decision-making suggests that opportunities exist for affected individuals, health care providers (HCPs) and family caregivers to engage in advance care planning (ACP), skills building for symptom management and preparation for surrogate decision making. Paradoxically, however, it appears that these discussions rarely occur between HCP, family caregivers and PWD or that information discussed is
not assimilated in a meaningful way (Birch & Draper, 2008; Caron, Griffith & Arcand, 2005; Dreyer, Forde & Nordvedt, 2009; Given, Sherwood & Given, 2008; Johnson, et al., 2009).

Ethical issues related to decision-making include autonomy, the right to make informed decisions about care, truth-telling within the context of the patient-provider relationship, information about risks and benefits of treatment, the right to culturally-sensitive treatment and some degree of self governance over the living and dying process (Johnstone & Kanitsaki, 2009). When decision-making occurs as part of an overall planning process in a trajectory of illness, the values held by PWD and their caregivers are discussed along with options for treatment across the spectrum of illness. Ongoing discussion of values and wishes early in the disease process is designed to allow PWD and caregivers to prepare for uncertainties that arise in crisis situations and proactively address decision points that will likely arise at future point in time. Early discussions about the nature of the disease process and ongoing discussions related to ACP between PWD, their caregivers and HCPs have the potential to alleviate a portion of the internal conflict experienced by the caregiver as the disease progresses (Monteverde, 2009; Perkins, 2007).

Family caregivers of patients with dementia report knowledge deficits related to prognosis and disease trajectory (Alzheimer's Association, 2011a; Birch & Draper, 2008; Mitchell, et al., 2009), infrequent and inadequate communication with HCPs (Mitchell, 2009), lack of preparation and guidance for the decision making role and uncertainty related to the responsibilities of the role itself (Birch & Draper, 2008; Caron, Griffith, &
Archand, 2005; Ducharme, Lévesque, Lachance, Kergoat & Coulombe, 2011; Givens, Kiely, Crey & Mitchell, 2009; Hebert, Schulz, Copeland & Arnold, 2009). Each of the challenges identified by family caregivers points to avenues of discussion and intervention which could be addressed in the presence of a meaningful HCP-caregiver interaction. Creation of an atmosphere in which discussions can occur may improve overall well-being for both caregiver and care recipient (Rabow, Hauser & Adams, 2004).

HCPs across many disciplines share an ethical mandate to provide a social good in the context of the professional relationship (Tarlier, 2004). Nursing shares this mandate, but has a special focus on empowerment of clients, co-construction of collaborative relationships and making meaning of illness and subsequent return to health (Tarlier, 2004; Willis, Grace & Roy, 2008). For this reason, nursing is uniquely suited for an active role in ensuring that caregivers of PWD receive the knowledge, guidance and preparation for the roles they undertake.

HCPs have both the ability and an ethical responsibility to support and foster family caregivers' preparedness to manage the caregiving role across the spectrum of the illness (Rabow, Hauser & Adams, 2004). Family members stepping into the caregiving role do so at a critical juncture in the PWD's disease process, yet are often unaware of what the caregiving role entails. HCPs are looked to for guidance, explanation of needed actions and problem solving as caregivers take on an active decision-making role (Keady & Nolan, 2003). Although ineffective communication between HCPs and family caregivers of individuals with life limiting illness has been documented for over a decade (Levinson,
Lesser & Epstein, 2010; Holley, 2007; Howlett, et al., 2010; Johnson, et al., 2009), changes in practice and outcomes have been slow to materialize. The disparity between reports from health care providers, patients and family members of those with life limiting illness suggests lack of concordance between information the HCPs believe they have given and information that care recipients or caregivers have internalized (Desharnais, Carter, Hennessy, Kurent & Carter, 2007; Edelman, Kuhn, Fulton & Kyrouac, 2006; Olson & Windish, 2010). Uncovering personal and observational accounts (data) about the content of communication between HCP, patient and family caregiver is difficult, in part because few research studies include actual observation of physician-patient-family conversations (Tulsky, 2010). As such, it is unclear whether needs for information and education are simply not addressed by HCPs, whether the information given does not match what is needed or whether the information is not transmitted in a way or at a time that renders it meaningful to the caregiver.

Multiple gaps in HCP: caregiver communication have been identified as contributing to lack of caregiver preparedness for the caregiving role. This study addressed the gap in our understanding of the caregiver experience of interacting with and obtaining knowledge from HCP throughout the caregiving process and provided information about what caregivers identify as meaningful in their interactions with HCPs.

**Purpose of the Study**

The purpose of this study was to describe meaningful health care provider interactions from the perspectives of family caregivers of persons with moderate to advanced dementia. A secondary purpose was to understand ways in which family
caregivers obtained needed information within the context of (or outside of) those interactions that facilitated preparedness for managing uncertainty associated with caregiving or providing care for someone with moderate to advanced dementia.

**Research Questions**

The two research questions listed below were addressed in this study:

1. What stand out as central themes in qualitative interview accounts of meaningful health care provider interactions from the perspectives of family caregivers of persons diagnosed with moderate to advanced dementia?

2. What strategies do family caregivers use to obtain meaningful information for managing uncertainty associated with caregiving for someone with moderate to advanced dementia?

**Scope**

The population of persons with dementia. Over five million adults in the United States have a diagnosis of Alzheimer's Disease and another 1.8 million have another form of dementia (Alzheimer's Association, 2014; National Institute of Neurological Disorders and Stroke, 2014). Dementia in any form is most often a disease of older adults. Ninety six percent of individuals diagnosed with Alzheimer's are over the age of 65, although about 200,000 (4%) are less than 65 years of age (Alzheimer's Association, 2014). Exact prevalence of Americans with dementia is difficult to capture and statistics provided vary by study and classification system used, however reports across studies indicate the number of individuals living with dementia is increasing as the population ages. Results
published in the *Aging, Demographics and Memory Study*, the most comprehensive study completed in recent years, indicated that 13.9% of Americans over the age of 71 are diagnosed with some form of dementia (Plassman, et al., 2007). These numbers, however, do not reflect the significant number of individuals living in community settings who are not formally diagnosed with dementia, but may be suffering from symptoms.

In a study conducted for the U.S. Preventive Task Force, researchers suggested that only about 50% of those meeting criteria for dementia are actually recorded as having the diagnosis (Boustani, Peterson, Hanson, Harris & Lohr, 2003). Data on the presence of disparities between racial and ethnic groups is equally difficult to capture and results are conflicting depending on study sample selected (Husaini, Sherkat, Moonis, Levine, Holzer & Cain, 2003; Potter, et al., 2009). A recent report published by the Alzheimer's Association suggests that non-White older adults are more likely to have any form of dementia, although non-Hispanic Whites are more likely to receive an actual diagnosis of dementia (Alzheimer's Association, 2011b).

As PWD progress through the moderate and severe stages of dementia, uncertainty and lack of clarity related to goals of treatment impacts decision making of caregivers and actions of health care providers (Hebert, et al., 2009). Increasing medical complications, uncertainty about efficacy of treatments, limited treatment options and challenges in communication complicate an already unpredictable trajectory of illness, resulting in many patients arriving at the end of life without effective plans in place to alleviate distress (Mitchell, et al., 2009).
**The population of family caregivers.** Family members comprise 80% of the 15 million unpaid caregivers who provide assistance for individuals with dementia. Over 17 billion hours of unpaid care is provided by caregivers each year for those with dementia, with average number of needed care hours per day and the stress of caregiving increasing as the disease progresses (Alzheimer's Association, 2014).

Family caregivers experience a wide variety of physical, psychosocial, financial and work-related stressors related to the caregiving role (Alzheimer's Association, 2014; National Institute on Aging, 2011; Zarit, et al., 2010; Ziemba, 2002). Psychosocial symptoms include a host of negative emotions, including loneliness, guilt, loss, anger, depression, anxiety and pre-death grief and stress related to decision making (Adams, 2008; Hebert, Dang & Schulz, 2006; Kiely, et al., 2008; Sadavoy, 2011). Financial stressors often arise in response to both an inability to continue working and the realities of hiring outside service providers (Alzheimer's Association, 2011a; Pinquart & Sörenson, 2003; Lilly, et al., 2012). Physical symptoms include compromised immune function and high levels of stress hormones (Sadavoy, 2011), poor self care, poor nutritional status (Pinquart & Sorenson, 2003; Schulz & Sherwood, 2008) and higher use of healthcare services and prescription medication (Sadavoy, 2011). The cost in added health services used by caregivers of PWD is estimated to be 9.3 billion dollars in 2012 (Alzheimer's Association, 2014). HCPs have an obligation to evaluate the toll of caregiving with family members of PWD, assess needs and understanding of disease progression, encourage advance care planning, emphasize the importance of self care and
provide guidance about ways to negotiate the health care system (United Hospital Fund, 2008; Zarit, et al., 2010).

Meaningful interactions, focused on individualized and pertinent needs of caregivers have the potential to improve preparedness and alleviate suffering of caregivers, improve caregiver well being and positively impact treatment of care recipients by ensuring that those making decisions have confidence in their ability to do so. The next step in ensuring that the family members of PWD are prepared to take on the caregiver role is to find out what information and interaction is meaningful for the study participants as they interacted with HCPs.

**Key Concepts**

**Preparedness.** Preparedness is a key concept affecting caregiver well-being. Caregivers who are prepared have an increased ability to engage in patient-centered treatment planning, skill acquisition, resource building and development of plans to minimize negative outcomes for both themselves and those receiving care (Jones, et al., 2010). Only if we, as HCPs, provide relevant, meaningful information can caregivers prepare themselves for what lies ahead.

Preparedness has been described as "readiness" (Schumacher, Stewart and Archbold, 2007, p 427) or "being ready" (Hebert, et al., 2009, p 8), perceived self-efficacy (Jones, Cheng, Jackman, Rodin, Walton, & Catton, 2010) and the ability of individuals to anticipate potential outcomes (Lazarus, 1966). Caregivers and patients who endorse feeling prepared report less psychological distress and a sense of being able to adapt and manage the stressful events that occur during critical or life limiting illness.
Conversely, those who feel unprepared experience difficulty negotiating changes, anxiety, depression and a loss of control (Jones, et al., 2010). HCPs are in an optimal position to impact preparedness through assessment, education and support of caregivers as they move across the temporal trajectory of caregiving, yet understanding of how to accomplish such a task remains unclear.

**Communication and meaningful interactions.** Effective communication is a rudimentary facet of patient-centered care and has the potential to impact treatment outcomes including satisfaction with care, awareness and enactment of treatment recommendations and effective management of symptoms throughout chronic illness (Levinson, Lesser & Epstein, 2010). In effective communication, information from at least one individual or source is transmitted, encoded, assimilated and assigned meaning or utility by the receiving party (Reinke, Engleberg, Shannon, et al., 2008). The meaning attached to information by family members to interactions, events, conversations or particular markers directly affects caregiver understanding and assimilating of information, thus leading to changes in preparedness for transitions, upcoming decisions or changes in functioning (Hebert, et al., 2006; Mishel & Braden, 1988). Meaningful interactions between HCP and family caregivers of PWD have the potential to profoundly affect preparedness of family caregivers as they navigate the changing terrain of life-limiting illness (Desharnais, et al., 2007; Hebert, et al., 2009). Opportunities to share knowledge, validate skills, assess needs and assign meaning to events experienced during the course of illness allow development of a provider-caregiver relationship that has the potential to foster growth and develop collaborative relationships (Levinson, et al., 2010).
Definition of Terms:

1. Family Caregiver: individuals, who, by birth, marriage or other close relationship act as care providers for individuals with dementia.

2. Meaningful interaction: interactions that family members define as important to their own (or the PWD's) functioning or well-being, or as affecting their own knowledge base or ability to engage in ongoing caregiving.

3. Preparedness: a construct, composed of skills-base knowledge, awareness of what the role entails, a commitment to providing care and the ability and willingness to integrate caregiving into life routines (Ziembba, 2002). Levels of preparedness vary according to different caregiving demands which change over the trajectory of illness.

4. Health Care Provider: physicians, nurses, social workers, physician's assistants, nurse practitioners or other licensed health care professionals.

Moral foundations of the study

The framework described by Powers & Faden (2006) in their theory of social justice provided a moral foundation upon which to ground this study. According to the framework, a just society is evaluated by looking at six core dimensions of well-being. The six dimensions include: the right to self determination, respect for self and others, the ability to engage in theoretical and practical reasoning, to enjoy health, and maintain attachments and to enjoy personal security (Powers & Faden, 2006). In this study, each of the dimensions identified was (or had the potential to be), compromised or threatened as caregivers faced the realities of balancing their own needs with rights and abilities of
Meaningful interactions with health care providers had the potential to affect caregiver well being across multiple dimensions and it was those interactions that were identified by study participants.

As PWD progress into more advanced stages of the illness, caregivers are faced with the reality that completely autonomous decision making by the PWD is no longer possible. Our society values the rights of individuals to make autonomous decisions, thus the stress incurred when caregivers must make decisions on behalf of PWD is often particularly problematic. Superimposed on the stressors of daily decision-making is the need to negotiate care across an indescribably complex and fragmented, market-driven health care system.

The framework by Powers and Faden (2006) was chosen for this study because nursing is grounded on a foundation of social justice. Nurses carry a primary ethical mandate to foster health and well-being of individuals and to provide a social 'good' to those entrusted to our care (Donley, 2010; Fahrenwald, 2003; Grace, 2001). Relevant to this study, nurses have the opportunity to address issues of justice related to access, resources, and the challenge of balancing conflicting needs that impact well being of caregivers. They also have an opportunity to take direct action to support caregivers and collaborate with other HCPs and society to provide service to those in need, empowering them to fulfill optimal levels of health and to heal across all aspects of their lives (Donley, 2010; Fahrenwald, 2003; Grace, 2001; Willis, et al., 2008).

**Research Method**

The study was conducted using Qualitative Description, a method grounded in the
naturalistic paradigm and consistent with the overall purpose of describing interactions with health care providers that are identified by family caregivers as important or meaningful. Qualitative description has been used, historically, to provide rich descriptions of family caregivers' roles as decision makers for patients referred to both palliative care (Weibull, Oleson & Neergaard, 2008) and to the Program of All-Inclusive Care for the Elderly (Beeber, 2005). It was particularly well suited for use in this study, when the goal was to obtain straightforward descriptions of participant experiences. Interpretation of findings was reported in ordinary language used by participants. Close adherence to words and tenor used during the interview ensured allegiance to descriptions provided by participants (Sandelowski, 2000; Sullivan-Bolyai, Bova & Harper, 2005).

**Significance of the Study and Nursing Implications**

Exploration of the caregiver experience in interacting with and obtaining meaningful information from HCPs constitutes a significant step in advancing the science of patient-provider health care communication and facilitating preparedness of caregivers for their roles as decision makers for those with dementia. Providers armed with awareness of what is perceived as meaningful by family caregivers can tailor interventions to improve (or preserve) quality of life, manage stress associated with caregiving and strive for outcomes aimed at honoring the wishes and preserving dignity of those suffering with dementia.

Nursing has been conceptualized as "facilitating humanization, meaning, choice, quality of life, and healing in living and dying " (Willis, et al., 2008, p. E28). In all nursing roles and through a variety of nursing practices, nurses attempt to provide care
and create conditions through which individuals receiving care are able make meaning of life experiences (Tarlier, 2004; Willis, et al., 2008). Whether serving as front line providers, administrators, liaisons, case managers or in advanced practice positions, nurses are particularly well suited to encourage and guide discussions about values and goals of treatment and to facilitate communication within a team environment (Ceccarelli, Castner & Harris, 2008; Seymour, Almack & Kennedy, 2010). Increased awareness of what caregivers find to be meaningful provides nurses with additional information to guide discussions and collaborate with members of interdisciplinary teams to ensure that caregivers of PWD are prepared to effectively carry out their roles.

Improved communication between health care providers, patients and families and understanding of ways in which meaningful interactions can impact chronic illness, quality of life, and affect caregiver and patient outcomes is a nationally recognized priority, corresponding with initiatives at the National Institutes of Health (NIH), the National Institute of Nursing Research (NINR), National Strategy for Quality Improvement in Health Care, the Ware Invitational Summit and the Alzheimer’s Association (Alzheimer’s Association, 2009; Alzheimer's Association, 2011b; Kaiser Family Foundation, 2011; Naylor, et al., 2012, U.S. Department of Health and Human Services, 2011a; U.S. Department of Health and Human Services, 2011b).

The outcomes of this project provide the foundation for identifying nursing interventions that may lead to better prepared, well informed caregivers who feel confident and prepared to function in their roles as caregivers of persons with moderate and late stage dementia. Caregivers armed with knowledge, clarity about their ability to
access resources and confident in their abilities to partner with health care providers throughout the complex trajectory of dementia may experience fewer symptoms of psychological distress, increased ability to navigate and adjust to change and may be better prepared to function as patient advocates.

**Organization of the Study**

This dissertation is organized into 5 chapters. The introductory chapter addresses the scope of the problem and the significance of preparedness and meaningful interactions as they relate to caregiver well being. Chapter 2 is a review of the literature on preparedness to take on the caregiving role and communication between HCPs and family caregivers in the context of progressive illness. Chapter 3 outlines the rationale for study design and methods of data collection. Chapter 4 contains study findings and discussion of findings and implications for practice and recommendations for future research are discussed in Chapter 5.
CHAPTER TWO

Review of the Literature

Introduction

The purpose of this study was to describe meaningful interactions with HCPs from the perspectives of family caregivers. A secondary purpose was to understand ways in which family caregivers obtained needed information within (or outside of) the context of interactions with HCPs that facilitated preparedness for managing uncertainty within the caregiving role.

In the following paragraphs, I review relevant literature related to caregiving in the context of progressive illness. The review of literature is organized into two sections. In the first section, existing knowledge about preparedness for the caregiving role, including discussion of the importance of the construct and challenges associated with attempting to measure preparedness is reviewed. I then examine the role that preparedness plays in successful transitions and conclude with a discussion of factors that influence preparedness for taking on and successfully negotiating the caregiver role.

The second section addresses content and style of HCP-caregiver communication in dementia and other progressive illnesses. Perspectives on communication are examined from both HCP and caregiver viewpoints, with particular attention to the disparity in approaches by the two groups. Challenges experienced by both groups are also examined. The section concludes with a discussion of ways to bridge the gap in understanding between the two groups.
Family caregivers of persons with dementia (PWD) experience multiple role transitions and decision points as loved ones progress through stages of the illness (Ducharme, et al., 2011). Each significant change in cognition or functionality experienced by the PWD act as a harbinger of loss for the caregiver, who must navigate territory requiring new skills, additional knowledge and role transition to decision maker while grappling with the literal and symbolic of a spouse, parent or friend (Cagle & Kovacs, 2011; Clarke, Shaw, Villalba, Alli & Sink, 2013; Given, et al., 2008).

Although each juncture in the trajectory of dementia represents an opportunity for professionals and caregivers to partner in the disease management process, caregivers reporting feeling isolated and "on (their) own," unprepared, and without a road map of what to expect (Alzheimer's Association, 2011a, p. 26; Desharnais, et al., 2007; Fried, Bradley & O'Leary, 2003; Laakkonen, et al., 2008; Lilly, et al., 2012; Tebb & Jivanjee, 2000). Despite the known challenges in communication, it remains unclear whether needs for information and education are not addressed by HCPs, whether information is not transmitted in a way that renders it meaningful to the caregiver or whether the timing of information is such that assimilation and accommodation of the information provided is not able to be internalized by caregivers.

**Preparedness for the Caregiving Role**

**Why Preparedness is Important.** The term "preparedness" appears in caregiver research as both a domain-specific and a task-specific construct. Preparedness has been linked to other concepts, including readiness, knowledge, mastery of a skill set, self-efficacy, perceived control, awareness of what to expect, willingness and commitment to
engaging in a particular set of behaviors or actions (Archbold, Stewart, Greenlick & Harvath, 1990; Ducharme, et al., 2011; Hebert, et al., 2009; Jones, et al., 2010; Schumacher, Stewart & Archbold, 2007; Shyu, et al., 2010; Ziemba, 2002). Regardless of how it is defined, preparedness for caregiving, particularly for individuals faced with a temporal trajectory of illness and changing needs over time, has significant short and long-term consequences. Increased levels of preparedness are believed to be protective against emotional distress and consequences of prolonged physical stress (Hebert, et al., 2009; Jones, et al., 2010). Conversely, the consequences of being unprepared for a loved one's illness and death include depression (Alzheimer's Association, 2014; Schoenmakers, Buntinx & Delepeleire, 2010), post-traumatic stress disorder and complications with the grieving process (Hebert, et al., 2006).

In addition to the physical tasks of caregiving, individuals who take on the caregiving role encounter are often asked to make treatment decisions on behalf of others. When asked about the decision making process, lay caregivers identify a series of intrinsically focused factors including the concept of personhood, personal values, preservation of dignity, spiritual beliefs, and beliefs about suffering as the foundation upon which many of their decisions are made (Elliott, Gessert, & Peden-McAlpine, 2009; Hansen, Archbold, Stewart, Westfall & Ganzini, 2005; Lopez, 2009; Sachs, Shega & Cox-Haley, 2004; Volicer, 2005). Surrogates also identify a host of unmet needs, which, in contrast, are more extrinsically based and fall squarely into an arena related to health care providers. Knowledge deficits related to disease trajectory, confusion about treatment options, uncertainty about expected role, an inability to identify goals for
treatment, lack of understanding of the implications of particular treatment choices and lack of communication with health care providers, all suggest a troubling disconnect in health care provider and surrogate communication and a lack of preparation for roles that health care providers expect family members to assume (Caron, Griffith & Arcand, 2005; Hebert, et al., 2009; Gessert, Forbes, & Bern-Klug, 2000; White, Braddock, Bereknyei & Curtis, 2007).

The degree of preparedness endorsed by caregivers is particularly relevant for HCPs interacting with caregivers of PWD, who engage in decision making for extended amounts of time prior to a loved one's death. In one recent report, less than one third of proxies for patients with advanced dementia stated they had received information or guidance from physicians about either patient prognosis or potential complications of proposed treatment options. In contrast, surrogates who endorsed knowledge of the patient’s approximate position in trajectory of illness and awareness of potential ramifications of continued aggressive treatment chose to limit invasive or painful procedures in the absence of clear benefit to the patient, choosing instead to pursue options aimed toward patient comfort or alleviation of distress (Mitchell, et al., 2009). HCPs across disciplines are in an optimal position to assess and foster preparedness of caregivers, yet understanding of how best to accomplish this is unclear.

In the following paragraphs, I review the literature on preparedness for the role of decision maker in the context of caring for those with chronic or progressive illness. Only studies completed after 2000 are included, with the exception of the seminal work on preparedness done by Archbold and colleagues prior to that time. The literature on
preparedness is organized according to the way in which preparedness was assessed or conceptualized, the impact of preparedness on role strain and the ability to manage transitions and factors affecting preparedness.

**The challenge of assessing preparedness**

Researchers attempting to measure levels of preparedness approach the task using one of two primary approaches. Objective measurement of preparedness is calculated using concrete indicators to compare what is needed with what actually exists (Lindstedt, 2012; Lurie, 2007). Objective assessment of preparedness is the primary means of determining whether governments, communities or individuals are able to respond and recover from unexpected catastrophic events.

Objective assessment methods have also been used in healthcare in the context of discharge planning or "repeat demonstration" of particular tasks or skills. Ironically, however, comprehensive objective assessments of caregiver preparedness have not been used to evaluate knowledge, skill sets, needs and resources of caregivers. Use of objective assessments to evaluate caregiver preparedness could help establish whether reported ability or preparedness to act as a caregiver translates into actual ability to function effectively in the role.

Subjective measurement tools, in contrast, are the primary method used to help HCPs and researchers obtain an understanding of caregivers' perceived preparedness to engage in a particular role or activity. Aimed at gaining insight into the strengths and needs of caregivers, self-reports provide information about how knowledgeable participants believe themselves to be about disease processes, anticipated outcomes and
needed interventions (Archbold, et al., 1990; Jones, et al., 2010). Inherent in this approach is the assumption that one's own perceived readiness to assume the caregiving role allows the caregiver to successfully navigate the terrain of caregiving and adapt to the role of caregiving (Steffen, McKibbin, Zeiss, Gallagher-Thompson & Bandura, 2002).

Although both objective and subjective approaches have merit, they are clearly measuring separate constructs: objective measurement of indicators calculates whether one has tools and training to complete a task, while subjective evaluation of perceived preparedness measures belief or confidence in ability to be successful in that task. The challenge for HCPs and researchers, then, is to determine how to best evaluate all aspects of caregiver preparedness. Neither objective nor subjective methods of evaluating of preparedness independently measure whether caregivers equipped to negotiate the many tasks of the caregiving role.

**Standardized assessment using subjective criteria.** Researchers attempting to measure preparedness recognized a need for a common language or metric to represent different levels and domains of the construct. The development of standardized tools to measure perceived preparedness represents an attempt to quantify levels of readiness to provide care.

Three scales have been developed to measure to specifically measure preparedness to function in a caregiving role across multiple domains. The *Preparedness Scale of the Family Caregiving Inventory* (PSFCI) (Archbold & Stewart, 1986; Zwicker, 2010), the *Nurse Evaluation of Caregiver Preparation Scale* (NECPS)
(Shyu, Chen, Chen, Wang & Shao, 2008) and the Caregiver Effectiveness Scale (CES) (Archbold, et al., 1995) each provide a metric that reflects perceived preparedness of individuals to engage in the caregiving role.

*Preparedness Scale of the Family caregiving Inventory (PSFCI).* The PSFCI developed by Archbold & Stewart (1986) appears to be the only validated tool that has been broadly used to measure overall perceived preparedness of caregivers to take on tasks across multiple domains of care. Caregivers provide answers to eight questions on separate Likert-type scales. Domains assessed include readiness to provide physical care, emotional support, to respond in emergency situations, locate resources, ensure that activities are enjoyable for care recipients, deal with stress of caregiving and engage in information-seeking from professionals within the health care system (Archbold, et al., 1990; Zwicker, 2010).

*Nurse Evaluation of Caregiver Preparation Scale (NECPS).* The NECPS, as the name suggests, was designed to allow nurses to rate caregiver's knowledge base and skill set in 5 areas: ability to engage in locating resources, working knowledge of the patient's diagnosis and functional level, aptitude for providing home care and performing necessary skills, and overall preparation for daily tasks of caregiving (Shyu, et al., 2008). As with the PSFCI, ratings of caregiver preparedness are completed using a three point Likert scale. Ratings are based on perceptions (in this case, of nurses) of caregiver preparedness rather than objective criteria. The scale is not publicly available and has not been used in other studies or alternative settings (Shyu, et al., 2008), thus further use is needed to evaluate reliability and validity across settings.
*Caregiver Effectiveness Scale (CES).* The CES developed by Archbold and colleagues (1995), asks caregivers to rate a change in perceived level of preparedness after an intervention aimed at increasing readiness to provide care has been completed. As with the NECPS, the tool was designed for a specific study and a comprehensive score is obtained by averaging Likert scale responses to a series of questions. It does not appear to have been used since the time of the original study, nor is it publicly available (Archbold, et al., 1995). The scale, does, however, offer an example of how an intervention designed to increase levels of preparedness may be assessed.

Each of the scales reviewed in the preceding paragraphs allows researchers and HCPs to obtain a quantitative score of an individual's perceived preparedness to take on the caregiving role at a specific point in time. Although the importance of caregivers' beliefs in their own readiness to provide care may be a critical element of success, it is unclear whether self-perception translates into a realistic assessment of actual skills and ability needed to perform in the caregiving role. This limitation is consistent across the literature. HCPs, when attempting to assess caregiver preparedness, will need to be clear about whether subjective assessment, completed by either the HCPs, themselves or by caregivers, represents an informed assessment of what is needed to take on the changing and constantly evolving tasks of caring for individuals with a progressive illness.

**Standardized assessment using objective criteria.** As indicated earlier in this paper, objective assessment using specific criteria to assess preparedness has not been used in caregiver literature. As such, there is not a validated scale to measure overall preparedness of caregivers using concrete objective criteria. Efforts to obtain objective
assessment of skills or awareness of resources have included use of a varied scales that measure specific skills or knowledge (e.g., awareness of and ability to access resources; planning for the future) including the *Scale for Caregiving Self-Efficacy*, the *Carer's Assessment of Managing Index* and the *Planning for Future Care Needs Scale* (Ducharme, et al., 2011; Steffen, McKibbin, Zeiss, Gallagher-Thompson & Bandura, 2002). The examples provided are but a few of the scales available to measure specific items that contribute to preparedness. None of the scales, used independently, offers comprehensive assessment of readiness to take on the caregiver role, nor do they necessarily measure items or aspects of preparedness that are identified as important to caregivers, themselves. As such, they have been used in combination with other assessment tools to gain some understanding of specific skills or criteria to evaluate caregiver preparedness in a more comprehensive fashion.

**The impact of preparedness on caregiver role strain.** Role strain, characterized by the negative emotional and physical stressors associated with caregiving (Archbold, et al., 1990), has the potential to negatively affect caregiver and care recipient well being. Role strain arises when the stress of providing care impacts the ability to provide care. It can occur at any time during the caregiving process, but often arises when a shift occurs from a state in which the care recipient and the care receiver function independently of one another to a place in which one member of a dyad becomes dependent on another (Waldrop, Milch & Skretny, 2005). The impact of preparedness on caregiver role strain has been studied in situations of acute change (stroke), terminal illness (cancer), chronic illness (non-specific disease states) and in progressive illness
Interactions between HCPs and family caregivers are one way in which preparedness and role strain can be assessed and interventions developed to ensure that caregivers are receiving the assistance they require to cope with the responsibilities of the caregiving task. While preparedness for caregiving is a significant issue across disease states, caregivers of PWD face particular challenges related to role strain due to the long trajectory, the often-unpredictable course of the illness and the combination of ongoing cognitive and functional decline.

The seminal study examining the effect of preparedness on caregiver role strain was completed by Archbold & colleagues (1995) and used as a model for subsequent projects by multiple authors. In the original study, seventy-eight caregivers of family members suffering from generalized cognitive or physical impairment were evaluated in the period immediately following hospitalization. The aim of the study was to determine whether caregivers’ self reported levels of mutuality and preparedness could predict role strain at six week and nine month endpoints. Both preparedness and mutuality were assessed using scales from Family Care Inventory developed by the authors (Archbold, et al., 1990). As indicated earlier in this text, preparedness, as measured using the PSFCI is a subjective assessment. Mutuality, a separate construct, refers to the ability of the caregiver to find meaning and reward in the caregiver-care recipient relationship and is also scored using participant self-reports.
Initial results indicated that higher levels of preparedness reported at baseline were associated with lower levels of role strain at the week six. Results were less robust at the nine-month evaluation. The authors suggest that the decrease in ability of preparedness to predict role strain over time may reflect the increasingly compromised state of the care recipient, although they acknowledge that a combination of other factors might be responsible. The importance of timing interventions was highlighted as a means of addressing caregiver preparedness, however, other ways in which HCPs might impact preparedness were not addressed. Mutuality, in contrast, was highlighted as the more consistent predictor of role strain over time. In dyads with low levels of mutuality, HCPs may suggest hiring alternative caregivers as needed to fulfill caregiving needs (Archbold, et al., 1990).

Although the early work of Archbold and colleagues provides insight into role of both mutuality and preparedness on caregiver role strain, clear gaps in understanding remain as to how HCPs might impact caregiver outcomes. It was not clear that caregivers responding to questions of preparedness had awareness of what they were to be prepared for, thus clear assessment of actual knowledge base is one avenue of intervention that might offer additional clarity. Mutuality, highlighted as an important predictor of role strain, is a largely un-modifiable construct, as it relates to the emotional attachment between care recipient and care receiver since HCPs have limited ability to impact change in dyads where mutuality is low. Preparedness, conversely, may hold promise for interventions by HCPs.
In an effort to expand on the early work by Archbold and colleagues, subsequent studies by different authors utilized essentially the same study design. Variables associated with preparedness and caregiver role strain were added in a cumulative fashion. In the following paragraphs, these studies, which comprise the bulk of the research on preparedness, are reviewed independently in order to capture the influence of particular variables on role strain. Understanding the impact of particular variables on caregiver role strain provides additional information about topics that might be meaningful to caregivers as they engage in interaction with HCPs.

Schumacher, Stewart, Archbold, Caparro, Mutale & Agrawal (2008) revisited the role of preparedness and mutuality on caregiver demand in a study with 87 caregivers of persons with cancer (PWC). The variable of "mood," added to the original variables of preparedness, mutuality, and global strain provided new insights into factors affecting overall caregiver well being. High levels of preparedness were again associated with lower levels of global role strain, but also with lower levels of fatigue, less difficulty in performing the tasks of caregiving, lower levels of confusion and lower scores in overall mood disturbance. Mutuality continued to be a predictor of overall strain, however, it had the most significance in regard to the emotional components (depression, anger, and tension) rather than the daily tasks of caregiving (Schumacher, et al., 2008).

Although multiple variables had been added to the original work on preparedness, mutuality, and role strain, questions remained about other variables that might affect well-being. In a recent Taiwanese study, 250 caregivers of PWD were asked to complete scales to measure the constructs from the previous studies by Archbold and
colleagues (preparedness, mutuality, caregiving demand, role strain, mental health, depression) along with new variables of caregiving rewards and balance. Caregiving rewards were identified as positive feelings related to being present, finding meaning, and learning that arises from the process of giving care. Balance, as defined by the authors, measured how well caregivers were able to balance competing needs of self and caregiving (Shyu, Yang, Huang, Kuo, Chen & Hsu, 2010).

As in the earlier studies, lower levels of preparedness and lower levels of mutuality were associated with a greater number of negative caregiver outcomes and compromised mental health. Statistically significant positive associations were also found between preparedness and the new variable of caregiving rewards. Caregivers who were unable to achieve balance between competing roles had more negative outcomes, however, they did not report greater role strain (Shyu, et al., 2010). Of particular importance for HCP caring for PWD, participants in this study had much lower levels of mutuality (M = 1.74) than those found in the cancer study (M =3. 28) or the seminal study with cognitively intact and compromised frail older adults (3.24). Although the authors raise the question of whether the discrepancy was related to diagnostic/ disease specific challenges or cultural differences (Shyu, et al., 2010), it may also be related to length of time acting in the caretaking role. In the study by Shyu and colleagues, caregivers had been in the role for > 3 years, while the other two studies involved caregivers who had been in the role for < 1 year. As with the earlier studies, preparedness was addressed only through self-assessment, thus it is unclear whether caregivers had knowledge and actual skills to carry out the caregiving role.
The body of work that arose from the seminal study of Archbold and colleagues offers insight into interactions between perceived preparedness of caregivers and additional mediating factors that affect perceived role strain and caregiver burden. The studies leave unanswered questions, including how HCP might impact preparedness and how perceived preparedness translates into actual ability to provide care. Even so, they provide important contributions to the preparedness literature that will guide future researchers for years to come.

The impact of preparedness on caregiver role strain holds significance for many caregivers, but especially for those providing care to PWD. Caregivers of PWD endure the additional stressors of watching ongoing physical and functional decline of care recipients, receiving little in the way of reciprocal appreciation and social isolation associated with the inability to leave the PWD alone (Whitlatch, 2008). The lengthy trajectory of dementia allows ongoing opportunities for HCPs and family caregivers to engage in dialogue about preparedness for the ever-changing role of providing care for PWD. However, knowledge of what caregivers identify as important is needed to ensure that meaningful dialogue takes place and that interventions and guidance provided by HCPs is relevant, timely and effective in impacting caregiver and care recipient well-being.

Expanding the construct of preparedness. Although significant knowledge about the construct of preparedness was obtained using the PSFCI tool across disease states, the information gleaned from studies using the PSFCI provided predominantly information related only to caregiver perceptions. The importance of HCP evaluation of
preparedness, identification of factors that contribute to preparedness and discrepancies between beliefs and actions all provide information that expands our understanding of preparedness as a construct. Efforts to address each of these issues will be reviewed in the following paragraphs.

**Factors that contribute to preparedness.** Patients, families and health care providers across disciplines agree that feeling prepared to cope with end of life issues is an integral part of coping with the dying process, yet ideas about what factors contribute to feelings of preparedness remain elusive. In an effort to gain clarity and draw comparisons between perspectives of care recipients (patients and families) and HCP, Steinhauser and colleagues (2001) conducted a mixed methods study with HCPs, family members and patients aimed at expanding understanding of preparedness as a concept. The study was focused specifically on end of life issues, thus deals with emotional and practical aspects of preparedness rather than the functional tasks of caregiving.

Analysis of focus group data and a quantitative survey results yielded some similarities but also striking differences between participant groups of family members, patients and health care providers. The need for prognostic information, weighted heavily by family members and patients, was given lesser importance by physicians. The researchers explanation of this finding pointed to the historical data indicating that physicians routinely voice discomfort with discussions about projected length of time before death, yet acknowledge that patterns of practice likely need to change to address the needs of care recipients. Discrepancies between endorsed beliefs of HCPs and patients and their actions were also clear. Fewer than 30% of American adults participate
in discussions or complete advance directives with health care providers (United States Department of Health & Human Services (USDHHS, 2008), yet both the importance of discussions and written documentation about advance care planning were rated as a key component of preparedness by both HCP and care recipients. The importance of discussing fears was endorsed by family members, but not by patients. Implications of this finding are unclear, although researchers suggested that the social and cultural mores of the study population (older, male, Veteran's Administration patients known for valuing stoicism), might have contributed to the discrepancy in between family and patient attitudes toward discussion of fears (Steinhauser, et al., 2001).

The design of the study by Steinhauser and colleagues (2001) was notable in that attempts were made to uncover similarities and differences in perceptions of patients, families and HCPs. Unfortunately, while aim of the study was "to expand the taxonomy of preparation" (p. 729), the authors failed to adequately define preparedness in the body of the article. Information extrapolated from their work suggests that preparedness includes both concrete tasks (advance care planning, discussion of prognosis, having legal and financial matters arranged) in addition to psychosocial and spiritual needs (e.g., completing a life review, discussing personal fears).

Understanding caregiver responses to questions about preparedness. Recognition of the need for better understanding of preparedness also led Ziemba, (2002), to explore and expand upon the construct in a mixed methods study with daughters of aging parents. In the study, 117 adult daughters engaged in caring for aging parents were asked to complete a battery of previously validated scales, including the
Preparedness Scale (Archbold, Stewart, et al., 1990), the Beliefs about Caregiving Scale (Phillips, Rempusheski & Morrison, 1989), The Caregiver Activity Scale (Given, et al., 1992) and the Caregiver Reaction Assessment (Given, et al., 1992). All measures used participants' self reported assessments. Qualitative interviews were completed with a smaller group of participants to explicate quantitative findings.

Analysis of quantitative findings suggested that participants felt "pretty well" prepared (p. 131), but qualitative data suggested that participants' self-ratings of preparedness were not necessarily good indicators of either actual knowledge or ability. Participants asked to elaborate on quantitative answers often revealed that answers had been based on willingness or intent to complete tasks or engage in activities rather than experience or knowledge of how to complete those actions. The combined analysis of interviews revealed that participants often lacked needed skills, knowledge and had difficulty navigating a fragmented health care system. The discrepancy between results of quantitative and qualitative measures suggests that participants' perceived preparedness reports may not necessarily be indicative of actual preparedness to perform the caregiving role (Ziemba, 2002).

The construct of preparedness was expanded to include three attributes: knowledge, commitment, and ability. Knowledge referred to having the necessary tools or skills for caregiving. Commitment described duty and responsibility. Ability, in this study, referred to the practicalities of assimilating caregiving activities into participants' lives and existing routines. This last factor, ability, accounts for largest amount of the variance in the model (43%), followed by knowledge (19%) and commitment (14%).
Areas in which participants felt least prepared for caregiving related to the emotional domain of caregiving, both in managing a parent's negative emotions and in managing their own emotional reactions. Difficulties in arranging for formal services were particularly challenging in terms of time required and knowledge about available resources (Ziemba, 2002).

The contributions of Ziemba to the preparedness literature include the expanded construct of preparedness and the questions raised about measurement tools available and the implications for practice. The need to provide additional support, meaningful information and guidance related to ways in which caregiving affects the caregiver's life is a critical aspect of the roles of all HCPs.

The impact of preparedness on ability to manage transitions. Periods of transition between the role of spouse, child or friend to that of caregiver occur at critical junctures across the trajectory of progressive illness. For many caregivers, the moment of transition begins upon discharge from a hospital setting in which the functional status of the care recipient has declined. For others, the moment of transition occurs at the time of diagnosis, at a moment of precipitous decline or when a need for additional services or placement in an alternative living setting arises. Each transition serves as a period between "before" and "after," offering a marker of time of affected individual's progression through stages of illness. For caregivers of PWD, transitions related to both cognitive and functional decline are ongoing, thus the importance of preparedness on ability to manage transitions is crucial. HCPs have the ability and responsibility of guiding caregivers through transitional periods, but knowledge of what is needed by and
meaningful to caregivers is a crucial element of impacting preparedness to function across the trajectory of dementia.

**Diagnosis.** Diagnosis of a progressive illness marks the first of a series of major transitions in roles for caregiver and care recipient and represents the initial opportunity for HCPs to assess preparedness for caregiving of another individual. In a study aimed at evaluating preparedness of caregivers following diagnosis of Alzheimer's disease, Ducharme, et al., (2011) recruited 122 caregivers of patients diagnosed with dementia in the previous nine-month period. Caregivers were asked to provide information about perceived levels of preparedness for caregiving and challenges experienced in the caregiving role. Scores on the PSFCI Scale indicated that 58% of participants reported high levels of preparedness for the caregiving role and more than 70% believed they were efficacious in obtaining needed support from family and friends. Interestingly, however, 57% of caregivers indicated that they had little knowledge of formal services, 61% had not thought about their relative's future needs, 70% of caregivers also reported low levels of emotional support and more than 90% reported they received little or no informational or instrumental support. These conflicting results give additional credence to suggest that perceived preparedness, while important in terms of feeling of self-efficacy may not be providing an accurate representation of whether caregivers need.

**Need for additional services.** Transitions related to increasing needs for care may be particularly challenging for caregivers due to the awareness that they are unable to provide everything that care recipients need. This reality may be particularly challenging for caregivers of PWD, who may fear that they will be looked upon negatively for being
unable to manage the needs of the PWD. Assessment of caregiver reactions to needing and receiving additional help is a key role of HCPs. Determining what is meaningful in discussions between HCP and family caregivers is a key way in which interventions to assess and impact preparedness can occur.

In an intervention study aimed at increasing preparedness of caregivers of both physically and cognitively impaired individuals, Archbold and colleagues (1995) recruited 22 caregiver-care recipient dyads from an HMO. All care recipients had received new referrals for home health visits. Research nurses worked with visiting RNs over a six-month period to provide expanded services, telephone availability to manage questions and crises and follow up assessment after discharge from home health services. The 40 item CES was used to assess perceived preparedness, predictability and enrichment of caregivers. Results indicated that although the nursing intervention led to an increase in perceived preparedness for attending to physical needs, it failed to significantly decrease caregiver role strain or caregiver depression. Reasons for this lack of significance are unclear. The researchers postulated, however, that both a small sample size and the length of the intervention might have contributed to lack of significantly decreased role strain in the experimental group (Archbold, et al., 1995).

Post-discharge from an acute care hospital. Vulnerability related to transition also occurs in the weeks immediately following discharge from an acute care facility. As patients move from a hospital setting in which many needs have been addressed by professional HCPs, the intensity of technical skills, emotional resilience and physical
energy required for caregiving come into stark relief as the identified patient moves home.

PWD are hospitalized for physical illnesses and cognitive or behavioral disturbances of dementia (BPSD). For caregivers of PWD, the post-hospitalization period may require adjustment to what is often a new baseline of cognitive functioning. Preparedness for caregiving of an individual who has declined both physically and cognitively may require both new technical skills and emotional resilience to cope with new deficits in the PWD resulting from additional insults to the brain. Studies have not been completed that specifically evaluate preparedness of caregivers of PWD in the period following hospitalization. Nonetheless, insight into caregiver preparedness during transition from hospital to a residential setting is exemplified in the following examples of research with caregivers faced with other chronic or progressive illnesses.

An example of evaluation of preparedness of family caregivers of stroke patients following discharge from an acute care facility was conducted by Shyu and colleagues (2008). Family members of hospitalized stroke patients were invited to participate in a discharge-planning program aimed at increasing their levels of preparedness to become caregivers. A secondary aim was to teach caregivers to find balance between the responsibilities of the caregiver role and the needs of themselves as individuals.

Within three days of hospital admission, an initial caregiving assessment was conducted using the PSFIC and the NECPS. Using the data provided from the caregiver self-assessment and the nursing assessment, discussions occurred with research nurses
on 4-5 different occasions during the hospital stay. Subsequent assessment using the same two instruments occurred again prior to discharge and at one month post discharge.

Post-test results of both the PSFIC and the NECPS indicated that the discharge-planning program was effective in increasing preparedness of the caregiver. The researchers suggest that providing individualized assessment and intervention during periods of transition is a useful intervention in increasing caregiver effectiveness. The NECPS may eventually be available as an additional tool to use for assessing caregiver preparedness. At the present time, however, it remains an unpublished work and is thus not readily available for use (Shyu, et al., 2008).

Lay caregivers are being asked to perform a myriad of duties previously managed in a hospital or rehabilitation settings. Patients discharged from hospitals to home settings with long term enteral feeding tubes are one example of caregivers being asked to perform complex medical tasks. In an attempt to evaluate preparedness of family caregivers to manage feeding tubes in the home, Silver and colleagues (2004) interviewed caregivers of persons with cancer, digestive disorders, head trauma and swallowing disorders to assess levels of preparedness for managing enteral feeding tubes several weeks after hospital discharge. Caregivers were asked to complete self-assessments on a preparedness scale (PSFCI), caregiver burnout, competence and overall effectiveness. All scales measured caregiver perceptions rather than objective measures. After analysis, the researchers concluded that low levels of preparedness were associated with caregiver overload, unmet training needs, low levels of competence and low reports of caregiver effectiveness. Most telling, however, was the limited amount of training that
caregivers had received to engage in what were non-intuitive, complex tasks of caregiving (Silver, et al., 2004). The need for increased caregiver training, evaluation and support is a missing aspect of patient care, particularly in an era of increasing technology and move toward management of chronic condition in residential settings.

Although hospitalization is often a time of intense change in functionality of PWD, no studies are available that document levels of preparedness of caregivers of PWD for the period of transition following hospitalization. Inpatient and outpatient HCPs are in optimal positions to assess preparedness of caregivers at the time that PWD are discharged from hospital settings. This period also represents a key opportunity to ensure that continuity of care for both the identified patients and caregiver occurs between inpatient and outpatient providers.

**Non-standardized assessments of preparedness.** While the studies outlined in the paragraphs above each use the PSFCI as a tool for obtaining a quantitative measure of preparedness, many researchers have chosen to use a single question as an indicator of participants' beliefs about their readiness to assume the caregiving role. An example of this is: “To what extent were you pre- pared for the care recipient’s death?” (Hebert, et al., 2006, p. 685). As with the PSFCI, studies using single question assessments of preparedness relied on participant self- ratings of perceived preparedness for the caregiving role.

Two striking factors emerge with this change in assessment approach. The first is that with the change in evaluation also comes a change in discipline of the primary author on most studies. Researchers choosing to use the PSFCI come from an almost
exclusively nursing background, while those using a single question assessment are physicians or social workers. This fact may speak to the need to ensure that tools available to health care researchers cross disciplines. Second, with the change in disciplines comes a shift from inquiring about preparedness of caregivers acting in an ongoing caretaking role to those who are functioning either in end of life settings or are in the bereavement period.

**Preparing caregivers for death of a loved one.** Caregivers of PWD and other terminal illnesses are eventually faced with a reality that no intervention exists that will alleviate the ravages of the disease or prevent impending death. Although a significant amount of research has focused on end of life decision-making by patients, caregivers and HCPs, only a handful of studies have specifically focused on preparedness of caregivers to deal with death of a loved one suffering from terminal illness. Recognition that preparedness for end of life is a crucial element affecting caregiver outcomes has led researchers to explore the role of HCPs in preparing caregivers for death of a loved one (Cagle and Kovacs, 2010; Hebert, et al., 2006). The studies reviewed are separated into those dealing with cancer and those focused on caregivers of dementia and other progressive illnesses. The rationale for this relates to the trajectory of illness in cancer versus progressive illness. While individuals with cancer have a more predictable course of illness and death, those with progressive illnesses often have an erratic and unpredictable trajectory up to and including time of death (Lynn & Adamson, 2003).

**Preparedness for death of a loved one with cancer.** In a study of 69 caregivers providing support for hospice oncology patients, social work researchers asked
participants to complete a survey that included pre-death and post-death narrative responses to questions about preparedness for death of a loved one. Preparedness, in this study, included knowledge of the concrete aspects of caregiving in addition to physical, social and emotional support. Caregivers reported needs across multiple domains, including practical information related to tasks, emotional and spiritual support, access to professionals, financial guidance and respite from caregiving duties. Caregivers who reported high levels of preparedness reported that experiences closely matched expectations. Knowledge of the disease and dying process, effective communication, development of a trusting relationship and support from HCPs were all identified as crucial elements affecting preparedness and ability to cope with the end of life experience (Cagle & Kovacs, 2011).

A major contribution of this study was the depth of qualitative information provided by participants. While the study was limited by the lack of actual interviews, it did provide narrative information that was coded and organized according to themes. In addition, the inclusion, by participants, of feedback related to all members of the interdisciplinary team highlights the importance of a team approach to care. While this study did not include PWD, it has direct relevance for caregivers of PWD. The trajectory of terminal cancer and the need to tailor information for caregivers experiencing loss over time highlights the importance of interdisciplinary teamwork in providing knowledge, emotional and spiritual support, education about resources to fit caregivers needs over time.
**Caregiver preparedness for death of a PWD.** In the first of a series of quantitative and qualitative studies with family caregivers, Hebert and colleagues (2006) set out to explore factors contributing to caregiver preparedness for the death of a loved one with dementia. Believing that a reliable and valid tool to assess preparedness had yet to be developed, the researchers used a single question to assess preparedness of caregivers for their loved one's death and standardized tools to obtain descriptive information about the sample.

In the initial study, researchers asked bereaved caregivers to rate their levels of preparedness for a loved one's death. Responses were categorized on a 3 point Likert scale. In addition to obtaining preparedness scores, demographic characteristics, assessments of physical and mental health and spirituality were obtained. Researchers found that ethnicity, caregiver education, socioeconomic status, the physical status of the patient and the caregiver's own level of depression were all linked to levels of preparedness. As in the Shyu, Yang, Huang, Kuo, Chen & Hsu (2010) study, low levels of self reported preparedness were associated with poorer mental health. Information about what caregivers believed would have contributed to increased feelings of preparedness was not collected (Hebert, et al., 2006).

Recognizing that additional information about caregiver needs was indicated, the research team designed a second qualitative study to identify types of questions that caregivers have when a loved one is nearing end of life. The ability to access information, they reasoned, had the potential to increase perceived and/or actual preparedness, thus impacting post-death adaptation / resolution. Caregivers were asked
to discuss three topics: "(1) the questions they believe are important to discuss with HCPs in order to prepare for the death, (2) which questions they asked HCPs, and (3) which questions they did not discuss with HCPs" (Hebert, Schulz, Copeland & Arnold, 2006, p. 476). Qualitative interviews and focus groups were used to allow for open discussion.

Topics put forth by caregivers ranged from those pertaining to concrete, practical and factual information to those relating to spiritual or existential needs. Specific areas of concern included management of family conflict, obtaining information, and reassurance of the caregiver's adequacy in the caregiving role. Findings confirmed that unanswered questions contributed heavily to caregiver distress, suggesting that additional information is needed about how best to ensure that caregiver questions are both asked and answered by HCP over the course of the caregiving experience (Hebert, et al., 2009).

**A Model of Preparedness.** In a final study, Hebert and colleagues (2009) again turned to qualitative methodology to expand on the findings of the first two studies. The goal of this final study was to create a conceptual model of preparedness to guide clinical practice. Focus groups of bereaved caregivers were asked about what they had considered important as they prepared for the last stages of their loved ones' illness and subsequent death. Results indicated that the prior life experiences, uncertainty and communication played significant roles in caregiver preparedness for end of life experiences (Hebert, et al. 2009).
In constructing a conceptual model, the three primary drivers: previous life experiences, uncertainty and communication with health care providers are each depicted as affecting preparedness for the caregiving role. Of these three factors, only one, prior life experiences, remains outside of the circle of influence of health care providers.

Prior experiences of caring for a loved with dementia, acting as a surrogate decision maker, or having familiarity with medical terminology used by health care providers are examples of life events that increase the preparedness of family caregivers for caring for a loved one with moderate to advanced dementia. Although HCPs do not have direct influence over prior life experiences of family caregivers, assessment of such experiences may foster preparedness of caregivers by guiding interventions that will build on existing strengths and provide education and support to bolster areas in which caregivers are less experienced (Hebert, et al., 2009).

Uncertainty experienced by family caregivers may be conceptualized as an inability to effectively organize or assign meaning to information or events. For those dealing with progressive illness, uncertainty often revolves around obtaining understanding of prognosis, managing the practical aspects of symptoms and routines of daily life, gaining clarity about personal values and defining the surrogate role within the context of the provider and patient relationships (Cherlin, et al., 2005; Hebert, et al., 2009; Mishel, 1981; Parker, et al., 2007; Song & Sereika, 2006).

Knowledge and guidance obtained by caregivers through interactions with health care providers and other support systems may provide understanding about symptoms and changes related to illness, the surrogate decision maker role and enhance perceptions
of preparedness to negotiate the changes ahead (Hebert, et al., 2009; Waldrop, Milch & Skrettny, 2005). Understanding obtained through interactions with HCP may help to manage the uncertainty of navigating changes throughout the trajectory of dementia.

**Summary.** Preparedness is a multidimensional construct that significantly impacts ability of family members to anticipate and prevent problems, provide care, cope with role transitions and navigate the complex landscape of the health care system. Caregivers of PWD are particularly vulnerable to the stressors as caregiving due to the protracted and unpredictable trajectory of the illness. The consequences of being unprepared for caregiving impact well-being of both caregivers and care recipients.

Methods of assessing preparedness that have been used in the caregiver literature rely predominantly on perceived preparedness (self ratings) of caregivers. Self-ratings capture one important aspect of preparedness and provide significant insight into the belief that a caregiver has in his/her own ability to provide care. Even so, perceived preparedness measures only those aspects of caregiving that are known to the caregiver at the point in time at which the measure is completed. Caregivers without knowledge or awareness of impending change may not recognize a lack of preparedness, thus ratings of perceived preparedness may not trigger intervention by HCPs.

HCPs are in an optimal position to evaluate and foster preparedness and provide guidance for caregivers of PWD throughout the prolonged course of dementia, yet understanding of how best to accomplish this is unclear. Interactions between HCP and caregivers offer one method to assess, intervene and impact caregiver preparedness, yet we lack awareness of what occurs during interactions that is identified as meaningful by
caregivers. Understanding what is meaningful to caregivers and how interactions with HCP foster preparedness is a critical aspect of meeting caregiver and care recipient needs, helping them manage uncertainty and ensuring better outcomes.

**Communication Between HCPs and Family Caregivers**

Communication between HCPs and family caregivers impacts treatment planning, decision-making, well-being and perceived quality of care for those affected by dementia and other progressive, life-limiting illnesses. Although it has been considered a key quality indicator in end of life care for more than a decade, awareness of the importance of effective communication has failed to translate into changes in health care delivery or improved outcomes for health care consumers or their families (Alexander, Keitz, Sloan & Tulsky, 2006; Levinson, Lesser & Epstein, 2010; Slatore, et al., 2010). For persons diagnosed with dementia or other progressive illnesses, lack of communication is particularly problematic. Prognosis and course of disease are discussed infrequently, if at all, and family members report that discussions that do occur often come too late for patients to make wishes known (Birch & Draper, 2008; Curtis, et al., 2008; Mahon & Sorrell, 2008). As a result, patients diagnosed with dementia or other progressive illnesses frequently reach the terminal phase of life without plans in place to allow for a peaceful death, are rarely enrolled in hospice (Birch & Draper, 2008; Mitchell, et al., 2009; Parker, et al., 2007) and often spend their final days in intensive care units as recipients of aggressive treatments rather than measures focused on comfort and care (Birch & Draper, 2008; Curtis, et al., 2008; Holley, 2007; Howlett, et al., 2010).
As patients deteriorate, family members are often asked to act as decision making surrogates for those who are unable to articulate their wishes (Kass-Bartelmes & Hughes, 2003), yet surrogates report lack of preparation for the decision making role, lack of knowledge of potential treatment outcomes, uncertainty, isolation, and receive inadequate communication and limited support from health care providers (Dreyer, Forde & Nortvedt, 2009; Givens, et al., 2009; Reinke, et al., 2008; Shanawani, Weinrich, Tonelli & Curtis, 2008; Strachan, Ross, Rocker, Dodek & Heyland, 2009). Each of these factors contributes to the negative emotional and physical consequences of feeling unprepared for the decision making role, including depression, feelings of abandonment, pre-death grief, post traumatic stress disorder and ultimately complications with the grieving process after a patient’s death (Hebert, et al., 2009; Kiely, et al., 2008).

A question of perspective. Clear distinctions about communication exist between perspectives of physicians and those receiving care (Desharnais, Carter, Henessy, Kurent & Carter, 2007). Physicians participating in communication research have focused primarily, though not exclusively, on barriers that prevent optimal communication from taking place and on the cognitive tasks associated with disease and symptom management. Families and patients, while endorsing the need for concrete knowledge, have spoken primarily to the affective and practical dimensions of managing the impact of illness, on the need for meaning-making as they move through phases of illness and the need for contact and relationship with providers during difficult transitions (Desharnais, et al., 2007; Hebert, et al., 2009). The contrast in findings between the two groups is evident in the paragraphs that follow. Whether these findings are related to
research design or simply a function of radically different viewpoints of physicians and care recipients is unclear. Nonetheless, the differences in perspective highlight challenges in communication that are inherent in our health care system.

Studies reviewed include those dealing exclusively with dementia and those relating to other types of progressive illness. The assumption underlying inclusion of those studies dealing with other types of progressive illness is that many of challenges hold true across caregiving situations.

**The physician perspective.** Physicians caring for patients with dementia or other progressive illnesses often give verbal support to engaging in collaborative decision making, advance care planning and full prognostic disclosure for patients under their care, yet identify a multitude of barriers that prevented optimal discussions and long range treatment planning from taking place (Birch & Draper, 2008; Curtis, et al., 2008; Gott, et al., 2009; Howlett, et al., 2010). Barriers cited include administrative or organizational challenges (lack of training, inadequate role definition, lack of reimbursement for time spent with patients and families) and issues of uncertainty (trajectory of illness, timing, emotional discomfort, difficulties with prognostication, lack of awareness of what patients and families need) (Alexander, et al. 2007; Davison, Jhangri, Holley & Moss 2006; Gott, et al., 2009; Hancock, et al., 2007; Reinke, Shannon, Engelberg, Young & Curtis, 2010; Rodriguez, Gambino, Butow, Hagerty & Arnold, 2007; Shanawani, et al., 2008).

**Administrative and organizational challenges.** In the landmark report “Approaching Death: Improving Care at the End of Life commissioned by the Institute
of Medicine in 1998, the urgent need for improvement in training for all health care professionals was cited as a major factor influencing the ability of HCPs to provide adequate, patient centered EOL care (Field & Cassell, 1998). Unfortunately, the lack of adequate training in EOL care continues, with physicians stating repeatedly that they have not received the training needed to effectively carry out such duties (Alexander, 2007; Davison, 2006; Gott, et al., 2009; Hancock, et al., 2007; Reinke, et al., 2010; Rodriguez, et al., 2007; Shanawani, et al., 2008). Efforts have been made to increase communication training in some medical school programs, yet in a recent study, only 49% of medical school seniors stated that they had actually given news of a life threatening illness to a patient and of those, even fewer had received or given feedback about such conversations (Billings, et al., 2010).

Training interventions designed to improve communication skills of medical residents or seasoned physicians have been either challenging to implement due to the time commitment involved or have been designed to be taught in artificial settings, often with either lay or professional actors simulating the role of patients or families (Levinson, Lesser & Epstein, 2010). Unfortunately, evaluation of the effectiveness of such interventions in ongoing patient-family-provider interactions has rarely occurred (Alexander, Kietz, Sloan & Tulsky, 2010; Levinson, et al., 2010; Liénard, et al., 2010).

When asked to identify barriers to communication, lack of time was identified by up to 64% of physicians as a major deterrent to engaging in fruitful discussions about advance care planning (Curtis, 2007; Knauf, Nielsen, Engelberg, Patrick & Curtis, 2005). Willingness to allocate time needed to fully discuss prognosis, ACP and end of
life wishes is impacted by reimbursement and daily scheduling (Back, Young, McGowen, et al., 2009). The procedure-driven Medicare system and many large insurance companies fail to reimburse physicians for additional “talking time” needed to complete ACP with patients and the result is literally failure to be paid for time spent, so for providers who see a multitude of patients with progressive illness, the question of how to manage financial realities of a procedure-driven reimbursement system can be daunting (Woo, Maytal & Stern, 2006). Although this barrier has been identified for many years, the continuing battle faced by physicians regarding reimbursement for ACP continues. Discussion about reimbursement for ACP was evidenced on the national stage during debates around items included in the most recent health care reform bill and indeed, the line item that allowed for such reimbursement was ultimately pulled from the Patient Care and Affordability Act (Pear, 2011).

In qualitative and quantitative studies, physicians, nurses and social workers caring for persons with progressive illnesses acknowledge that in many cases patients have not been given adequate information about the life-limiting nature of their disease (Gott, et al., 2009; Hancock, et al., 2007; Johnson, et al., 2009; Mitchell, et al., 2009). Physician specialists, nurses, case managers and primary care providers all suggest that discussion of trajectory lies outside the scope of their immediate responsibility. In an era of specialty medicine, clear role delineation of who carries the responsibility for communicating about ACP with patients is often not present and the result of a complicated health care system is that no one has discussion with patients and families (Johnson, et al., 2009; Medicare Payment Advisory Commission, 2008). Lack of
ownership of the educator role leaves families and patients unprepared for the realities and decision-making required in late stage disease (Gott, et al., 2009). Unfortunately, when crisis situations occur, HCPs suggest that family members and/or patients are in too much distress to engage in discussions or make informed decisions about end of life planning (Gott, et al., 2009; Johnson, et al., 2009). The uncertainty arising from lack of knowledge and preparation for decision-making near the end of life causes distress for caregivers, HCPs and those receiving care.

**Uncertainty.** Issues of reimbursement, training, and role definition may be manageable through changes in existing policy, yet even if organizational hurdles to communication are surmounted, physicians face murky waters of confusing clinical scenarios, conflicting needs of patients and families, the realities of powerlessness to control outcome and their own discomfort with displays of emotion (Crawford, 2010; Hancock, 2007). An overwhelmingly present theme permeating research studies with healthcare providers is difficulty managing the challenge of uncertainty.

**Erratic Trajectory.** Trajectories of many progressive, life limiting illnesses are characterized by relatively long periods of seemingly infinitesimal decline punctuated by abrupt periods of deterioration resulting from either exacerbation of the progressive illness, itself, or as a result of a comorbid condition (Mitchell, et al., 2009; Sachs, Shega & Cox-Haley, 2004). Unlike events resulting from trauma or cancer, the rapid plunge downward seen during acute exacerbation of illness may not signify permanent decline. A steep drop in physical or cognitive functioning is, in fact, often followed by a return to a baseline that is quite close to a previous level of functioning. The ongoing cycle of
stability, decline and return to baseline (or near-baseline) is deceiving for patients, families and physicians alike, and physicians suggest that the seemingly fickle nature of progressive illness contributes to lack of awareness of when to time discussions for patients with COPD, dementia, heart failure and end stage renal disease (Birch & Draper, 2008; Gott, et al., 2009; Holley, 2007; Ryan & Sawin, 2009; Strachan, et al., 2009).

Loss of hope. Physicians express trepidation that engaging in discussions about limitations of illness, palliative care and the need for advance care planning will cause patients and/or family members to lose hope and cease to engage in maintaining functionality or health-promoting behaviors (Birch & Draper, 2008; Gott, et al., 2009; Parker, et al., 2007; Holley, 2007). They also report concern that even their best predictions may be inaccurate and that the act of “being wrong” about the phase of illness, particularly following abrupt decline, may cause additional burden for their patients (Parker, et al., 2007; Holley, 2007). Health care providers who do attempt to dialogue with patients and families about trajectory of illness and prognosis have suggested that it is difficult to know what level of information should be included in the conversation, how to discuss that information, and what words will be clear without seeming harsh or unfeeling, particularly when clear requests for information are not articulated (Crawford, 2010; Lefebvre, Levert, Pelchat & LePage, 2008). Moreover, HCP overestimate what they tell patients and underestimate what patients want to know (Kinnersley, et al., 2009). Open-ended questions such as “what do you want to be told?” or “what do you want us to do?” have proven to be inadequate in guiding conversations effectively, however, clear algorithms for discussion remain unproven as
effective methods for identifying the types or degree of information desired (Curtis, et al., 2008; Mahon & Sorrell, 2008).

**Discomfort.** Discomfort with the topic of death is widespread and continuing to identify a “cure” and avoiding “failure” is a factor for many physicians (Holley, 2007; Howlett, 2010). Moreover, physicians endorse discomfort with witnessing the emotional vulnerability of patients and the lack of control of patient reactions (Yedida, 2007). The result of this discomfort, not surprisingly, is that physicians and patients have vastly different reports of content when subject matter is sensitive or uncomfortable. Topics that are particularly problematic include desired place of death, pain management, and hospice care, while topics that have higher concordance scores are more concrete or factual in nature (Desharnais, et al., 2007).

**Indirect language.** Lack of communication about prognosis may also be linked to both the “cloaked” language often used by physicians to speak of terminal diagnoses (Hebert, et al., 2009; Rodriguez, et al., 2007) and to the often complex terminology used by health care providers (Parker, et al., 2008). The complexities of terminology are further evident when discussing use of the word “progressive” to describe life limiting illnesses. Some patients and families interpret “progressive” to mean that the disease will not be cured, but fail to understand that death, when it comes, will be a direct result of the illness, itself. Both families and patients report that they were unaware that a disease was terminal until the words were spoken to them by a physician (Cherlin, et al., 2005; Gott, et al., 2009). Lack of understanding leaves patients unable to make choices known, leaves family caregivers unprepared, and results in patients with progressive, life limiting
illnesses are reaching the final stage of life without ACP in place (Ceccarelli, Castner & Haras, 2008; Curtis, et al., 2008; Howlett, et al., 2010; Sachs, 2009).

**Summary.** Challenges in effective communication arise when physicians caring for those with progressive illness experience uncertainty, organizational and personal barriers to initiating discussion and discomfort related to the topic of death. Awareness of consequences or negative outcomes related to lack of preparation for the challenges of caregiving loom far into the future when day-to-day decisions about treatment are made. Discussions about prognosis, are put off or laden with cloaked or ambiguous language in hopes that patients will rally once again, yet all too often patients pass the point at which engagement and sharing of wishes is no longer possible (Hebert, et al., 2006). The implications of avoiding discussions about trajectory, prognosis and end of life with PWD and their caregivers are significant. Individuals diagnosed with progressive and terminal illness may not engage in advance care planning, resulting in limited or absent ability to make autonomous decisions. Family members, unprepared for the roles they eventually assume, are faced with additional stress of making decisions without the input of those directly affected.

Meaningful interactions between HCPs and family caregivers can only take place if HCPs are able to overcome the personal and professional barriers that currently interfere with effective communication. Understanding what impedes communication is a critical aspect of beginning to impact change.

**Perspectives of patients and families.** Communication with HCPs offers patients and families affected by progressive life-limiting illness an opportunity to obtain
information, manage uncertainty, receive support and navigate change (Hebert, et al., 2009, Waldrop, et al., 2005). Unfortunately, opportunities for meaningful interactions are hampered by “disconnects” between provider and recipient in terms of knowledge needed, timing of information, and understanding of the importance of relationship (Birch & Draper, 2008; Gott, et al., 2009; Kinnersley, et al., 2009). Information received from patients and families about communication with HCPs is limited by the almost exclusively end of life setting in which research has been conducted.

Knowledge. Communication from physicians related to prognosis and treatment is considered by patients and families to be among the most important pieces of information that a physician can give, yet many caregivers report that this discussion rarely occurs until patients are near the end of life (Cherlin, et al., 2005; Curtis, et al., 2008; Hebert, et al., 2006; Holley, 2007; Howlett, et. al, 2010; Parker, et al., 2008). Whether this report is based in reality is unclear, in part because few studies on communication have been conducted that have included both physician and care recipients (Tulsky, 2010; Fine, Reid, Shengelia & Adelman, 2010). What is apparent from reports, however, is that information provided about prognosis and illness trajectory in progressive illnesses fails to have meaning for many care recipients and thus is not assimilated into the knowledge base of the care recipients involved.

Timing. Caregivers and patients affected by progressive life-limiting illness often report needing similar information early in the disease process. Information needs diverge, however, with worsening illness (Curtis, et al., 2008; Hebert, et al., 2008; Parker, et al., 2008). Patients may appear to be less interested in additional information as their
disease progresses and may want less information about changes in health status (Knauft, et al., 2005), while caregivers become more involved in the later stages of illness and report a greater need for information about both the concrete aspects of care such as symptom management and availability of resources and the management of emotional and spiritual distress (Parker, et al., 2008).

The transition to the surrogate role marks a definitive change in the roles of both HCP and family surrogate, yet little is known about the physician-surrogate relationship (Torke, Alexander, Lantos & Siegler, 2007; Waldrop, et al., 2005). As family members step into the surrogate role, additional questions surface about responsibilities, guidelines and choices arise, yet family members across studies report that opportunities for communication were infrequent (Curtis, et al., 2008; Givens, et al., 2009; Hebert, et al., 2008). Lack of clarity about the surrogate role, uncertainty about what knowledge is needed, and stressors associated with changing demands are complicated by feelings of guilt, fear, and anxiety about the ability to manage (Alzheimer's Association, 2011a).

Surrogates report uncertainty about what to expect and are hesitant to ask basic questions about disease process or death, either because they do know what questions to ask or because of a fear of being judged (Dreyer, et al., 2009; Hebert, et al., 2009).

*Relationship.* Patients and family members look to physicians, nurses and other health care providers for guidance in moments of extreme vulnerability (Cherlin, et al., 2005). The emotionally and spiritually complex tasks of navigating the unknown world of terminal disease, conflicting fears about the future, changes in levels of autonomy and uncertainty about the ability to manage competing demands leave patients and families in
need of additional supports (Cherlin, et al., 2005; Gott, et al., 2009). While physicians, independently, cannot alleviate all concerns or solve all problems, a key aspect in supporting patients and families is through interdisciplinary referrals and through simply being present, assuring those receiving care that they will not be abandoned (Back, et al., 2009).

Summary. The majority of the literature on communication between HCP and family caregivers has been conducted in end of life settings or with bereaved caregivers. The difficulties and dissatisfaction experienced by family caregivers faced with end of life issues, coupled with a dearth of research focused on caregiver needs earlier in the trajectory of illness, suggests that continued efforts are needed to better understand ways in which meaningful communication between HCP and caregivers can take place

Bridging the Gap: Understanding Meaning. Communication is composed of specific elements that, taken together, allow for information exchange between the involved individuals. The interplay of content and meaning attributed to events or statements combine to determine whether information that is sent by one individual is assimilated, encoded and utilized by another (Clark, 2004). As transitions occur during the course of life limiting illnesses, physicians, patients and family members, subconsciously or consciously, attach levels of meaning or significance to each event that occurs. Effective provider-recipient communication includes all parties achieving understanding of the meaning of transitions for those involved, whether those meanings are clinically or emotionally based (Reinke, et al., 2008). Differences in meaning translate into lack of awareness for family members of the significance of particular
markers in the illness trajectory and often lead to lack of preparedness for patient death in spite of ongoing, progressive decline in functioning (Hebert, et al., 2006). Illustrations of this disconnect in meaning assigned to events by HCPs and care recipients are seen across the span of progressive, life limiting illness. Decreased exercise tolerance, increasing fatigue in daily activities, and fluid retention are markers of progressing cardiovascular disease for physicians, yet aggressive treatment of symptoms is misinterpreted by families and patients as prolonging life rather alleviating discomfort (Howlett, et al., 2010). Patients with COPD assign high levels of meaning to the transition of requiring supplemental oxygen, yet attach lesser significance to hospital admissions. Conversely, physicians view hospitalizations, rather than oxygen requirements as the more meaningful transition point in the illness progression (Reinke, et al., 2008). For patients with dementia, repeated urinary tract infections or respiratory ailments may be interpreted as a harbinger of illness progression by physicians. Family members often interpret these same infections as problematic, but treatable conditions that have been successfully conquered in the past. Ensuring that patient, family members and health care providers have similar understanding or interpretations of the emotional or physical meaningfulness of particular exacerbations of illness or changes in functioning is a key component of effective communication (Reinke, et al., 2008).

**Summary.** Existing research on communication in progressive life-limiting illness shows clear differences in experiences of physicians and care recipients. Providers primarily focus on organizational, administrative and personal barriers that prevent effective communication from occurring, yet little has occurred in over a decade.
to impact either the training needs of physicians or to support physicians participating in a more patient-centered approach to health care. Patients and families speak of the need for knowledge, yet quickly move on to stress that emotional support and relationship with providers is needed as they navigate the complex world of progressive, life limiting illness. Needs of families and patients change over time and vary tremendously between individuals, yet those affected state clearly that while needs change, they are less concerned with physicians being “right” than with physicians being engaged in relationship so that dialogue can occur (Hebert, et al., 2009; Lefebvre, et al., 2008; Yedida, 2007).

Uncovering personal accounts about the content of communication between HCP, patient and family caregiver is difficult, in part because few research studies include actual observation of physician-patient-family conversations (Tulsky, 2010). Unfortunately, HCPs rarely assess what information was assimilated or understood by patients or families and opportunities to intervene with additional information are rarely taken (Lefebvre, et al., 2008). Families and PWD have clearly articulated a need for improved communication between themselves and health care providers. Research aimed at evaluating concordance of patient and physician perceptions after interactions is needed to evaluate whether families and patients are simply not being told information about prognosis and disease trajectory, whether the issue is one of assimilation and accommodation, or whether the issue lies more in either delivery or timing of when information was given. Establishing methods to assess knowledge base of patients and families and devising interactive methods of identifying needs of patients and families is
the first step to development of interventions that will guide early decision making and treatment planning. Caregivers armed with knowledge, clarity about their ability to access resources and confident in their abilities to partner with health care providers throughout the complex trajectory of dementia may experience fewer symptoms of psychological distress, increased ability to navigate and adjust to change and may be better prepared to function as patient advocates.

Increased understanding of what constitutes a meaningful interaction will lead to improved assessment of what is needed by caregivers over time. HCPs, armed with knowledge of what caregivers find important, will be better able to provide appropriate and timely interventions and guidance. Caregivers who receive timely, relevant and meaningful information and feel prepared to carry out their roles will be poised to make decisions and choices that will translate into better care for PWD and will be better equipped to care for themselves in the process.
CHAPTER THREE

Methods

Introduction

Through a review of existing literature, I have established that challenges in HCP-caregiver communication impact preparedness for decision making in the caregiving role. Uncertainty, lack of knowledge of the disease process, inadequate preparation for the decision-making role, and infrequent and ineffective communication with HCPs have all been reported by family caregivers (Dreyer, et al., 2009; Givens, et al., 2009). HCPs acknowledge the challenges in communication and a lack of caregiver preparedness, yet have limited insight into avenues of intervention that would alleviate the problem (Washington, et al., 2011). The gap in our understanding of the caregiver experience of interactions with HCPs and lack of knowledge of what constitutes a meaningful interaction between the two groups has profound implications for the preparedness of caregivers for their roles as decision makers and patient advocates. The purpose of this study was to describe meaningful interactions with HCPs from the perspectives of family caregivers of persons with moderate to advanced dementia. A secondary purpose was to understand ways in which family caregivers obtained needed information within (or outside of) the context of those interactions that facilitated preparedness for managing uncertainty associated with caregiving/caring for someone with moderate to advanced dementia. This study provided answers to the following questions:
1. What stand out as central themes in qualitative interview accounts of meaningful health care provider interactions from the perspectives of family caregivers of persons diagnosed with moderate to advanced dementia?

2. What strategies do family caregivers use to obtain meaningful information for managing uncertainty associated with caregiving for someone with moderate to advanced dementia?

In this chapter, I discuss the rationale of choosing qualitative description as the method for my study, review underpinnings of the method and outline the data collection and analysis process.

**Qualitative Description.** The research method known as Qualitative Description is situated within the naturalistic, descriptive paradigm and rooted in the framework of social psychology. Underlying the approach is an epistemological assumption that reality can be understood only when viewed from the contextual standpoint in which it is constructed and assigned meaning. Accordingly, qualitative description is used when the purpose of the research is to obtain rich, straightforward descriptions from an emic perspective of participants (Denzin and Lincoln, 2005; Sandelowski, 2000, Sandelowski, 2010; Sullivan-Bolyai, Bova & Harper, 2005).

I chose qualitative description to address the gap in the dementia literature between what is known about the lack of caregiver preparedness for the decision making role and what is needed in order for HCPs to impact caregivers' readiness to act as surrogate decision makers. Understanding what is considered meaningful or significant to
family caregivers engaged in dialogue with HCPs will guide intervention development aimed at increasing caregiver preparedness.

I reported findings in ordinary language, with close adherence to the words and tenor used during the interview in order to ensure allegiance to descriptions provided by participants (Miles & Huberman, 1994; Sandelowski, 2000; Sullivan-Bolyai, et al., 2005). Use of the qualitative descriptive method was congruent with the aims of describing characteristics and content of meaningful interactions with health care providers and obtaining straightforward information about ways in which family caregivers obtained needed information within (or outside of) the context of those interactions and communication contexts.

**Setting.** Multiple sites were used for collection of data in this study. The goal of using multiple sites was to facilitate inclusion of participants from a variety of socioeconomic, racial and ethnic backgrounds and treatment backgrounds.

As PWD move from early to moderate or severe stages of impairment, they live and receive care in a variety of settings. Changes in residence or levels of care often correspond with critical junctures in the disease process and in the caregiving role (Keady & Nolan, 2003). Recruiting participants from a variety of settings contributed to diversity of perspectives within the sample of caregivers across multiple stages of the disease process.

The study was conducted in community settings, two nursing homes (one urban, one suburban) and two assisted-living facilities (ALFs) with memory care services. Each of the selected nursing homes was approved by the Joint Commission on Accreditation of
Healthcare Organizations (JCAHO). ALFs were certified through the Massachusetts Executive Office of Elder Affairs, the state agency responsible for oversight of ALFs in that state.

Payment for care and services varies across residential settings designed to meet the needs of PWD. ALFs require residents to pay privately or through funds provided by private long term care insurance. Residents of ALFs may have a variety of chronic co-morbid medical conditions, however few require skilled care for acute medical needs. ALFs with memory care units are for-profit residences and provide specific programming geared toward residents affected by dementia. Persons residing in ALFs with memory care units typically represent individuals from an upper socio-economic bracket with financial resources that offer opportunities for a wide array of services to be provided.

Unlike ALFs, payment for NH care is most often provided with some combination of Medicare, Medicaid or private insurance. Residents with dementia who are admitted to nursing homes often suffer with co-morbid medical conditions that require skilled nursing care. Although a limited number of NH residents pay for care using private funds, most have exhausted their financial resources, resulting in qualification for state-sponsored Medicaid funding.

PWD living in non-institutional settings utilize services from publicly and privately funded resources. Medical needs of this segment of the population also vary, ranging from those requiring little medical intervention to end of life hospice care. Financial resources of PWD and their caregivers living in community settings range from
those with limited resources to those who are able to receive services paid for through private funds.

Family caregivers of PWD were recruited from NH, ALF and community settings to ensure that family members of individuals from all socioeconomic brackets were included and that individuals who required skilled nursing care were included. The inclusion of caregivers from multiple settings contributed to the overall diversity of participants represented in the study.

Primary and mental health care for residents of the selected nursing homes or the ALF may be provided by either community HCPs or by professionals under contract with the individual facility. Most commonly, nursing home residents elect to be cared for by HCPs who are hired by the individual facility to provide treatment. Individuals in ALFs often choose to continue with community practitioners, although some ALFs also provide access to a consulting psychiatrist, internist and/or nurse practitioner. Individuals in non-institutional settings may receive treatment from any of the professionals described above.

Participants in this study received guidance from a variety of HCPs, including primary care physicians, nurse practitioners, neurologists, psychiatrists and psychologists. Enrolling participants who had interactions with different types of HCPs added richness and depth to the findings of the study and allowed exploration of the roles of both primary treatment leaders and of adjunct staff members in creating meaningful interactions with family caregivers.
Sample. Multiple convenience sampling strategies were used in recruiting participants. I began recruitment using purposive sampling. In purposive sampling, participants are invited to enroll in the study based on the presence of a particular characteristic or set of characteristics (Creswell, 2007; Miles & Huberman, 1994). The common characteristic in this study was that all participants self-identified as family caregivers of persons in the moderate or advanced stages of dementia. As study enrollment continued, I sought maximum variation across the sample population, and attempted to enroll individuals from diverse backgrounds, in addition to those that represented "negative" (different) viewpoints (Creswell, 2007). Use of maximum variation strategies ensured that both common and uncommon viewpoints or situations were represented in data analysis (Creswell, 2007; Miles & Huberman, 1994). Snowball sampling, a technique used to recruit interested participants through communication from other information-rich sources was also used (Creswell, 2007).

Sample inclusion criteria. In order to meet inclusion requirements, each participant was ≥ 18 years of age and self identified as a caregiver or surrogate decision maker of a person with moderate to advanced dementia. Information related to the caregiver's legal status as a substitute/surrogate decision maker was recorded, however, documentation as a legal representative (Health Care Proxy or Health Care Power of Attorney) was not required for participation since this study was aimed at the caregiver experience rather than information about PWD, themselves. The rationale for this distinction was the knowledge that large numbers of PWD do not complete Health Care Proxy appointments or Health Care Powers of Attorney pre-morbidly. Family members,
whether they are acting as legally appointed designees or as informal caregivers, are often present and in discussion with HCPs during both regular and crisis situations, thus their experiences were relevant to the study, regardless of their legal status.

The rationale for including only family caregivers of individuals identified as being in moderate to severe stages of dementia was related to tasks of caregiving across different stages of the illness. Caregiving tasks and level of involvement for caregivers of persons in later stages of dementia would be significantly different from those who were providing care for PWD with only mild impairments (Adams, 2008; Alzheimer’s Association, 2013). Accordingly, the need for meaningful interaction to prepare caregivers for additional responsibilities would change as PWD progressed through stages of the illness.

Documentation of the PWD's cognitive testing was not required. Formal cognitive testing is not always completed by HCPs who provide care for PWD, thus it was acknowledged during study design that specific staging by the HCP would not necessarily be available to the caregiver. Furthermore, the study design did not include enrollment of PWD or access to protected health information, thus it was known prior to recruitment that the results of any testing would not be available to the researcher.

**Sample exclusion criteria.** This study had very limited exclusion criteria. Caregivers who identified themselves as caring for individuals in the mild stage of dementia were not included, as their needs and interactions with HCPs were anticipated to be significantly different for those caring for individuals in moderate to severe stages of the illness. No one under the age of 18 was enrolled. Non-English speaking
participants for whom a translator was not available were not enrolled. This last exclusionary criterion was related to my own lack of fluency in languages other than English.

In recognition of the need to obtain a diverse participant sample, a plan for exclusions to enrollment for individuals in categories already well represented in the sample was developed. In the plan, recruitment of certain categories of participants would cease if the need for participants with particular characteristics had been met, while other categories of participants were underrepresented. It was not necessary to implement any such exclusionary requirements, however, as participant recruitment progressed naturally and with appropriate diversity of participant characteristics, locations and ages represented. No participants volunteered for this study who were from non-English speaking backgrounds.

**Sample Size.** No formulas currently exist to calculate adequacy of sample size in qualitative descriptive research, however, when data collected from participants ceases to reveal new information and the majority of potential participants have been interviewed, saturation is assumed to be achieved (Creswell, 2007; Sandelowski, 1995). The goal of a qualitative descriptive study is to accurately describe the experiences of participants in a complex or unique situation (Sullivan-Bolyai, et al., 2005) which requires reaching data saturation as described above.

Twenty participants were recruited into the study. The proposed sample size for this study was 20-30 participants, however saturation was reached well before the 20th
participant was recruited. As such, recruitment stopped after the 20th participant was enrolled.

The estimated goal of 20-30 participants was consistent with qualitative descriptive research with family caregivers in other settings (Sullivan-Bolyai, Knafl, Tamborlane & Grey, 2004; Funk, Allan & Stajduhar, 2009; Nusbaum, et al., 2008). Sample size varies widely across qualitative descriptive studies and ranges from <10 participants to >50 participants (Sandelowski, 1995; Sullivan-Bolyai, et al., 2005).

Procedures

Participant Recruitment.

Source of participants and recruitment methods. Participants were recruited from the following locations:

1. Community settings in both urban and suburban locations. Recruitment outreach locations included support groups for caregivers of persons with dementia, senior centers, local churches, care managers and individuals referred by professional caregivers or personal acquaintances of other participants or the researcher.

2. Two ALFs with designated Memory Support Units for residents with dementia. One ALF was in an urban location, the other suburban.

3. Two nursing homes, one urban, one suburban, with dementia special care units.

Recruitment strategies.

1. Following IRB approval, an introductory letter outlining study purpose
was sent to the administrative directors of each community organization, ALF or NH chosen for inclusion the study.

2. Flyers were posted in approved locations at the NHs and ALFs and senior centers.

3. IRB-approved flyers or letters of introduction were included in family news newsletters when facility administrators requested that mode of recruitment be used.

4. When approved by facility directors, an information table, with flyers and informational cards was set up at several facilities during visiting hours.

*Plans for including diversity in sample.* In keeping with the tenets of qualitative descriptive research and using purposive, maximum variation sampling, I focused on obtaining analytically rich information from a group of participants representing all socioeconomic, ethnic and racial groups in the geographic area selected for the study (Sandelowski, 1995). Recruitment sites included those accepting private (cash) payment, public funding and private insurance. Sites were located in ethnically and racially diverse areas of geographical region chosen (see Table 1). Although the recruitment sites reflected a potentially racially diverse population, racial minorities were under-represented in the recruited sample. Efforts were made to address this issue by talking to on-site staff about additional ways to recruit participants groups that are not well-represented, however the final sample did not reflect a racially diverse population.
Table 1: Census Data for Participant Sample

<table>
<thead>
<tr>
<th>Race</th>
<th>County #1</th>
<th>County #2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caucasian</td>
<td>67%</td>
<td>85%</td>
</tr>
<tr>
<td>African American</td>
<td>23%</td>
<td>4.5%</td>
</tr>
<tr>
<td>Hispanic</td>
<td>18%</td>
<td>6%</td>
</tr>
<tr>
<td>Asian</td>
<td>8%</td>
<td>9%</td>
</tr>
<tr>
<td>Multiracial</td>
<td>1.7%</td>
<td>1.5%</td>
</tr>
<tr>
<td>Native American</td>
<td>&lt;1%</td>
<td>&lt;1%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Income</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Median income of taxpayers</td>
<td>$59,496</td>
<td>$78,040</td>
</tr>
</tbody>
</table>

(U.S. Census Bureau, 2010)

Human Subjects Research

Enrollment and informed consent procedures. Individuals who expressed interest in participating in the research study were given an opportunity to set up an appointment at the location and time of their choosing. Individuals contacted me either by using the cell phone number provided on the flyers and in the informational letter or via the Boston College email address provided on the research flyers.

At each appointment, I reviewed and explained the details of the research project, the purpose of the research and the informed consent. Participants were given the opportunity to ask questions about the research in order to ensure that they were able to make an informed decision about whether to pursue enrollment. Following review of the informed consent, I gave each eligible participant the opportunity to either 1) sign the
consent at that time and proceed with the interview, 2) sign the consent and set up a future time for the interview, or 3) take a copy of the consent, along with my phone number and contemplate the decision to enroll. Eligible participants who elected to defer enrollment after obtaining introductory material were be asked to notify me by phone or email when a decision had been made. No data collection occurred until the informed consent had been signed. Each participant was given a copy of his/her signed informed consents unless the participant indicated that he/she stated that a copy of the informed consent was not desired.

**Protection of participants.** The greatest risk to participants involved in any interview research is related to confidentiality. Numerous safety measures were put in place in this study in order to protect participants. All participants were asked to select a pseudonym for use through the audiotaped interview. Pseudonyms were also selected by the participants for other persons mentioned during the interview to ensure that identities of all parties were protected. Any names inadvertently used during the interview were deleted from the transcribed document and the chosen pseudonym was inserted prior to transcription. The same technique was used to replace names of facilities and individual HCPs. All data was be reported as group data in order to ensure confidentiality of participants.

All risks involved in this project were psychosocial in nature. No study related interventions took place. The only foreseeable risk or discomfort for participants that was identified prior to recruitment related to each participant's level of comfort in disclosing perceptions, beliefs or ideas related to interactions with HCPs. All participants
had the opportunity to revoke consent or terminate the interview at any time. No participants chose to do so. Each participant was also given the opportunity to review the transcript of his/her own interview prior to data analysis. Participants who chose to receive transcripts were sent copies of the transcript via the mechanism of their choosing (email or via the postal service). Transcripts sent had been de-identified prior to release. No participants expressed a belief that his/her statements had been inaccurately depicted, however in the event that such a situation had arisen, the identified statements would have been either stricken from the transcript or revised according to participant directive/explanation.

Data Collection

Method. The primary procedure for collecting data was a single, audiotaped, semi-structured interview. Interviews took place at a location of the participant’s choosing. Participants were told during the initial contact that interviews were anticipated to last no longer than one hour. Actual interviews ranged in time from 35 minutes to just over 3 hours. Participants whose interview exceeded the one-hour projected time limit were given the opportunity to either continue with the interview, terminate the interview or continue it at another time. No participants elected to stop the interview prior to completion. Had any participant chosen to stop the interview prior to completion, information gleaned from the partial interview would have been included in research findings unless the participant revoked consent to do so.

The topic area of the interview was discussion of what constituted a meaningful caregiver-health care provider interaction from the perspective of the participant.
Subtopics included strategies that family caregivers used to obtain needed information in order to manage the uncertainty of caring for a loved one with a life limiting illness (specifically moderate to advanced dementia). An interview guide was constructed prior to IRB submission and included direct questions and probes (see Appendix A). Participants were also asked to complete a brief demographic form (see Appendix B).

Field notes were recorded within two hours of each interview. The purpose of field notes was to ensure that non-verbal behaviors and observations were accurately and promptly recorded (Miles & Huberman, 1994). I recorded times and dates of all field notes to ensure accuracy of the audit trail.

In keeping with the qualitative descriptive method, participant exemplars were included in data analysis to depict the caregiver experience. The goal of using participant exemplars was to capture the experience of caregivers through use their own words.

Use of semi structured interviews, observational data and participant exemplars allow context-specific facts and meaning about interactions with HCPs to be described from the perspectives of the participants. Each of the techniques used is congruent with the overall goal of qualitative descriptive research (Denzin and Lincoln, 2005, Sandelowski, 2000, Sullivan-Bolyai, et al., 2005).

**Location.** Interviews took place at a location of the participant's choosing. Locations chosen by participants for interviews included participant homes, residential facilities at which the PWD resided and churches.

**Data Analysis.** I transcribed several of the interview audiotapes, however the majority of audiotapes were transcribed by a HIPAA-certified data transcriptionist. Data analysis
began immediately after transcription had occurred or was received. Analysis continued to occur simultaneously as additional interviews occurred to ensure that the compilation of data was inclusive of newly emerging information. The need for interview questions to be modified did not arise. In keeping with tenets of qualitative description, however, interview questions were reviewed as interviews progressed to determine whether modification of questions was needed for purposes of clarity, comprehension or completeness (Lincoln and Guba, 1985; Sandelowski, 2000; Sullivan-Bolyai, et al., 2005).

Transcribed interviews were analyzed using conventional content analysis as described by Hsieh & Shannon (2005). Conventional content analysis is an analytic technique used in qualitative descriptive design to allow the words of the participants to emerge along with the context in which those words were spoken. Each transcript was read in its entirety prior to the coding process. The transcript was subsequently divided into specific sections according to the question being addressed. Recurrent words, phrases and identified feelings were identified, marked in the transcript and assigned in-vivo codes (Hsieh & Shannon, 2005). A list of in-vivo codes and their definitions was constructed initially and documented in a codebook. Codes and definitions were followed by lists of categories and themes.

As the number of completed interviews increased, initial codes were changed, as needed, to reflect additional meaning or to increase clarity. An audit trail was be kept to document the rationale and timing of each recoding event. After coding was completed, data from all interviews was grouped into broad categories that reflected the attributes of
each coded group. Categories are specific attributes or items of data (Graneheim & Lundmen, 2005). Categories, themselves were not mutually exclusive, therefore coded data occasionally appeared in several different categories during the process of analysis. As codes and categories were studied, patterns describing participants' experiences were identified and described. Patterns are pieces of information that appear, often across categories (Creswell, 2007). Themes are broad unifying ideas or issues (Creswell, 2007). The themes and patterns that emerged served as the reportable data that gives voice to the experience of the participants (Graneheim & Lundmen, 2005; Sandelowski, 2000).

Concepts and themes that flowed through the data were reported as group data or commonalities in order to preserve anonymity of participants and study sites. In order to accurately represent the participants’ experiences, however, recurring words and phrases used by individual participants were reported with minimal interpretation or explanation by the researcher (Milne & Oberle, 2005; Sandelowski, 2000). Describing participant experiences with minimal interpretation was consistent with studies using a qualitative descriptive design (Sandelowski, 2000).

**Rigor.** The goal of qualitative descriptive research is to achieve both descriptive and interpretive validity. Descriptive validity, the accuracy with which the words of the participants are accurately reported was assured through use of the audiotaped interview process, verbatim transcription and the use of recorded field notes. Interpretive validity, the accuracy of the meaning attributed to the words of participants, was assured by including examples of actual words or phrases of participants when interpretations were
are made and through use of independent data monitoring by members of my dissertation committee (Sandelowski, 2000; Whittemore, Chase and Mandle, 2001).

I adhered to qualitative rigor techniques outlined by Lincoln and Guba (1985), Sandelowski (2000) and Whittemore and colleagues (2001) to ensure that standards of credibility, transferability, dependability, and confirmability were maintained. While my role as researcher included occasionally providing guidance during the interview to ensure return to the original question if needed, the participants were allowed to explore their thoughts with minimal constraint (Whittemore, et al., 2001).

Credibility and authenticity are measures of descriptive validity that refer to the "truth" or accuracy with which participant data is interpreted and represented in the findings of the study. Authentic representation of participant words was achieved through inclusion of direct quotes when appropriate, portrayal of participant perspectives and adherence to a technique of minimal intrusion into participant relaying of events, thoughts or perspectives. Two methods were used to address credibility and authenticity of findings: member checking and independent monitoring of data. I used member checking to give participants an opportunity to review my findings and to determine whether their words and experiences were represented accurately in the data. I reviewed analysis with members of my dissertation committee to ensure that my findings were theoretically valid (Lincoln & Guba, 1985; Whittemore, et al., 2001).

Transferability, the likelihood that data would be applicable in other contextually similar situations, was addressed through inclusion of both demographically and ethnically representative participants in the sample (Lincoln & Guba, 1985).
Demographic characteristics of the sample were obtained through completion by participants of a brief demographic survey to ensure that anyone reviewing the data seeking to apply findings to similar participant groups had an accurate understanding of the context and characteristics of the sample and settings in which the study occurred.

Dependability and confirmability were be addressed through a dated audit trail of all field notes, in-vivo coding and thematic coding, and establishment of referential adequacy of the data with concepts/themes. Additionally, expert checking occurred through independent review by my dissertation committee of coding process and findings (Lincoln & Guba, 1985).

Summary. The research method of qualitative description was chosen to describe interactions with HCPs that were identified as meaningful by family caregivers of persons with moderate to advanced dementia. The purpose of using qualitative description was to ensure that allegiance was given to facts, participants' words and meaning. Minimal interpretation was used in data analysis. Participants were self-selected family caregivers of persons with moderate to advanced dementia. Maximum variation sampling strategies were employed to ensure that a diverse sample was recruited.

Audiotaped, semi-structured interviews were used as a primary method of data collection. Data was analyzed according to conventional content analysis techniques with attention to standards of internal and descriptive validity.
CHAPTER FOUR

Results

In this chapter, I describe family caregivers’ accounts of meaningful experiences interacting with and obtaining knowledge from health care providers (HCPs) about treatment and care of loved ones with dementia. Meaningful interactions, whether perceived by participants as positive or negative, were described by self-identified family members of persons with moderate to severe dementia (PWD). The experiences they chose to share crossed the trajectory of illness, from the time of diagnosis to impending death. Pivotal interactions for caregivers occurred around issues of diagnosis, resources, and end-of-life decision making, but also when discussing the more mundane aspects of managing day-to-day life. Meaningful moments occurred in community-based physicians offices, non-profit community organizations, private homes, hospitals and in long term care (LTC) facilities. Regardless of setting, type of provider, stage of illness or outcome, the emotional valence attached to each of these experiences was significant and powerful. This was evidenced by the longevity of memories of events that had occurred earlier in time and the fervor with which participants shared their stories. Their recommendations for ways that HCPs can better serve caregivers going forward were insightful, thoughtfully stated and based on what mattered to them in their own stories.

Four central themes were found that described participants’ stories. Those themes, along with their respective subthemes, provided insight into the experiences of participants and helped to answer the questions outlined in Chapter 1. Overarching
themes were organized according to the paths followed by many participants as they became involved in the caregiving role and interacted with HCPs of PWD.

The caregiver experience of interacting with HCPs of PWD often began in either a primary care office or an emergency room visit. From there, navigation of the health care system and caregiver attempts to create individualized, patient-centered care continued. Those experiences were captured in the theme "a broken health care system." Remaining themes centered around identification and location of resources, the presence or absence of partnerships with HCPs and communication of what family caregivers identified as important. Taken together or separately, the themes described illustrated pivotal moments in which nurses and other HCPs could impact the caregiver experience and positively affect caregiver well-being. In the final section of this chapter, participants made recommendations for improving the caregiver experience and for making the health care system more accommodating to PWD and their family members.

Contributions made by participants in this research study will increase HCPs’ collective awareness of what caregivers experience as meaningful, illuminate ways in which nurses and other HCPs can support caregivers, and provide information to guide decision-making and foster health and well-being of caregivers and PWD. The identified themes and subthemes are:

I. A broken system of health care
   A. Realizing something is wrong: Experiences in outpatient care
   B. Going to the hospital
   C. Rules for many versus attention to specific, individualized care
D. Providers are not available to talk with me
E. How does anyone who isn't in the system do it?
F. We're all frustrated: Politics and policies
G. Summary

II. Looking for resources/ figuring it out

A. Formal Resources: looking to the professionals
   1. When a person with dementia goes to the hospital...
      a. Moments of crisis on geriatric psychiatry units
      b. Medical admissions
   2. What does get discussed in outpatient HCP offices?
   3. It all depends...finding information in long term care.
   4. The Alzheimer's Association--it's awesome.

B. Informal resources
   1. Friends/ family/ lay persons in the community
   2. Technology and literature
   3. Additional options

III. The Importance of Partnership

A. Provider availability and accessibility
B. Interactive and respectful dialogue
C. Mutual goal setting

IV. Knowing what matters and retaining personhood

A. Know my person
B. Show me my person matters
C. Know what is important to me ...Include me.
D. Keep the PWD at the center
E. Summary

V. How Providers Can Help

A. Provide support and education to prepare caregivers for their Roles
B. Improve communication between HCPs and caregivers
C. Take ownership of your roles as professionals
D. Use best business practices to develop better customer service

Participant Demographics

The participants in this study were recruited from two nursing homes, two Memory Care Assisted Living Units, and community settings. The characteristics of the sample are outlined in Table 2, while the characteristics of their respective loved ones with dementia are outlined in Table 3.
Table 2. Participant Demographics

<table>
<thead>
<tr>
<th>Gender of Participant/ Relationship to PWD</th>
<th>N=20</th>
<th>Percent of Sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>4</td>
<td>20%</td>
</tr>
<tr>
<td>Husband</td>
<td>2</td>
<td>10%</td>
</tr>
<tr>
<td>Son</td>
<td>2</td>
<td>10%</td>
</tr>
<tr>
<td>Female</td>
<td>16</td>
<td>80%</td>
</tr>
<tr>
<td>Wife</td>
<td>3</td>
<td>15%</td>
</tr>
<tr>
<td>Daughter</td>
<td>10</td>
<td>50%</td>
</tr>
<tr>
<td>Daughter-in-law</td>
<td>2</td>
<td>10%</td>
</tr>
<tr>
<td>Sister-in-law</td>
<td>1</td>
<td>5%</td>
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<tr>
<td>Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>20-40</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td>41-60</td>
<td>11</td>
<td>55%</td>
</tr>
<tr>
<td>61-80</td>
<td>5</td>
<td>25%</td>
</tr>
<tr>
<td>81+</td>
<td>4</td>
<td>20%</td>
</tr>
<tr>
<td>Background in health care</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>6</td>
<td>30%</td>
</tr>
<tr>
<td>No</td>
<td>14</td>
<td>70%</td>
</tr>
</tbody>
</table>
### Table 3. Characteristics of the PWD

<table>
<thead>
<tr>
<th>Characteristics of the PWD</th>
<th>N = 20</th>
<th>Percent of Sample</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Living Situation</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Memory Care Assisted Living</td>
<td>8</td>
<td>40%</td>
</tr>
<tr>
<td>Nursing Home</td>
<td>9</td>
<td>45%</td>
</tr>
<tr>
<td>Community Dwellers</td>
<td>3</td>
<td>15%</td>
</tr>
<tr>
<td><strong>PWD/ Experience with HCP</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychiatrist</td>
<td>1</td>
<td>5%</td>
</tr>
<tr>
<td>Geriatric Psychiatrist</td>
<td>11</td>
<td>55%</td>
</tr>
<tr>
<td>Primary Care Physician</td>
<td>20</td>
<td>100%</td>
</tr>
<tr>
<td>Nurse Practitioner</td>
<td>4</td>
<td>20%</td>
</tr>
<tr>
<td>Nurses</td>
<td>20</td>
<td>100%</td>
</tr>
<tr>
<td>Social Workers</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>7</td>
<td>35%</td>
</tr>
<tr>
<td><strong>Global Deterioration Scale Score</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Moderate</td>
<td>7</td>
<td>35%</td>
</tr>
<tr>
<td>Moderate-Severe</td>
<td>7</td>
<td>35%</td>
</tr>
<tr>
<td>Severe</td>
<td>6</td>
<td>30%</td>
</tr>
<tr>
<td><strong>Recent Hospitalizations</strong></td>
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<td>Once in last 7-12 months</td>
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<td>Once in last 3-6 months</td>
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<td>Multiple hospitalizations in the last year</td>
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A broken system of healthcare

“A broken system of health care” describes challenges faced by participants as they negotiated a health care system that they deemed ill-prepared to facilitate well-being and quality of life for either the PWD or their caregivers. Interactions with HCPs of PWD within the health care system were, by extension, often difficult and unsatisfying. Struggles with communication occurred between caregivers of PWD and HCPs, between concurrent HCPs providing treatment and across inpatient and outpatient settings. The disconnect and frustration associated with communication issues, coupled with confusion about available resources and poor organization was captured in the theme about a broken system of health care that was difficult to negotiate, had limited practicality and was at times, obstructive for PWD and their caregivers. Participants described efforts to ensure that their voices were heard, that needed resources were identified and obtained, that pertinent information was disclosed to other HCPs, family members and the PWD (when appropriate) and that the wishes of the PWD were honored.

Realizing something is wrong: Experiences in outpatient care. When asked to reflect on meaningful interactions with HCPs, most participants returned to a time before the PWD received an actual diagnosis. Participants described moments of concern and suspicion that a cognitive problem existed and recalled moments of looking to outpatient physicians, in particular, for guidance. Attempts to engage physicians in conversations about perceived cognitive issues with a loved one often resulted in being turned away or ignored. Some participants who spoke of the experience voiced awareness of the conflicting push-pull for HCPs who had to balance patients' rights of
self-determination, reasoning and autonomy with the needs of the caregivers, themselves. Participant's voices and choice of words often denoted understanding or awareness of ethical and systemic challenges faced by the physicians involved, however the tones and gestures used also conveyed frustration and overt anger about feeling unheard and dismissed. The anger that emerged was directed at the system of health care and also aimed at providers within that system. In the following examples, both “Aubrey,” the daughter of a resident in a Nursing Home and “Meeker,” whose mother was in Memory Care Assisted Living discussed attempts to have conversations about their respective mothers with primary care physicians:

“I had contacted her first primary care physician who she loved. I told him that I was concerned...that I thought she was having memory issues. He pretty much shut me down...I would have thought that if there was a change in her baseline, he would at least be willing to talk to me about it. He was just... I considered him a nasty SOB.”

–Aubrey

“Her primary care physician was obstructive. He would not listen to us. I mean every time we called him with an issue or went with her to an appointment and expressed concerns about her memory he kept blowing us off. .. every time we said something and asked for something he was a day late and a dollar short and (then) something happened in the interim (a car accident)... It wasn't until they sent him that (evaluation of her driving) and listed all of her deficits...that he even considered that she might have some problems.”

–Meeker

The challenges faced by Aubrey and Meeker as they attempted to obtain guidance from their parents' respective physicians offers a glimpse into the caregiver experience as they begin to negotiate and interact with providers around the care of a PWD. Many participants in similar situations demonstrated a strong awareness and moral sensitivity about the need of HCPs to protect and honor individuals' rights to privacy, however
concerns about issues of safety and well-being of the identified PWD often led to exasperation and intense distress.

After a diagnosis of cognitive impairment had been confirmed, asking outpatient HCPs to communicate the diagnosis to the PWD was often equally problematic. In the following example, “Malala,” the daughter of a person living in Memory Care Assisted Living, reflected on the experience of attempting to have the diagnosis disclosed to her mother by a primary care physician (PCP) and provided observations about what would have been helpful:

"We actually had to fight with the PCP and say somebody has to tell her that she has been diagnosed with Alzheimer's. This is absolutely ridiculous...I think it would have been helpful to first of all if he described to her that she had Alzheimer's, that she had mild to moderate or whatever he was deciding she had. And how that could show up in her everyday life, which would have been helpful to her, not that she would necessarily remember. But it would certainly have been helpful to us to know what that means. There's all sorts of things beyond not remembering. I mean there's perception issues and all these other things that you never hear about until someone thinks to tell you that."

--Malala

As with "Malala," "Sky" emphasized the importance of disclosing the diagnosis of Alzheimer's disease and having conversation about its meaning, but added an additional layer of insight as she described the actual tone and manner in which the diagnosis was conveyed to her father. In the example below, she described the concise and impersonal tone used by the HCP and the manner with which the diagnosis of Alzheimer's disease was communicated, accentuating her words of “straight out” by using her hand to make a horizontal slash through the air. As she contrasted that initial experience with a subsequent interaction, she noted that the difference in style and manner in the second interaction allowed for a more personable, interactive discussion.
The first time I saw him, I thought he was kind of like straight out, well...I’m just thinking as a receiver of his care, from looking at it from my father’s point of view...I thought he was kind of like straight out, well, this is the results...

But then we saw him again a couple months later, six months or so. He was (using a) totally different approach...Where before, he was like, he was the researcher or the practitioner who was trying to diagnose or give results, now he was in a different role. But this time, it was OK, this is the situation, let’s deal with it. And he seemed to do a lot better job." —Sky

The descriptions and observations of physicians asked to convey a dementia diagnosis and convey its meaning offer clear insight into why caregivers may characterize the system as "broken." The importance and meaning attached to the moment that an individual is given a diagnosis and the need for HCPs to be present and emotionally supportive was clearly articulated by participants in this study. Specific words spoken and the interactional style of HCP's stood out as meaningful moments in the caregiver experience.

As time passed and cognitive and functional impairment of the PWD progressed, meaningful HCP interactions identified by participants continued to center on specific issues that impacted autonomy of the PWD. Limitations on driving, with a literal and figurative link to independence, were singularly problematic and emerged from multiple interviews. Described by one participant as what her mother (the PWD) saw as "the beginning of everything being taken away," the discussion of safety and driving was a moment in which some participants reached out to HCPs for guidance and help in communicating and strategizing about their concerns. As with the issues of diagnosis and disclosure, participants often expressed frustration with the interactions they had with HCPs about the driving issue. Physicians were perceived as being resistant to engaging
other professionals or organizations within the broader health care system who could be helpful (e.g., an occupational therapist (OT) or community organization). Reasons for that perceived resistance were unclear. The two participants whose words are shared below were particularly animated in both their facial expressions and the volume and tone of their voices. “Emery” succeeded after multiple attempts with what she described as a "cowardly" primary care physician, in getting a driving test ordered for her mother. As she emphatically relayed the tale, she pushed her hands away from the table and in a sarcastic, but almost crowing tone, described the outcome.

“...(we were) expressing concerns about her driving and so he (the primary care physician) asked both of them (her sisters), 'Have you driven with her lately?' And they both had to say 'no' because we all drive... we wouldn't let her drive anymore. And I said, 'as a matter of fact I have, I said. She ran through a stop sign cutting off another car and never knew they were there.' He said, 'oh, all right, then we'll order a driving test for her...' She flunked it gloriously. Like totally bombed it and all of a sudden we had a little more credibility."

–Emery

“Susan” described a similar situation and clearly conveyed her disgust when she explained that she had asked multiple providers to participate in discussion with her father about the driving issue. Both a neurologist and a primary care physician (PCP) refused to intervene. While Susan acknowledged that HCPs may have limitations in either skill set or comfort level around various issues, she thrust her hand forward and shook her head from side to side, alluding to what she perceived as HCPs who fail to accept professional responsibility to either intervene or refer to an appropriate specialist. Susan explained:

"the neurologist said he would recommend not driving, but that he wasn’t going to say (to my father): ‘I’m not going to tell you you can’t drive, but I would recommend that you not drive. But it’s up to you. That’s what I don’t get. And
The difficulty in addressing issues related to independence and autonomy of the PWD was evident across many interviews. Examples given once again highlight caregivers' awareness of the ethical magnitude of intervening and potentially changing the life of the PWD. They voice a need, however, for HCPs to be willing and able to either assist in such difficult conversations or be able to offer outside resources to address these emotionally difficult issues. Awareness of the all-too-human limitations of HCPs did little to minimize some participants' distress. Participants voiced awareness that the health care system, in this case, provided alternatives that could be accessed, but perceived physicians as resistant to intervening.

**Going to the hospital.** Over the course of time and progression of illness, many PWD required hospitalization for medical treatment. From participants’ perspectives, acute care hospitalization of a PWD carried its own set of challenges. Trips to the emergency room, surgical procedures and medical admissions were perceived as wreaking havoc on well-being, coping and functionality of both the PWD and being emotionally taxing for their respective caregivers. Contributing to the chaos and firmly embedded in this aspect of the caregiving experience were problems identifying and obtaining clarity about HCP roles, lack of education and training of HCPs working with PWD in acute care settings, difficulty sharing and obtaining information across the hospital system, and angst and frustration caused by perceived lack of follow-through of HCPs on pertinent issues.
Challenges with obtaining information and clarity around roles of HCPs were identified by “Meeker.” HCPs often failed to introduce themselves, she explained, leaving her to guess at individual roles. She alluded to being in plain sight in her mother’s room, watching providers come and go, yet rarely did they engage her in conversation. The confusion and isolation added an additional of complexity to an already difficult situation.

*I couldn't even tell who the nurses were. That's the other thing is that no one ever tells you who any of those people are. ... That is true no matter where you go. ... And the nametags are all very small and then they all have the little white boards, but they don't keep the white boards up. So, it says that the nurse is Bob, but then this woman walks in and like OK, so that's not Bob. ... You're never sure who these people are. You're never sure who is the appropriate person to ask anything. -- Meeker*

Lack of education of HCPs across the system appeared in another illustration of the challenges encountered by PWDs and their caregivers, "Emery" describes admitting her mother to the hospital for a surgical procedure. After arriving at the hospital on the morning of surgery to accompany her mother to the perioperative area, she noted that the nurses assigned to provide care for her mother seemed to lack appreciable understanding of the limitations that accompany a diagnosis of even moderate dementia. Pre-operative and post-operative checklists, questions, teaching and evaluation all require patients to participate and understand directions. “Emery” paraphrased her conversation with one of the peri-operative nurses:

"... She's not a reliable reporter anymore. ... She's not going to press that little button because she's not going to feel pain and besides she can't even read the little button because it's so small and she has to get out of the bed practically to reach the little button. ...And she's not going to remember there is a little button. ...And they just keep repeating to us oh, well, we'll teach her how to press the little button. I'm like no, the little button is...like that's not a viable... Then we go down
to the pre-op and the nurse says to me “has she eaten this morning?” I said I have no idea. You should know that. So, she says to Mom, have you eaten? I said, “You cannot ask my mother if she's eaten this morning. You have to find out from someone else.” That's really serious. Even I know that you can't do surgery on someone who's eaten. ... And they do that all the time. They ask some really important medically significant questions and it's like what don't you get?"

--Emery

While many aspects of the caregiver experience were laden with challenges, participants in this study specifically indicated that their own levels of anxiety and challenges related to communication increased during hospitalizations and in moments of transition between the hospital and the next level of care. Follow-through by HCPs on paperwork and plan of care in these instances were particularly important.

For Susan, the fact that her father had a Do-Not- Resuscitate (DNR) order became an issue during the bookended experience between an emergency room visit, hospitalization admission and subsequent trip to a short term rehabilitation center. As Susan reflected back on the experience, she shared that the DNR status was a priority because she knew that it was something that she knew that her dad had chosen. Honoring her father’s wishes remained at the forefront of her mind through the hospitalization. The challenges with ensuring that the DNR status was shared amongst providers, coupled with what seemed to Susan to be extraordinary lapses in provision of care made trusting HCPs within the health care system difficult. Susan explained:

"First, he’s seen by an emergency room doctor, who doesn’t know him, has never seen him before...I said I want you to know I know my dad’s not very ill right now, but I want you to know that he’s a do not resuscitate. And the nurse said OK. And then, (I) come back later and the doctor’s explaining the test. I said, “did the nurse mention that my dad’s do not resuscitate?” “No, she didn’t.” And I said well, this has been his choice all along. He has a living will. I’m his health care proxy already. And he said “well, that’s something that you need to deal with with the primary care.”... So the nurse calls the primary care doctor."
And...someone in the office said, he’s in the emergency room, why would I be dealing with this? So then it got back to the emergency room doctor. So by that time, oh, we have a bed ready. We’re taking him upstairs so the doctor on the floor can make him a DNR. It’s like no one wants this, nobody wants to take responsibility for this.”

Susan’s difficulties continued as she accompanied her father to a medical floor.

She described attempts to be patient and work with the system as the next day passed:

"And so, the next day, I took off work. I went to the hospital. I waited for the doctor to come in, starting at like 7:30, 8:00 in the morning. No, I called at 7:30 or 8:00, and the nurse said the doctor’s not in yet. She may not see your dad for another hour or two. So that morning I didn’t go in early, but I was there probably by nine. And waited for the doctor to come. The nurse that was taking care of him said yeah, I don’t know why he isn’t here. [LAUGHTER] So I waited. I waited till 2:00 pm. I was patient. I was patient... So the PCP had said if you ever need me for anything, even if he’s in the hospital, give me a call. So I called the office. And I knew, I was like, I was mad at this point. And I said I need some help. I said my dad’s in the hospital. He has an infection in his blood, and he has not yet been seen by a doctor since he was admitted from the emergency room yesterday afternoon at 4:00 pm. And it’s now 2:00 pm. So you can see how this all played out. The charge nurse and the hospitalist come like storming down the hall..”

And at the end of that hospitalization, Susan’s father was readied for discharge to a short term rehabilitation center:

"And I said he’s a do not resuscitate. And they looked at the paperwork and they said oh, no, this isn’t dated by the doctor... My dad’s on a stretcher in the hallway, like all bundled up. It’s not good? Like this is the one that I had to go through the ER doctor, the PCP, the hospitalist. Are you kidding me? So then, the nurse said well, the doctor’s already wrote the discharge orders, I’m not sure where he is. And I’m like well, I think you should find out where he is...”

Challenges of the hospital environment, from admission to discharge, added to the stress level of already-taxied caregivers. Moments that stood out for participants of hospitalized PWD were those in which the hospital system and the providers within that system failed in some way to provide clarity or assurance that they and their respective loved ones were in good hands. Whether the issue was lack of clarity of role, confusion
about plan of care, education of staff, attendance and attentiveness of providers or transmission of information, caregivers were left with uncertainty and felt a need to advocate for what they perceived to be acceptable levels of care of their loved ones.

**Rules for the many versus attention to specific, individualized care.** In both inpatient and outpatient situations, participants shared frustration with what they perceived as failure of HCPs to see the “big picture” of care for PWD. Instead, they explained, HCPs operating within the system appeared to be performing tasks that were dictated by rules governing delivery of care rather than what made sense for the PWD. Often highlighted was the importance of HCPs incorporating knowledge and education about day-to-day realities associated with the illness. For caregivers, a practical approach based on what made sense for a particular PWD was identified as their criteria for good care (patient-centered care).

“Reagan,” whose wife was in the final stage of dementia in a home setting, explained that even when someone has an advanced dementia, the list of “to do” items followed by HCPs in the name of evidence-based practice presents challenges. In the exemplar below, he shared the story of attempting to get antibiotics for his (incontinent) wife, who was believed to have a urinary tract infection. He went on to explain that the measure of what constitutes excellent care should be centered on what makes sense in the real world of the PWD, not the evaluation that may occur by regulatory bodies or is listed in a medical textbook.

“*You feel like a number...They (the PCP’s office staff) are saying, we are not going to give her any drugs. I am saying, she’s dying. You are not going to give me any Bactrim to treat a UTI because I can’t get a urine sample? (And other things...) They are telling me I’ve got to go get a mammogram, an annual*
mammogram. I’m saying, that’s stupid. They are treating me like I am a bad caregiver because I won’t do it. Three years ago, they wanted to do a colonoscopy and I am like, why? They just have a checklist that they have to do. I get that they are probably worried about liability because, you know... I don’t mean that they are doing this in a mean kind of spirited way. It’s just that they are not educated. They don’t have a clue. —Reagan

"Emery," who shared responsibility of decision-making and caring for her mother with two sisters, also pointed out the need for a straightforward approach toward actions and practice in many HCPs' offices. She alluded to one specific daily practice that is commonplace in many outpatient offices as an example: making reminder calls about upcoming appointments. Directives for office staff, she explained, were put in place with the presumption that the person on the receiving end of the reminder call was cognitively intact and able to plan and execute a plan for arrival at the designated location. Such calls, when placed to the identified “patient” (the PWD) were less than helpful for PWD and their families.

In the example that follows, an appointment had been scheduled for Emery's mother at an outpatient PCP's office. Transportation was arranged and a patient advocate procured to accompany her mother to the appointment. Upon arrival, it was discovered that the appointment time had been changed. Emery's mother had received the reminder call from the PCP's office and indicated that the appointment could not be kept.

"In the medical world what happens is they called her and said we need to change your appointment. They did but she didn't remember and of course she didn't tell us. It's almost impossible to get them to change that....They were calling her right before we moved her here (to an ALF) even though she was diagnosed with Alzheimer’s... despite the fact that she signed forms giving us permission to access to everything. And that they had been specifically told not to call her and to call (my sister) because she was the closest."

--Emery
The examples provided by participants of ways in which the health care system is built around rules for the many rather than attention to specific individual needs spanned settings from outpatient care to end-of-life care for PWD in nursing homes. Caregivers often acknowledged that "rules" or "lists" were put in place to promote standardized, safe and effective care for the majority of consumers, but explained that rigidity around those "rules" often led to challenges and moments that seemed contradictory to what was best practice for PWD.

"Sam" shared the following offering about negotiation of end-of-life care for her mother in a nursing home following a “comfort measures only” directive:

"...I went to them and said, do you have anything else to offer? I said, if there’s nothing else to offer, then I want her placed in palliative care. In a meeting, they would say it (that the goal was palliative care), but then executing it was a whole different ballgame... So I signed all the paperwork... Come to find out that then they did a chest X-ray on her. And I said, “time out.” Why did we do a chest X-ray on her? What was that going to (do) then? (That’s) going to put the onus on me to decide what to do, I said, and that is what you’re doing. It’s not fair. You’re making me make these decisions. I got resentful that I was the one being forced to make these decisions...I actually said in a team meeting, these are not my wishes. These are my mother’s. It’s not on me. It’s on my mom. It’s my job to fulfill them, is what I said to them on that Thursday. I said, these are her wishes, not mine. So don’t put it on me." —Sam

Sam continued to describe meeting with HCPs involved in her mother's care:

"We did have a pretty awful interaction. I went there on Wednesday. And I asked for a family meeting on Thursday morning. And at that point, I knew that my mom was dying. I don't think everybody else there did. No one else believed me. ...There was not one shadow of a doubt in my mind. And the meeting started with the director of nursing telling me that the laws are different here in Ohio than they are in Massachusetts. And I said, what law are you referring to? She said, we cannot stop feeding people. We don’t stop feeding. I said, did anybody ask you to? I said, no one’s asked you to stop feeding her. I’ve asked you to stop force feeding her." —Sam
The specific knowledge of not only what was said and heard, but also that it was so etched in her memory that she recalled the specific day of the week that the events described above happened, was illustrative of the importance and stress that accompanies the role of caregiver for a PWD.

**Providers are not available to talk with me.** Participants spoke repeatedly about what they perceived to be a lack of time or availability that HCPs had to speak with them about their loved ones. Most often, comments referring to lack of time were made about physicians, however several participants also included nurses in their illustrations. Limited time during appointments with physicians to partially or fully answer questions, lack of availability of HCPs to return calls and connect during moments of crisis, reliance of physicians on nurses or other collateral providers to communicate information and limited time of nurses to talk with family caregivers all factored in to the overarching theme of "Providers are not available to talk with me."

In the first example of providers not having time, “Lucille,” whose husband had been diagnosed with Parkinson’s disease and later with Alzheimer’s, recalled a time when she and her husband were trying to understand a mental status change that had occurred. The issue at hand was one of recurrent and disturbing “bad dreams.” In recalling their struggle to actually get a clear response from an outpatient HCP, Lucille stated:

"They were bad dreams...People were trying to get him. People were going to shoot him. It was always something really traumatic. So once again, made a special trip to the neurologist to talk about this and whatever...He was too busy for us. And it's an awful thing to say, but he was. I was still asking questions as we were being led out to get the appointment for the next time. So I was very, very disappointed."

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Lucille
In a second example from outpatient care, the issue was one of getting in touch with a HCP during a time of crisis. "Reagan" described a great deal of anxiety and fast-approaching panic, when he shared the following experience related to an escalation in his wife's difficult behaviors and his perceived lack of good and timely responses from a neurologist:

(\textit{The neurologist} is running all around the globe... and we are here and we are starting to experience behavioral issues, agitation. I am reading all of these books and everything on what to do.... There is nobody to talk to. I think the wheels are falling off and I am like, holy shit. I'm worried that caregivers are going to quit. I'm trying to run a company. I was scared, freaking out... we were in a crisis mode. (The Neurologist) finally calls me and I was riding my bike home. I still remember it. It was like, thank God you called, what are we going to do... that lapse was bad. We were not getting the care we deserved and needed.

—Reagan

Reagan had a carefully structured and exquisitely designed plan of care for himself and his still-young wife. His ongoing attempts to problem-solve around issues of home care were coupled with daily stressors of work, extended family and trying to care for himself. Reagan reached a self-described, near-breaking point when behavioral escalation added an additional layer of stress to the fragile ecosystem in which he lived and worked. The bicycle ride to and from work was what he described as a stress release, illustrating his attempts to multitask around issues of transportation, work and stress reduction. Reagan's need to be able to connect with the designated provider during moments of extreme stress was clear, as evidenced his choice of words ("the wheels are falling off") and by the fact that he answered his cell phone during his bicycle ride home from work. During the telling of this exemplar, Reagan's hands moved from a resting position to one in which his upturned hands reached out, open-fingered in front of him, while his body
leaned forward toward the interviewer. The physical gestures augmented Reagan's words, adding emphasis to the impact his story.

Moving into the hospital setting, participants fared no better. Susan, recalled one hospital admission and spoke of waiting almost 24 hours to see a hospitalist. When the hospitalist arrived, Susan stated....

"Her whole song and dance to me was you don’t know how many patients I have. I have 20 patients. I looked at your dad’s lab. I knew what was going on, and I prioritized, and I could not get to your dad yet. I had other, sicker people. And I said, I understand you might have 20 people to see, but my concern is my dad, and I want you to talk to me about my dad. And I said, you have to change the hospitalist system..."

--Susan

In an equally frustrating experience, "Martha" described her husband's admission to a geriatric psychiatry unit and limited contact with either a psychiatrist or the nurses when she stated:

"I only sat in with him (the psychiatrist) at an original conference...The nursing staff were very helpful, but one couldn’t really one-on-one with them...but (they) were difficult to engage often, because there they were, dealing with medications. I know what demand that is, tremendous demand on their time."

And finally, as participants moved to long term care settings, statements such as "I never saw the doctor” were frequent. Some participants noted that the accuracy of information passed both to and from HCPs to caregivers suffered simply because of the frequency of handoffs. In the three examples that follow, participants shared their experiences about the lack of direct contact with physicians and the role of nurses as conduits of information:

"...(we) go to the nurses and say, what’s happening with this, what’s happening with this, is she on these medications, what are you doing about this, what are you doing about that. Then they would turn and they’d contact the doctor, and either the doctor would reply or the doctor wouldn’t reply, or we would get what we..."
wanted or we didn’t get what we wanted, or we would have to contact the doctor ourselves. There is definitely a disconnect, it’s almost like the telephone, you know that game, the Telephone Game? It all gets melted down the more you go from person to person to person.”

— Barb

"They don’t talk to me. Unless you push it. I mean, the nurse practitioner was very nice. I’ve never talked to a doctor here. I think what they try to do is they try to run it all through the staff. So the staff will call me up, say, by the way, the doctor saw your dad today, he said this, this, this, and this..."

— Stan

"We had, I did have a primary care there that was assigned because that was what the facility did. Never saw him, only talked to his staff via the phone,(they) really relied on the nurses at this facility to be the go-between there."

— Aubrey

The role of nurses, in addition to being conduits of information, seemed somewhat unclear to several participants. Silsbee, whose wife was in a nursing home, spoke of the aides as being the primary contacts of information and care. The nurses were identified only as "too busy." His tone, as he made the following statement, was quite matter-of-fact, as though the scenario he described was simply "the way it was."

"it's the aides. Actually, they're the ones actually taking care of her. The doctors, as I say....the nurses are too busy with other things to take care of an individual patient."

— Silsbee

Sam relayed a similar observation when sharing a story about her mother, who at the time, was residing in a nursing home. Sam, herself a nurse, spoke of the nurses working in long term care:

"aloof...they were kind enough to her...but I think they were all med pushers. I think that was a good portion of it...they were pushing meds.” — Sam

The perceived lack of time and availability of HCPs to meet with family caregivers was a theme that crossed many participants' stories. In outpatient care, the issue appeared most often as one of physician time during appointments or availability in
moments of crisis. The situation in both inpatient and long term care was even more widespread, with nurses, physicians and case managers all being cited as unavailable.

**How does anyone who isn’t in the system do it?** Five participants were professionals within the health care system. During interviews, those individuals neither alluded to the fact that they had more information than most lay caregivers or asked the question outright "how does anyone who isn't in health care do this?" In particular, participants were aware that their own comfort levels in dialoguing with (or challenging) medical professionals, knowledge of medical terminology, and familiarity with the way that the healthcare system worked provided them with additional knowledge that came from years of exposure. That self-awareness and the knowledge that because of familiarity with how the system works, they chose their words carefully, was expressed by Barb and Susan below:

"I can’t imagine these people who don’t have experience, don’t have medical knowledge, who may be ill, may be elderly themselves, how do they advocate for themselves? I don't know how they do it... as a nurse and as a pharmaceutical rep, I have been trained in the three Bs, be brief, be brilliant, be gone."

--Barb, RN

"I've worked in a hospital, I'm a nurse, I know I wasn’t being a pain in the ass. But this was my first time with really having this experience with him in the hospital. I'm obviously not a shrinking violet and I have experience, and for me, by the time I was talking to the doctor, I had tears in my eyes. You know what I mean? I was so angry... Then I started to question myself. I started to question myself."

--Susan, RN

Problems with navigation and structure of the health care system contributed to challenges for care recipients and was a key theme posed by participants who worked within the health care system as nurses. Susan's comment that she "started to question herself," speaks to the stress level of even a seasoned HCP as she dealt with her father's
medical admission. Her acknowledgement of the difficulty that she, as a nurse, knew she was not "being a pain in the ass" specifically points to an awareness of what needs to occur to be a ‘good' family caregiver who is positioned with a loved one in a hospital. Barb, in contrast, alludes to using a particular technique when interacting with HCPs that allowed her to give and extract information in a shortened period of time. Her technique, the "3 B's" meant that she carefully structured her own dialogue to get and give the maximum amount of information quickly.

**We’re all frustrated: politics and policies.** Participants who worked in either the health care system or in a business setting (and worked within a business model) had much to say about the politics and policies that impact health care delivery for PWD. Specific topics discussed included the physician compensation system, affordability of home-based and LTC for PWD, Medicare reimbursement policies related to care of PWD, and conflicts of interest inherent in payment systems for private care management and in LTC settings. Participants who raised these issues suggested that problems encountered had direct links to legislative policies that governed funding or reimbursement systems.

*Compensation.* As previously mentioned, lack of availability of physicians to meet with family members was identified by many participants as problematic. While the vast majority of participants offered no suggestions for why physicians, in particular, seemed absent, participants who did suggest reasons for the absence clearly linked the problem to one of compensation. An awareness of fiscal realities related to the physician reimbursement system and billable time were highlighted as reasons that physicians
remained absent or were less present than caregivers suggest would be helpful.

Awareness that time spent talking with families was not a reimbursable ticket item was voiced by Aubrey, who works within the system. She voiced hope that that new policies related to health care reform would make an impact in physicians' willingness to listen and provide support to family members, but then poignantly suggested that perhaps "we," as HCPs, have simply forgotten how to care.

"...I think they need to take the time, even if it is not compensated for, to really understand, they need to understand the patient not holistically in terms of holistic medicine, but as an entire person... I think physicians really need to take a step back, take more than the 15 minutes, and really get to know their patients. Maybe these accountable care organizations are going to force that on that....let's coordinate the care, let's be that center of the wheel, that is what they need. And they need to--I know it is hard to listen to families...but I also think it is very important to hear families and try to boil down what they are hearing and then try to figure out how to support that....We don't take the time to educate or in some ways, I don't think we take the time to care, either." —Aubrey

A less obvious statement about compensation comes from the participant, "Sky."

Rather than referring directly to billable hours, she highlights the scheduling demands of providers and uses that to explain and excuse HCPs who don't appear to know many details about their patients as people.

"...they (the HCPs) only see the people on a very limited basis, and they really don't have any idea how they are the rest of their lives. And five minutes of time, it's not really fair to them to put them down for not picking up on it, but it seems like there should be some way that they could get it, understand it. ..."

—Sky

Participants' statements about compensation, whether overtly referring to physician reimbursement or viewed through the lens of scheduling demands, were an acknowledgement that time and care provided were at least partially dependent on physician compensation. Reformation of the payment system was seen as one
component needed to re-teach providers to provide education and support to family
caregivers of PWD.

**Affordability.** A second fiscal issue that arose during many participant interviews
related to the direct or indirect cost of providing care for PWD over time. Topics
addressed by participants included lack of insurance coverage for stay-at-home care
options, lack of policies governing cost, marketing and operation of Assisted Living,
Medicare reimbursement issues and challenges with the MassHealth/ Medicaid system.
The message across interviews was consistent: care of PWD is simply not affordable for
most individuals. "Aubrey" again captured the problem well, when she explained:

"Nothing is affordable. There is such a progression, there is such a tail on
this disease that it has to be affordable The policies aren’t written so that they
can actually be of use, in my opinion, so people are left to their own financial
means and they have to try to stay at home and pull in aides, private aides or
companies or whatever, and then when all else fails, spend down their assets and
land with care, you know? ...A lot of facilities are plugging it in with VNAs and all
the rest of them that come in and have a nurse on site that can do the skilled
component."

--Aubrey

Attempts to mitigate the cost of care impacted choices around caregiver attendance
at support groups, the ability to stop working and stay at home to provide direct care,
depletion of assets, reliance on Medicaid and decisions about residential care.

Reagan, whose young wife had early-onset Alzheimer's disease shared the reality
that funding simply doesn't exist for most individuals under the age of 65, especially if
the caregiver and/or the PWD had been financially stable prior to diagnosis. As he
stated,

*it’s like there is no...there is no relief. There’s no financial resources available to
people our age. If you are 65, there are things you can do. And for us,
especially... we had a reasonable income. So, if you have any income and you’re
young, you are screwed. So, I have to keep working.--If I attend a support group,*
"Susan," whose father developed a wound on his foot during a stint at an ALF, shared another challenge, this one related to Medicare and a non-reimbursable procedure needed by her father. The wound required intravenous (IV) antibiotics. Susan described the challenges around reimbursement related to daily IV medication administration at the ALF (or "home"). The problem, she explained, was that per Medicare policy, the administration of IV antibiotics could be done in the home by family members. Medicare would pay for a visiting nurse to teach a family member the procedure, but would not reimburse for a visiting RN to continue to perform the task on a daily basis. The options for administering the medication were either for Susan to go by the ALF daily and perform the task or pay for a private care nurse to perform the task daily. The ALF did not have available skilled personnel to perform the task and thus additional charges would be added to procure a visiting nurse to administer the medication. Her comments are below:

"Medicare doesn’t cover it... Again, like really? the person has dementia, an infection, needs IV antibiotics in the home. Medicare will pay for the medicine and pay for the doctor’s visits all along with this diagnosis, but they won’t pay for skilled care because the way that the IV medicine is now, like if you or I had it, we’d give it to ourselves. That’s not skilled. So Medicare doesn’t pay for it."

--Susan

Understanding the reimbursement system of Medicare and how that system affects care provided to PWD was also highlighted by Stan when referring to physical therapy for his father.
"My great anecdote about this is great, is, so he was on like the 15 days of (physical therapy)--Medicare was paying for therapy. Well... he’s got dementia, so he’s never going to get better, so they stop. They never told me they were stopping... And I didn’t know about the 15 days. I mean, you know, I have other things to do. I didn’t know that was... but that’s another thing you find in the healthcare system, you have to do your own work. ... So then I said to them, well OK, what happens now? Well, he gets on the walking program. OK, what’s the walking program? The walking program there, at the time, was basically they would go to him and say, at lunchtime do you want to go to lunch, do you want to walk down to lunch? And if they said no, then that was it. So now you’re saying to a dementia patient, because the response might not be right, which hello, that’s, you know, one of the big symptoms, that they’re going to pay a penalty and not be able to walk. So he wasn’t getting walked. --Stan

At the opposite end of the age spectrum, we find Martha, the 88 year old spouse of a PWD. Martha used a private care management group throughout her husband's illness and although her husband had recently passed away, she continued to work with the care management group for added support. During the interview, she acknowledged that her (quite affluent) situation was atypical, in that she had the financial ability to continue to contract for a "terribly expensive" service. Her allusion to steadily dwindling funds reflected awareness that the choice to use a care manager lessened any presumed inheritance for her children.

"I have kept the geriatric care manager. My children are in (a West Coast city) and in (a city in the Southern part of the United States). And I’m on my own here. And so I needed the guidance. But it’s terribly expensive. But I could afford it. And that’s where the money’s gone. And so I continue"--Martha

Most participants in this study had already been faced with the need to at least investigate financial options for institutional or private care. Residential placement in Memory Care Assisted Living facilities required considerable private payment, but placement in ALFs was often seen as the preferential long term care choice if PWD did not require significant or daily medical attention. Several participants referred to a strong
likelihood that increased care needs would require an eventual move from a Memory Care ALF to a NH placement, however policies that dictate criteria for such a need remained ambiguous. The ambiguity in policy was seen as both a locally based issue and a larger legislative one. "Jessie," whose husband had been in a memory care ALF unit for many years acknowledged the nebulous nature of governing policy at the local level:

"I think the only thing I would like to know more (about...) is, when it is that people are no longer welcome? I know that some people have been banished because of the behavior... I would like to know what the limits are and I don’t think that that has been exactly laid out... That’s one of those things, probably, that I should try and find out about. -- Jessie

The final move from a largely unregulated facility (the ALF) to a highly regulated NH placement required most participants to make use of the Medicaid funding option.

The challenge of negotiating the MassHealth/ Medicaid option was captured in words of "Stan," whose father is currently in a NH. A businessman, himself, he explains the challenges of application and appeal system. The system, he explains, is almost exclusively automated and his perception was that the system was designed with hopes of routing consumers to appropriate "destinations" where questions are answered electronically. Unfortunately, obtaining confirmation denoting receipt of paperwork, answers for questions that are situation -specific or unusual and the chance of speaking with a live human being were rare. The situation, he went on to say, was further compounded when a court date was required because of a paperwork or computer glitch.

Stan shared his annoyance and disgust in the following excerpt:

"Mass Health just assumes that you’re cheating. That’s where they start, that’s the starting point. And the amount of time that I had to spend... just explaining certain things, and you know, then they’d send you a note. I got a note one day randomly. "Your mother’s coverage is ending because of a..." It was a mistake.
But to reach someone on the phone...You have to fill out a piece of paper...It doesn’t even give you a number to call to explain. So in the beginning I’m like," oh shit. OK, they don’t get it, I understand that."... So I’m trying to call. OK, I’m trying to get a live person. Never happens, never happens...And I finally, and I got into the automated system where they’ll say, we don’t require anything further from you at this moment.... I mean, they said I don’t need anything more, so I’m just going to see what happens...

The system is designed to weed people out. In fact, this is my favorite part, which I’m sure you know about this, but I didn’t know about it. So when you go for a hearing, so they made a ruling on one of my parents...And we had other information, OK? ... you have the right to have a hearing, right? Fill out the form. So we fill out the form. The next communication says that my request for a hearing has been denied unless I send them copies of my power of attorney documents, or healthcare proxy documents, I don’t know, and something else. Now, I would never be in the system for a hearing had I not been (the power of attorney), do you know what I mean? But, and I talked to my lawyer, she said they just want to get rid of people...

--Stan

The extraordinary expense of providing care for a PWD was identified as problematic for many participants. Options to mitigate the cost of that care were described as difficult to access or navigate and fraught with systemic challenges. The gaps in available fiscal assistance were identified as problematic and directly linked to available care for PWD and use of services by family caregivers.

**Conflict of Interest.** Fiscal conflicts of interest were cited by several participants when discussing Assisted Living Facilities, geriatric care managers and physicians who consult to long term care facilities (LTCFs). "Emery," whose mother was in an ALF shared her explanation of why ALF personnel would not necessarily direct or guide family caregivers toward a move to a NH. The reason, she suggested, was at least in part because of the financial ramifications that a move would create for the ALF. While she was currently quite satisfied with the Memory Care ALF where her
mother resided, she was aware that she, as a caregiver, would have to monitor the needs of her mother and potentially determine if a further move was needed.

"I think that this whole assisted living model trying to accommodate Alzheimer's patients is just a nightmare...They're like multi-level hotels...the wallpaper and coloring and everything on each of the three floors was exactly the same. So it's no wonder people were always getting off on the wrong floor... I think people can sort of exist in that model (ALF) until a problem arises, but... It's not a working model when (the ALF company personnel are) not willing. Because of course it's money driven. So, they're not going to say to these families your mother or your father, this is not a good and appropriate place for them anymore. Their memory has reached the point that they need to go somewhere else. They don't do that very often."  

--Emery

"Stan" had also used a geriatric care manager and became aware of such a conflict when there was a problem with care at one facility. Stan looked to the private care manager as an advocate for his parent, but encountered a distinct lack of willingness to engage in potentially conflictual dialogue with personnel at the facility. Stan shared:

My geriatric care manager, when we go into the meeting with (names a NH), I said, you know, I really want to bust their balls...because this is really wrong, and blah, blah, blah. Well, she didn’t want to. Why? Because she works with them all the time. Because tomorrow, she has to deal with the family who needs a place at (that facility) and she has to call them up. Here to me was a huge problem with the whole system. She is a consultant for (names a service group). So that’s how she gets paid from, whatever, $50 an hour or whatever, OK? So she has to deliver revenue to her organization. How does she deliver revenue to the organization? Getting lots of clients and keeping clients happy. How does she keep clients happy? By having the resources. OK? Well, if I go to her and say, jeez, I really want to go to (names a NH) and she says, oh I don’t have good relationships there because I had somewhat of a bad experience. So she was conflicted.  

--Stan

Stan questioned, as well, the policies and conflicts for physicians who may work at multiple facilities. He shared his belief that physicians and other HCPs who contract with LTCF are able to increase their levels of compensation dramatically without needing
to provide significant care or be available to speak with family caregivers. The specific example offered of such an individual was a physician who was both the medical director in one facility and identified as a consulting physician in at the second location. Stan's parent had been in both locations and at both settings, Stan "wrote him notes." In neither case, however, did he have personal contact with the physician or see evidence of his work. The experience contributed to Stan's opinion of HCPs working in LTCFs:

"I always look askance sometimes at physicians, MDs and dentists and stuff who work with nursing homes, because I think they figured it’s a good way to make easy money, because they can see, like, 50 patients in an hour and then bill Medicare. "  

--Stan

Questions about conflict of interest for both private care organizations (geriatric care management groups and ALFs) and HCPs contracted with LTCFs were raised by several participants. These potential conflicts of interest were referred to by participants as areas with potential ramifications for PWD whose caregivers were less aware that the conflicts existed.

**Summary.** The overarching theme of "a broken health care system" encompassed subthemes of communication and care across health care settings, a system built on rules for the many rather than attention to individualized care, provider availability and politics and policies that influence care of PWD. Participants depicted a system that was impractical and difficult to navigate, and HCPs within that system who seemed at times to be unwilling or unable to provide needed assistance. The efforts exerted by participants as they negotiated care for PWD were directed toward ensuring that the needs of PWD were met, that wishes were honored and that information was shared. Ethical dilemmas related to autonomy and conflicts of interest played a key role
in participants’ awareness of the challenges faced by themselves and HCPs involved in care of PWD.

Looking for Resources and Figuring it Out

All participants faced moments in which changes in the PWD's physical, cognitive or functional status, lack of knowledge about the disease process or lack of clarity about options for care contributed to moments of uncertainty and confusion. In those moments, participants looked to HCPs and a host of other available resources for additional information that would help them manage uncertainty associated with being a caregiver, advocate and decision-maker for someone with moderate to advanced dementia. Moments of uncertainty arose during episodes of crisis, while figuratively being propelled down a highway at breakneck speed, but also appeared in moments of quiet, when the stress of caregiving became weighty and adrenaline present during a crisis had run its course. In both situations, caregivers described "looking for resources and figuring it out" through a combination of formal and informal channels of inquiry aimed at providing knowledge and guidance for the road ahead.

When asked to describe strategies by which resources for information were identified, obtained or utilized, few participants answered the question directly. Instead, examples of information-seeking, resource identification and resource utilization were shared as stories about their histories as caregivers for PWD unfolded. The first strategy, accessing formal resources, encompassed moments in which participants looked to HCPs or a non-profit organization for information. Formal resources were most often accessed by participants seeking to obtain knowledge, instruction, decision-support or respite in a
deliberate, strategic way. Examples provided included attempts to learn about a specific variant of dementia, obtain a diagnosis or recommendation for placement in long-term care or obtain social support.

The second strategy used by participants to manage uncertainty was to use a hodgepodge of informal resources that, cobbled together, allowed participants to address the issue at hand and move forward in the caregiving role. When participants used informal resources, they described asking friends and family for information, reading lay literature and using technology to access online resources.

The theme "looking for resources and figuring it out" captured the many diverse, yet often convergent paths taken by participants as they identified ways to obtain information that could help them manage the uncertainty and ever-changing demands of caregiving. Participants used a variety of formal and informal resources to seek additional information, assistance, instruction or respite and to get their own needs and the needs of the PWD met successfully. Taken together, the experiences shared by participants cast light on informational needs, discussions that were meaningful and "stuck" in memories of participants, and illuminated ways that caregivers "look(ed) for resources and figure(d) it out."

**Formal resources: looking to the professionals.** Participants often looked for information and attempted to manage uncertainty by accessing formal resources. Formal resources, in this study, included HCPs or the Alzheimer's Association, a non-profit organization dedicated to supporting PWD and their caregivers. Participants who accessed formal resources described attempts to gain information that would further their
understanding or guide them toward next steps. Participants' familiarity with the HCPs involved in care and exposure to HCPs across disciplines often varied according to setting. For this reason, participants' experiences of seeking information from HCPs were separated according to location in which care was provided. All experiences described as part of hospital admissions occurred in situations of relative crisis. Conversely, those seeking information from HCPs in outpatient settings or LTC settings described both crisis and non-crisis situations.

A single non-profit organization, the Alzheimer’s Association, was also included as a formal resource, but was treated separately, as that organization included both HCPs and formally trained laypersons. As with outpatient care, information and resource-seeking efforts with the Alzheimer's Association included both crisis and non-crisis situations.

**When a PWD Goes to the Hospital...** Moments of uncertainty and opportunities to "look for resources and figure it out" often occurred in times of crisis or change. For many participants, those moments took place in the context of hospitalization of a PWD. In hospital settings, HCPs were seen as resources who were expected to provide information and support, direct care and participate in discussions about next steps in care. Several participants described positive experiences in which they obtained needed information from HCPs during hospitalizations and were connected to resources for next steps. Others, however, expressed disappointment about what they perceived to be lack of information, guidance, direction or support.
Examples of “looking for resources and figuring it out” during hospital settings were provided by multiple participants. Each participant cast light on one or more interactions in which they looked for resources and attempted to gain information during a PWD's inpatient stay. "Lucille," "Amy" and "Martha" described experiences during PWD admissions to geriatric psychiatry units. In contrast, the exemplars provided by "Harry" and "Jessie" took place in the context of obtaining treatment for one or more medical comorbidities on an inpatient medical unit.

Moments of crisis on geriatric psychiatry units. Admission to a geriatric psychiatry unit invariably took place in a moment of crisis. "Lucille," described one such event when she shared the traumatic experience leading up to her husband's admission.

"It was a nor'easter rain storm. My daughter and son-in-law's house was shower and go to work the next day. And they experienced Sunday night the worst he'd ever been. It took the three of us to keep him happy. He wanted to go catch the bus and why weren't we letting him go? Gave him his night meds and he did sleep although we were all listening all night long...."

--Lucille

After her husband was admitted and evaluated, Lucille attempted to obtain information about a change in her husband's diagnosis. The reason for her confusion, she explained, was that prior to hospitalization, her husband had carried a diagnosis of Parkinson's dementia. During the hospital admission, the diagnosis was changed to Alzheimer's disease. Lucille described the moment when she sought out the geriatric psychiatrist and asked specifically for an explanation of the difference between diagnoses:

“I asked to speak with the geriatrist psychiatrist...And I said well, what's the difference between the two? And he said well, it's a different part of
the lobe of the brain. And it will be, it'll progress a little faster than the Parkinsonian dementia will. And I remember sitting there and crying because I mean it just hits you, you know? Dementia's dementia when you sit back and look at it afterward, but somehow when someone says "Alzheimer's," it just punches you in the gut. It's like -- it has a lot of power. So it's like you just go home and try to figure out what's going on... If someone had just taken that 10 minutes with they could have left me there with a mop. I would have been fine, you know what I mean? But just...they're so clinical that there's a lack of emotion.”

--Lucille

As Lucille described the interaction, her voice quavered. While recollection of what she was told was limited, her clarity about the lack of emotional support was firmly embedded in her memory. Whether additional information was actually given to Lucille was unclear, because, as she so poignantly stated, she heard the word "Alzheimer's," had a visceral reaction and her brain essentially stopped processing. Her comments about the delivery of the information ("they're just so clinical that there's a lack of emotion" spoke to the trauma of the entire experience.

Lucille moved from the information-seeking mode of actively looking to a formal resource for information to trying to "figure out" the meaning of the diagnosis and next steps to take after she left the hospital to go home. Her description of the experience and the physicality of her response upon hearing the diagnosis of Alzheimer's ("it just punches you in the gut") was illustrative of the power of words used by the HCP to convey information. For Lucille, her physical response upon hearing the word "Alzheimer's" superseded any further recollection of conversation. Lucille left the interaction on emotional overload, yet her understanding of what Alzheimer's meant and how it might unfold was lacking.
"Amy," too, recalled seeking resources from HCPs on a geriatric psychiatry unit, however her experience was quite different. The hospitalization took place shortly after the death of Amy's father and the subsequent discovery of the depth of her mother's impairment. She explained that both the diagnosis of her mother's illness and the need for placement occurred within the course of a single hospital stay. Amy described events leading up to the hospitalization and then the admission, itself:

"I mean I wasn't really looking for anything to be there, but yeah. ...then when we cleaned out her apartment, we found, um, steak and potatoes in the oven that had been put in there but forgotten about. I found a grocery list that was the same grocery list every single week...it was never changed... little things like that just began to fall into place and yes, you know, this is really what's happening... we did find her (to go back a step), that she was out kind of wandering, and kind of lost. A couple of times when we saw her we'd pull over when we saw her and she didn't even know who we were. She wouldn't get in the car with us...

We decided to talk to the doctor and (he said) she should be tested. So she went there (to the hospital) and she had some psychological testing...it was determined that she had the start of dementia...and it was recommended that because of our family circumstances, working and stuff, um, that maybe she should be placed in a care facility. So that's how she ended up here. It was recommended by some doctors in (the hospital). They recommended this facility so we came over." --Amy

As with Lucille, Amy looked to HCPs for information and guidance at the hospital. Unlike Lucille, she was almost matter-of-fact when she stated that the doctors' had indicated that her mother "had the start of dementia" and had made a recommendation was that she "be placed in a care facility." The suggestion made "by some doctors" in the hospital was accepted by Amy and her family and the placement of her mother in a NH occurred. Amy's situation, which included a recent family crisis, no formal diagnosis of dementia prior to hospitalization, and a need for immediate decision-
making was profoundly different from the description provided by Lucille of her own situation. Amy did not question (at least in the research study interview), the doctor's recommendation or comment on her own willingness to accept that recommendation. Instead, she went on to share positive thoughts about the facility where her mother now resided.

"Martha's" husband had been diagnosed with dementia many years before his hospitalization on a geriatric psychiatry unit. Admission to the unit occurred after several episodes of aggression toward staff in his long term care facility (LTCF). In thinking back to the hospitalization, she recalled that her interactions with professional staff were limited. The psychiatrist and case manager were part of an original conference, she stated, but then went on to say that she did not recall meeting with either more than once. Nurses were identified as being “too busy” or being unavailable to sit with her for 1:1 discussions, though she acknowledged that they were helpful. The aides were mentioned often and with clear dismay as being unhelpful and disengaged. Martha explained:

"I only sat in with (the doctor) at an original conference. The (case manager) was excellent in reporting...very, very thorough. I don't know if I ever met with her again. ...The nursing staff...were very helpful, but one couldn’t really one-on-one with them... And the nurses who I talked to were difficult to engage often, because there they were, dealing with medications. I know what demand that is, tremendous demand on their time. We had problems with his personal care. It was very complex for me to try to persuade an aide to get clean clothes up in the closet...The mealtime...was unsatisfactory for me... I could write a book about what it was like at that table, the paper plates, the small plastic utensils, the attending people who showed no warmth." --Martha

The description provided by Martha in the excerpt above (and throughout her interview) described a need for social support and intervention on her husband's behalf
rather than guidance about specific diagnosis-related issues or a plan for next steps. She did not describe a need to manage uncertainty or obtain additional resources, but clearly described her distress about care provided and her husband’s personal belongings. It was clear from Martha’s descriptions that whatever was needed was not obtained and that the entire experience was unsatisfactory.

The descriptions by Lucille, Amy and Martha share several commonalities, yet all had profoundly different outcomes in terms of caregiver satisfaction with the ability to obtain information or guidance and with managing uncertainty. Lucille described hearing unexpected and confusing information, being left in an emotionally vulnerable state and left to "figure it out" on her own. Amy received information that was life-altering for her mother and given on the heels of a previous family crisis, yet she described the information given as being helpful. Martha, whose husband had a long standing dementia diagnosis at the time of the event, did not share any specific questions that had been voiced, but did share the concerns about the hospital environment and care provided. She described her experience as extraordinarily painful and unsatisfactory, not because of specific questions left unanswered, but because she found the staff to be disengaged or unavailable and perceived the environment to be lacking warmth or human connection. For Martha, she continued to try to "figure it out" years after the experience had occurred.

Medical admissions. In addition to hospitalizations on geriatric psychiatry units, hospitalizations on medical units during a physical illness were described by a number of participants. Although the psychiatric and medical environments were clearly different,
participants' descriptions of medical admissions, interactions with hospital staff and HCP availability were not dissimilar to those described on geriatric psychiatry units.

"Harry," whose mother was admitted to a medical unit numerous times, described each event as being problematic. Harry described looking to formal resources to provide information (and thus manage his anxiety), but then explained that he had been unable to locate personnel to answer the questions he had. He described the way that inpatient admissions usually unfolded:

"we’d call an ambulance and should go to (the hospital). It usually was on a weekend... they would give her tests and because it was on a weekend, (hospitals apparently don’t do much on weekends or you can’t expect them to), I could never get a test result until I bothered them, down in their office or something. As I’m trying to get a bed for her, I would get nervous and I would go up on a weekend to determine where was she going on the Monday. If there was one person for each floor in the hospital to take care of people, finding that out, it would always be on a weekend, somebody out, somebody covering for another person.. I was having a lot of problems that I shouldn’t have encountered."

--Harry

As Harry described his experiences, he outlined ways in which he looked for resources to manage his uncertainty and anxiety. During the telling of his story, he repeatedly shook his head from side to side and his voice shook at various intervals. His assessment of the repeated admissions was that information was difficult to procure, that HCPs were often unavailable and that resources were not shared. As with Lucille, in the earlier example, he left for home and tried to "figure out" what should happen next.

"Jessie" spoke of her husband's hospitalization on a medical unit for pneumonia. Using a low- pitched tone alternating between a matter- of- fact statements and sarcasm (e.g., the "pods of 43"), she often shook her head from side to side or grimaced and
periodically clenched and unclenched her hands. Jessie described her husband's admission for pneumonia as follows:

"they (the HCPs in the hospital) don't particularly make it a business to find out who their present patient is in a sense. They know what his problem is and what medication he needs, but they don’t make any, they didn’t, while Jack was there, make any friendly, warm overtures or anything... I hardly ever got to see the docs. They all came in in pods of 43 but I wasn’t there. I didn’t stay all day. I stayed there a lot. So, I often missed them. Then, the nurse would say, well, the docs came in a couple hours ago, so they won’t be back until tomorrow or whatever. The nurses didn't share much... I think the case manager was the one that made the arrangements for the rehab and that kind of thing. She was nice. I mean, people weren’t awful. It’s just that... it didn’t work very well." --Jessie

Jessie didn't question the competence of the HCPs involved her husband's care. She did, however, feel strongly that they were out of touch with the who their patients were and failed to "make any friendly, warm overtures or anything." Her limited ability to see a physician, coupled with the limited sharing by the nurses, left her somewhat uninvolved in discharge planning. Her assumption that the case manager made the arrangement for a rehabilitation stay suggested that she may not have had discussion with a team in which discussion about each team member's responsibility occurred. Jessie indicated that she "stayed there (at the hospital) a lot" but described the lack of information flowing from HCPs. As with Martha, Jessie's distress at the perceived lack of compassion and human connection on the part of HCPs at the hospital was palpable.

In both medical and psychiatric inpatient health care settings, information about resources came from a joint group of HCPs. Particular disciplines were rarely mentioned in depth and none in relation to recurring discussions about care. Instead, isolated or one-time events (e.g., "the original conference" mentioned by Martha) or
vague references to HCP presence or absence were mentioned. Participants' recollections about information provided to participants largely revolved around a change in status, diagnosis, discharge planning or a need for social support. No participants shared experiences about being given information about resources other those related to long term placement. Only one participant, Amy, indicated that the resources provided fulfilled her need for information.

**What does get discussed in outpatient HCP offices?** Many participants described attempts in outpatient HCP offices to obtain the dementia diagnosis, a referral to a specialist or address singular issues such as driving, preventative treatment or outpatient treatment of a medical illness (e.g. urinary tract infection). Each of those issues was discussed in depth in "a broken health care system" and will not be revisited here.

Aside from the issues mentioned above, however, participants did not directly mention ways in which they looked for guidance or information in outpatient HCP offices with the exception of the topic of trajectory of illness. Two participants described conversations about trajectory of illness and each had strikingly different outcomes.

"Silsbee," whose wife had been diagnosed with dementia many years earlier, indicated that the HCP who had diagnosed his wife had indicated that they "wouldn't notice much" for the five or six years. Silsbee indicated that the assessment was accurate, but then stated that he was wholly unprepared for what he perceived to be an abrupt decline following that time period. During the telling of the event below, Silsbee wrinkled his forehead and gazed at a wall as he stated:
Ten years ago or twelve years ago when the doctors first said "you have Alzheimer's." they said (and they were right), for the first 5 years...uh...we won't notice anything. ...And they were right, but after 5 years or 6 years...wham...she suddenly just fell off a cliff. Everything went wrong. In a, well I don't know, well I say, a very short period of time...three, four, six months, maybe. Nobody warned me that anything was going to happen so fast...When it did start, I talked to him (the physician) and he said well I can't really help you. Talk to so-and-so in his office. And that wasn't very helpful to me either. I kept thinking, that wasn't much help. --Silsbee

Silsbee's observation that "nobody warned (me) that anything was going to happen so fast" was informative in several ways. While he clearly recalled being told that "for the first 5 years" he and his wife would notice few changes, he had no recollection of hearing anything about what might happen after that. As in the description of Lucille's experience in the hospital, Silsbee was "looking for resources" mode when he asked the physician about his wife's decline. And as with Lucille, he returned to "figuring it out" when the directive to talk to so-and-so" in his office was deemed less than helpful. Indeed, several years after the described events occurred, Silsbee continued to try to "figure out " what might have occurred to trigger the decline.

"Jessie," described a discussion with an outpatient neurologist about trajectory of illness for her husband, "Jack." Jack had been diagnosed with mild cognitive impairment and had been monitored over a period of months. Jessie began to notice decline and reported that decline to the HCP during an appointment. The information she received from the neurologist is shared below:

He said many people... this is one thing I thought I took in... he said, many people with high intelligence have big cognitive reserves and they don’t show a lot of loss for a long time. That was interesting for me. That was new information. He said, often, if it goes on, they may have a very precipitous decline. That is not
unusual. He gave us a lot of information, enough for where we were, I certainly thought. I didn’t have further questions of him. --Jessie

Jessie’s experience, unlike that of Silsbee, was described as a dialogue in which she gets “enough information for where we were....” Her comment, "I didn’t have further questions of him" led to additional discussion between Jessie and the interviewer. Jessie indicated that she often decided to refrain from asking questions. She described her reasons why:

"What’s going to happen is going to happen and I don’t need to know about it. I certainly have a pretty clear idea of what is going to happen.... I don’t want to have my choices right there. I will just see what happens when it comes and deal with it. That’s why I never read the 36-Hour Day." --Jessie

Jessie chose to avoid asking questions for which she did not want answers. The involved HCPs did not push the issue. Although Jessie openly shared her rationale for avoiding speculation and projections with the interviewer, she did not indicate that she had had the same discussion with the HCP. As such, it is unclear whether they came to a mutual agreement about transmission of information or whether the issue of providing further knowledge did not arise. Regardless, her clarity around the issue was striking.

Despite a wealth of positive and negative discussion about HCPs in outpatient settings across interviews, the topic of looking for resources from outpatient HCPs rarely surfaced. The exception was around interactions around diagnosis or singular events. It was unclear whether participants requested additional information or resources at other moments in outpatient HCP offices.

*It all depends...finding information in long term care.* Most participants for this study were recruited from either ALF or NH settings. In those settings, participants
looked for resources from a variety of different HCPs. As with inpatient settings, discussions with HCPs centered around obtaining information about changes in care or status.

Program directors and social workers were identified as resources for information about dementia, in general, and for information about the participants' respective PWD. In an example of a program director being identified as a resource, "Jessie," described the program director of the memory care unit as a valuable resource:

"(The program director) will occasionally give me information. ..If Jack is being obstreperous about something, which he sometimes is now, she will say, you know, that happens, that’s normal, don’t worry about it. She is very soothing and she would tell me more if I wanted to. She has given me stuff about the different kinds of dementia that there are, which I was quite interested in." --Jessie

Nurse practitioners (NPs), likewise, were seen as both available and as ready sources of information by several participants. Their presence in nursing homes, particularly, was highlighted as being useful in managing the uncertainty of day-to-day medical issues. Aubrey explained:

"(the NP) is at the property at least once a week if not more, even if Mom is not on the cycle, if something is going on, she is right there...I talk to (the NP) once a month, we strategize on what she’s on and what she’s not on." --Aubrey

Care planning meetings were identified by one person as a source of information, however, others indicated that planning meetings were difficult to attend because they were scheduled around facilities’ needs rather than the caregivers’, or not very helpful.
"Amy," who vacillated between "information-seeking" and "figuring it out" indicated that, for her, care planning meetings were helpful because of the specificity of the information discussed. As Amy stated:

"we've been at these care planning meetings and they talk about stuff. And they're very explicit, explaining terms and the whole medication thing." --Amy

"Stan" was less enthusiastic. While he acknowledged that care planning meetings took place at the NH, he indicated that the meetings were often difficult to attend if caregivers were still in the workforce. He went on to point out that he was not given options about the timing of the meetings. Given that, he found care planning meetings unhelpful because he could rarely attend them. Stan explained:

"They do these care meetings, right? And they’ll send you a note and they’ll say, OK, we have a care meeting scheduled. Because I just got one. And if you can’t make that time, then you have to wait until the next round..". --Stan

Support groups at the LTCF were singularly unpopular for participants in this study. Lucille and Silsbee addressed both the perceived ability of the HCPs at the facility to do the group and the usefulness of the support group overall:

"I don't think they're particularly good at it but they have support groups...which I found completely worthless." —Silsbee

"I don't want to go and hear everybody's symptoms, problems, and you know? that's too sad for me. Because I know what's going on. You have my heart, you have my blessing, but I'm going through enough and I don't want to hear it again. So that's maybe selfish, but that's for me." —Lucille

Particular groups of caregivers were identified as key sources of information in NHs and ALFs. Program directors, social workers and NPs were each highlighted as
particularly useful in acting as resources for both general education and specific information related to particular PWD. As was the case in hospital settings, physicians and nurses were again seen as largely unavailable to act as resources to any of the participants.

*The Alzheimer's Association--it's awesome.* One community-based non-profit organization, the Alzheimer's Association, was overwhelmingly identified as "valuable" by every participant who accessed it as a resource. Participants who utilized the Alzheimer's Association were information-seekers, who looked for resources in both crisis and non-crisis situations. In crisis situations, the 24-hour helpline was seen as a lifeline for those who were struggling and needed immediate answers or an immediate listening ear. Support groups for caregivers and PWD, 1:1 consultations, a robust online website and a well-stocked library of educational tapes and books provided resources in non-crisis situations, including advance care planning, obtaining new skills and making connections with others.

The Alzheimer's Association was described as "awesome," "helpful both with resources, but also just kind of with listening" and "pointing (me) in the right direction."

The excerpts below describe different resources under the Alzheimer's Association umbrella. Each provides an example of a resource that participants identified as helpful in managing uncertainty associated with being a caregiver for a PWD:

"I did call the Alzheimer’s Association several times and they were awesome. I had long talks with their caregiver people...When things started falling apart with the work situation and all of that, I called them and had a long conversation with them. I described what was going on with her, just the general situation. They told me that I should
hire, basically, a social worker or -- The Alzheimer’s Association pointed me in that direction and, if they hadn’t have done that, it would’ve gone on a lot longer before I knew what the hell to do. I would have been struggling and I think we would have run into some pretty bad problems.” —Reagan

"the thing that’s been the most helpful for me is the Alzheimer’s Association... they have a 24/7 hotline, and I’ve called there and they’ve been helpful both with resources, but also just kind of with listening. Listening and saying that’s normal, or you might want to look at this or that". "--Susan

"I decided to have him go to this daycare thing a couple of times a week, which was a relief for me. It gave me a day off, two days off...got it through the Alzheimer’s (Association), yes, I’m sure it was." --Jessie

"I went to the Alzheimer's place, I did my own research... We went to the Alzheimer's Association, did research, got the books, did the reading." -Sam

" We were involved with them. Later on, we were in a group (at the Alzheimer's Association) , both of us for quite a long (time)... It was helpful hearing what other people were going through and how they resolved issues. It was helpful for me just to be able to talk and have people know what I was talking about. My family was wonderful, but, unless they are right there with Jack, they don’t know what’s going on, but these ladies knew, because they either were in it or had been in it" --Jessie

The Alzheimer's Association was used by participants who described themselves or were seen as information -seekers. The wide variety of resources allowed participants to pick and choose types of support that were helpful at different times or for individuals with different personalities.

**Informal Resources.** Informal Resources were used by all participants as a way to manage uncertainty and to strategize about next steps during times of crisis or change, however, as with the examples provided in the "formal resources" section, informal resources were rarely used proactively. Informal resources identified by participants
included family & friends, technology & literature and a miscellaneous category of items that did not clearly fit into other categories.

**Friends, family, and other lay caregivers.** The role of friends and family as resources varied widely across the spectrum of participants. For many participants, family and friends provided needed support to each other and served as resources for information. For others, neither family nor friends were mentioned as sources of information or support in the context of managing uncertainty related to being a caregiver of a PWD.

Lucille, Harry, Aubrey and Emery provided examples of interdependent and supportive relationships with family and friends. Their observations are listed below and show the importance of both giving and receiving support in the relationships:

"I have a couple of good friends who have experienced this with family members. We talk, compare things. So I think I'm as informed as I can be without really getting into textbook material and trying, you know? I read. I walk my golden retriever. I call friends up. We go to matinees."

- Lucille

"I spoke to a lot of my friends ...they went through this type of thing with their parents... A friend of mine was an undertaker and I thought he would know what the best facilities were to let her go to and so forth. So, I had a lot of help from that end, talking to all of these people."

-- Harry

"I have a lot of friends that have lived through this, one of my dearest friends had a mother that passed away from Alzheimer's, and she used to work for me. She knew my mom, so she would be like, this is what you can expect next or here is something to look for, or whatever... I try to be that level of counsel to my aunt now, who has my uncle at home, kind of things to watch out for or have you thought about this, if you go to the doctor and he says this, find another one. I was actually helping another colleague here whose mother is having problems, she is in an assisted living and they are not happy with the primary care."

-- Aubrey
"we are eternally grateful for the fact that we're all in the same I can't imagine anyone doing this by themselves. Honestly I cannot even imagine that." --Emery 

Reagan, who had developed an in-home care program for his wife, described the value of friends and individuals from the community whom he has hired as lay caregivers:

_The girls and me, we figured it out as we went. It is funny because it has evolved. It used to be a beautiful, kind of a nice home was set up. It has evolved into this where it is pretty cool because we’ve been able to maintain it, look like a home, but it is a nursing home. I call it a nursing home for one. It is just perfect. The girls have helped me...We are always fooling around and tinkering to try to maximize it...it has been good for me because it gives me a way of kind of, I guess, it is some semblance of control. I am controlling the environment for her and it has been good for me. It has been great. I spend my days just trying to figure out what is going to work the best, but I had the help._ --Reagan

As Reagan described, he found individuals who have provided person-centered care for his wife and worked hand-in-glove with each of them. In the process of working together and helping each other, Reagan explained, he had found a measure of peace.

In contrast to participants who garnered support from family members, some participants explained that they were the _de facto_ caregiver in the family and thus received little support from others within the family of origin. Aubrey, who had previously shared the example of providing counsel to her aunt above, described her immediate family of origin as singularly unhelpful. As Aubrey described what occurred with her mother, she said:

"She tanked, I started a new job, my husband was down there, we were literally both ends of the clock down there because of course, she was
closer to me and family said, well she is closer to you, you’ve got to deal with it. I get that, but you were part of the decision to make the move, but whatever. Love family dynamics, they are always great fun."

-Aubrey

Pinot, too, experienced challenges within her family. While she expressed of admiration for her father, she acknowledged that he was often obstructive when Pinot was trying to make decisions about her mother's care:

"We (the participant and her father) were working together, but... it was hard, because I would say, I would challenge a medication, and my father would say, no, no... the doctor said. I couldn’t effect a lot of change. But I would talk to my siblings a lot, because we all saw things differently than he did. And it was always, don’t you think we can push this? Don’t you think we can do that? It’s like, no... and he would not let my mother receive morphine. I ended up slipping to her a few times. But he would, he was adamant about that morphine. And for pain management, he would let her have Oxy. And that was a real big challenge. So my father was more the challenge."

--Pinot

And Reagan, whose words about working with lay caregivers were mentioned above, spoke to the challenges of interacting with family or friends in the midst of the daily demand of caregiving. He was appreciative of all of the interest and concern, but indicated that he had been forced to set limits about contact:

"... I don’t think (people) have any idea as to the time pressures that this takes. I have days, weeks when I can’t even take phone calls from my kids. They just keep calling me and I just send them a text back, like, no time, no time, no time, because there are so many people involved. I’ve got the caregivers and I’ve got the doctors and I’ve got the friends and the family and everybody saying, I could just spend my day reporting in on how she’s doing. They are all well-meaning and it’s great that we have people that care but you just don’t have time."

--Reagan
The role of family and friends was critical to a number of participants. In many cases, the role was positive and one in which an interdependent relationship provided needed support, companionship and the ability to give back or feel useful. In others, the absentee role of family members exacerbated feelings of being alone or overwhelmed when attempting to manage the caregiver role.

*Technology & Literature.* Information and resources obtained in non-crisis situations were obtained primarily from friends, family, online resources and books. Fiction or non-fiction popular books (e.g., *Still Alice*) were mentioned by numerous participants, who described using books to find a virtual connection with others who have gone through similar situations. A variety of online resources were used. Some online resources, including the Alzheimer's Association website, were actually formal resources, but the category was included as an informal resource because of the wide variety of websites accessed. Participants shared the examples below:

"I've read many books. One of them, oh what is it..the one that is my favorite... it was Still Alice.. And I've re-read parts of that because I can see the connection between Alice and my own mother. That was my favorite because it wasn't it wasn't like a textbook." --Amy

"I looked over some books, Still Alice, some books I had a couple of different books" —Sky

"I am reading all of these books and everything on what to do... I’ve been all over the place online" —Reagan

"I started to look online, I started to ask questions, and then I went back to school and learned a lot more." —Aubrey

"I looked online...you know, to see about what nursing homes had stars" —Emery
"Through research on the internet, (we) saw this particular location (the current ALF)."

--Barb

**Additional options.** Several participants looked for (and found) additional resources that did not fit in the above categories. These included geriatric care managers (3), an individual to evaluate driving of the PWD (1), a daycare (1) and an Elder Law attorney (1) and conferences (1).

It was interesting to note, however, that one particular individual highlighted 3 of the items above. Her statements were grouped below:

> I had somebody come in and test him every six months, a driving person, because I just wanted to make sure that he would pass muster. I thought it was good for insurance purposes and also for my being safe in the car....(and) a daycare twice a week...I know that I went to a couple of conferences about Alzheimer’s and dementia in general. I got things, lots of information.

—Jessie

Three individuals identified having geriatric care managers (GCMs) as resources. Care managers were identified as extraordinarily helpful in terms of providing information, but also as "terribly expensive" (Martha). Nonetheless, they were acknowledged by all three as quite useful. One example is below and combines the Elder Care Law attorney and the GCM resources together.

Aubrey explained her introduction to the idea of a GCM and her evaluation of what that individual provided

> "I had an Elder Law attorney. She was the one that actually pointed me to some Geriatric Care managers who helped me, they are obviously the people that are out in these facilities every day so they get to kind of see what the population is like, what the staff is like, what the level of care is, so it really started with (the Elder Law Attorney) saying, first and foremost, get a GCM. I learned a ton from them in terms of the different places, and they actually met me and toured some places with me and
said, here is what you look out for. I got an education because I asked the questions."  

--Aubrey

Individuals who found identified the resources in the last category of "Other ideas" were information seekers who looked for resources and figured out next steps through a variety of less usual avenues. Each of the additional resources except day care require a significant outlay of financial resources. Day care, depending upon the circumstances, may be covered (or partially covered) for some PWD through state-funded initiatives.

**Summary.** All participants identified moments during the experience of caregiving in which they looked to formal or informal resources for information, support or guidance. For many participants, the attempt to look for resources or figure out next steps occurred during situations of uncertainty, especially surrounding change or crisis. For a smaller subset of participants, however, resource-seeking occurred throughout their PWD's illness and was aimed at managing uncertainty through proactive information seeking and accessing support for ongoing decision-making.

Informal supports, including friends & family, books and online resources, were mentioned as being helpful to participants far more frequently than formal supports. In particular, social support through family or friends and use of literature or technology were mentioned as useful in both crisis and non-crisis situations. Only one formal resource, the Alzheimer's Association, was mentioned as being consistently helpful to participants. In contrast, HCPs, the other source of formal support, were not consistently seen as sources as information or as being available to provide guidance. Exceptions, in which participants highlighted single HCPs as resources for information and guidance
certainly occurred, however most often, HCPs were mentioned in some context of being unavailable for in-depth discussion or strategizing about next steps. When grouped by discipline, participants identified physicians, across settings, as largely absent. Physicians were seen as resources for information only in the context of obtaining a diagnosis or, on one occasion, a recommendation for placement. Similarly, staff nurses, across settings, were identified as being largely absent or too busy to be sources of information, although NPs were cited as being more available for discussion. Case managers and program directors were not seen as particularly available or helpful in inpatient settings, however were seen as resources who provided information about dementia or individual support in LTCF.

The Importance of Partnership

In "the importance of partnership," participants described compelling --and often shining-- examples of collaborative working relationships between themselves and HCPs. These self-described partnerships had several common characteristics, including caregivers and HCPs who were willing to participate in respectful and interactive dialogue, HCPs who were available and accessible by the caregiver, and the ability of both parties to engage in mutual goal setting aimed at providing person-centered care for the PWD. Each of the three elements offered opportunities for HCPs and caregivers to engage in authentic communication, problem solving and treatment planning aimed at compassionate treatment and honoring the wishes of the individuals involved. In addition, participants who described partnering relationships often described a history of both negative and positive interactions with multiple HCPs over time. As participants
shared examples of partnership and acknowledged the importance of the HCP partnership in their own caregiving roles, they acknowledged the positive experiences and contrasted them with previous negative events.

**Provider availability and accessibility.** The ability to connect with a HCP in moments of change, uncertainty or crisis, was, for many participants, a defining moment in an evolving relationship with a HCP and a key element of a working partnership. Indeed, all participants who described themselves as "partnering" or "working collaboratively" with HCPs shared quite specific examples of moments in which providers were accessible to the caregiver and available to address needs of both the PWD and the caregiver in a timely fashion.

Interestingly, (and perhaps reassuringly), "accessibility" and "availability," were not terms that were used to describe an expectation that the provider be immediately and personally available to the participant. Instead, both terms were used to suggest that the participant was able to either speak with the HCP directly or leave a voice mail, a message, or an email for the provider. The response, in which the HCP returned the call, message or email in what seemed to the participant to be a reasonable length of time was the measure by which participants evaluated HCP accessibility and availability.

Fundamental differences between partnering and non-partnering relationships were explained by "Aubrey" in examples below. In each example, the HCPs were assigned to her mother's care by long term care facilities (LTCFs). One HCP was considered by Aubrey to be a "partner," the other was not. The partnering relationship, Aubrey described:
"(was) a really positive relationship because she knew the population she was dealing with and if I called her and said, here is what I am seeing in Mom, she trusted me enough to work with me over the phone. You know, if I called her and said, I think she’s got a UTI, I’m going to grab a sample, she would immediately call in an order and get going on it. She was that kind of helpful person, and really, for me it is all about partnering in the care."...Aubrey

In marked contrast to the first example, Aubrey described attempting to contact a second HCP who routinely saw her mother, but with whom a collaborative partnership did not exist. In the second example, Aubrey reached out for help, failed to receive what she believed to be a timely response, and as a result, her mother had "a bad reaction" to a medication. From Aubrey's perspective, the HCP's lack of accessibility and availability had very real consequences for her mother. Ultimately, this experience, along with other similar events of the same nature with the HCP, colored her entire recollection and opinion of the provider going forward. As Aubrey explained:

"there was a Geri-Psych person that was aligned with (the facility), who really shouldn’t be doing Geri-Psych at all and apparently still is. She wasn’t responsive to the families. Like if she increased a dosage and I saw bad signs in my mother, I could never get her on a weekend... never. She increased a dosage and my mother had a bad reaction to it and I could not get her until Monday."--Aubrey

In both examples above, Aubrey demonstrated, by reaching out to each HCP, her own willingness to take ownership for her end of the collaborative process. Her assessment of each HCP's willingness to partner in care was based on her assessment of the HCP's responsiveness, willingness to accept her observations as important or valid (as demonstrated by a return call back to discuss the issue at hand), and in the immediate consequences for her mother--the PWD.
"Jessie," whose husband is in an ALF, shared similar thoughts on the importance of HCP accessibility and availability. Like Aubrey, Jessie reported that reached out to HCPs to share observations to report changes in her husband's activities or status. She, too, highlighted the importance of a timely response and outcome. In the excerpt below, Jessie spoke of the collaborative partnerships she had her husband's neurologist and his primary care provider. She explained that she would:

"...call the neurologist or his doctor and (I will) run that (her observations) by them and, often, they will say, that's a good idea. We have been very lucky and I know I can call (the current neurologist) and he has called me back every single time soon..."

~Jessie

Jessie's comment that the neurologist would call back "...every single time, soon" highlighted that for her, as with Aubrey, the ability to reach out to a HCP and know that a response and an opportunity for follow up dialogue would consistently be forthcoming was a crucial element of a partnering relationship with a HCP.

While participants often spoke of a wish that HCPs be accessible or available, several also voiced awareness that external demands on a HCP's time might preclude the provider from meeting caregivers' needs. The inability to meet the needs of the caregiver did not necessarily color long-term opinions of those HCPs. Conversely, recognition of constraints or limitations that precluded granting of caregivers' requests, and the HCP's openness about communicating those challenges, often preserved a positive relationship in the caregiver's mind. As "Reagan" explained:

"(The first HCP) is a researcher and she is great, but that lapse (when the HCP was traveling) was bad...Fortunately, she turned us over to (a colleague) who, in my opinion, is the best doctor I have ever had the pleasure of working with. She has been incredible. She works with
me...she knows that I am all over the meds. She has been the medicine person. She has just been fantastic." --Reagan

In relaying the story above, Reagan shared the negative experience of having the first provider be unable to meet his need. Ultimately, however, his reflection upon the provider ("she is great") and his acceptance of her contribution to his wife's team was preserved. His appreciation for the provider's willingness to "turn them over" to a colleague who could better match Reagan's needed was a part of his overall recollection and assessment of the first HCP.

**Interactive and respectful dialogue.** In each example of a HCP: caregiver partnership, participants voiced a belief that observations or suggestions made to HCPs would be seen as valid, valuable or important. Equally important, however, were dialogues about changes in the PWD or the plan of care. Participants valued HCPs' demonstration of the ability and willingness to engage in interactive and respectful dialogue, particularly when they made suggestions around changes in care.

"Lucille" described the importance of interactive and respectful interactions when she shared an experience of conferring with a relatively young HCP. In the excerpt below, Lucille explained:

"(the neurologist said), "They're going to have to give this to him today because he's very aggressive." And he (the neurologist) takes the time to tell me what medication is and why it's there. I'm not a med student here, you know? And there's emotion involved. And then he'll say afterward, do you give it to him and find some other way to protect him from being hurt or hurt? So no (I said), 'if this is your suggestion, I'm willing to go along with it, you know? This type of thing--I trust him even though he's a kid. He's very good at it -- and if I don't understand it? He'll explain it to me. I mean we get that full half hour. I mean it's usually just small talk at the end because he wants to make sure he's not observing anything else... I
don't mind driving down here to do... whatever to get him in there. And actually have this person be a person, you know? Not so clinical that we're just a number or a name or whatever." --Lucille

The importance of being able to ask questions, hear explanations, gain understanding and be part of the decision-making process around treatment was crucial to Lucille, as was the HCP’s understanding that "there's emotion involved." Lucille's respect for the HCP was evident when she described being able to trust the provider, "even though he's just a kid."

"Barb," whose father-in-law is in Memory Care Assisted Living, described the respectful and interactive collaboration that had developed with a geriatrician that she and her husband had selected for her father-in-law. She elaborated:

"now, (the geriatrician)... she calls me. She calls and says OK, this is what is going on, this is what I think, will you check her and see and get back to me, and that is what I do..., she says what’s going on, tell me what is going on? What do you think? She will talk to the patient first...then she will talk to me and say, what do you think. And I will give her the rest of the story. " --Barb

Acknowledgement from the HCP of the value of having Barb's perspective about the PWD and the issues at hand was an important part of the provider: caregiver partnership. The willingness of the HCP to reach out and engage Barb in dialogue, coupled with the respect that was demonstrated when the HCP asked Barb for observations contributed to Barb's evaluation of the relationship as a collaborative partnership.

**Mutual goal setting.** The final component of the partnership equation was illustrated by participants when they spoke of the need for mutual goal setting around care of the PWD. As Rachel indicated, what she wanted was for the HCPs to partner
with her so that they could all be "on the same side." Rachel's awareness that having her
mother be at "the center of it" would bring both sides together was evident when she
said:

"The sense is that some of the staff are angry with me (because of being an
advocate for her mom)...I want people to be on her side and say you know what?
This is an issue and how can I help?... really put her at kind of the center of it"
--Rachel

The idea of putting the patient's well-being at the forefront was likewise alluded
to by "Sam" as she shared her recollection of the months leading up to a transition to
hospice during her mother's care. Multiple medication options and non-pharmacologic
interventions had been tried with Sam's mother, yet none of the alternatives had relieved
her mother's evident distress. Sam advocated for a move to palliative care and asked the
NH staff to bring in hospice. Challenges continued to exist with the on-site NH staff,
however Sam and the hospice RNs were able to share a mutual goal of having her mother
be free from pain and to effectively partner in her mother's care. As Sam explained:

"Hospice helped. The hospice people that came in helped tremendously. They
were very helpful. Once they knew she was dying, they provided an aide to sit
there the whole time. The nurses were very aggressive with pain management
and helping to make sure that the other people did. The other nurses from the
facility were a little less aggressive. They would have held pain meds. And I said,
no, do not hold it. I said, if you go to touch her, she will cry."
---Sam

Reagan, whose wife, early on in her illness, had stressed the importance of quality
of life, captured the magic that occurs when a HCP, the caregiver and the PWD agree
upon mutual goals. He shared:

"We want best quality of life and it just seems like, ...there should be some
kind of a different, I don’t know, maybe people like you will come up with
a different plan.....I just get the feeling that (the neurologist with whom he
partners in care) cares about me and her ...just wants our quality of life to
be good and just wants to drop, to do anything to make that happen... she is compassionate and she really cares, which seems pretty unique in the medical profession nowadays." --Reagan

And in a final example that eloquently illustrated the mutual goal setting that took place in HCP: caregiver partnerships, Aubrey's voice again came to the forefront when she stated:

“I met with the doctor... ‘well what do you want for her? I said I want peace, I don’t want her to be on a ton of things, I want her to be able to be in a community without feeling lost, scared, whatever. So we dialed back some of the medications’” --Aubrey

The HCP caring for Aubrey's mother reached out to ensure that the overarching goal was understood and honored. Aubrey's concluding statement, that "we" dialed back some of the medications" was illustrative of her belief that she was a partner in the experience of providing her mother's care.

Summary. Five participants in this study shared examples of partnerships with HCPs. Common components of partnerships included availability of and accessibility to HCPs, willingness of both HCPs and caregivers to participate in respectful and interactive dialogue, and the ability of both parties to engage in mutual goal setting aimed at providing person-centered care for the PWD. When these three elements of partnership were present, providers and participants were able to communicate, collaborate and focus treatment around effectively and collectively meeting the needs of the PWD.

Knowing What Matters and Respecting Personhood

In Saint-Exupéry's classic, The Little Prince, the main character stands before a field of roses and tells them about his own single, very precious rose. His rose he
explains, is completely different from any of the other roses in the field. His rose is "unique in all the world." The little prince explained:

"Of course an ordinary passerby would think my rose looked just like you. But my rose, all on her own, is more important than all of you together, since she's the one I've watered. Since she's the one I put under a glass. Since she's the one I sheltered behind a screen. Since she's the one for whom I killed the caterpillars...Since she's the one I listened to when she complained, or when she boasted, or even sometimes when she said nothing at all. Since she's my rose."

Antoine de Saint-Exupéry, 1943, p.63

Each participant, during the course of an interview about meaningful interactions with HCPs, told the story of a PWD, who, like the prince’s rose, was unique in all the world. As the stories unfolded, participants directly or indirectly, described the importance of HCPs knowing what mattered. And, as with the prince, what mattered to participants was that HCPs knew, appreciated and honored the singularity of each PWD who stood before them, that they knew what mattered to caregivers and that they appreciated the importance of keeping each PWD at the center of treatment decisions.

**Know my person.** Participants described, through a variety of stories, the importance of HCPs seeing beyond a diagnosis and acknowledging the person that was present before the curtain of dementia descended. As "Aubrey" explained, "it's about how do I see them vs. how do you see them?" Aubrey visited her mother in a NH often and shared stories with staff of her mom over time. She described several of the interactions, then stated:

"I felt like I was smoothing out my mother’s rough edges ...kind of trying to create the person that she was that they couldn’t necessarily see in the person that was presenting themselves. But that wasn’t always
easy. Sometimes she was [candidly] the devil bitch woman from hell, but
in them understanding her story and what she fought through... in them
understanding her story and what she fought through, she was in her own
right, was an accomplished person.” --Aubrey

Aubrey described the importance of having her mother appreciated and respected
for the person she had been across her lifespan, not just as a PWD. Her hope, she
explained, was that staff would remember her mother's history when emotional or
behavioral dysregulation occurred, and in remembering that history, would understand
more about her mother's reactions to particular events on the unit.

Unlike Aubrey, who initiated the act of sharing her mother's story with staff,
"Stan," described the experience of having HCPs at a NH ask him for information about
his mother at the time of admission. The impact of having HCPs reach out to him was
profound. He described his first meeting with the HCPs at the new facility:

"and they said, tell us about your mother and what's
she, you know, it was like they were listening...they were really
caring. And you could tell that at the end of the day --Stan

As Stan explained, the staff didn't begin the interaction by asking about his
mother-with-dementia and what her functionality was at the time of admission. Instead,
they simply requested that he tell them about his mother. The distinction, Stan explained,
implied that his mother would be known and considered not just as a patient or resident,
but as a person....in other words, his mother mattered.

Conversely, many participants indicated that HCPs did not ask (or were perceived
not to care) about the person's premorbid history...or at least not in the depth that
participants thought would have been helpful. Many of those participants made
recommendations aimed at improving HCPs' ability to interact and collaborate effectively with both family members and the PWD; other participants simply explained what was missing.

"Meeker," described an interaction between her mother and a neurologist. The neurologist, Meeker explained, seemed to lack the skills and compassion needed to have a meaningful discussion with a PWD. Meeker described the initial assessment by HCP, in which her mother apparently answered a question about post-college work by stating that she was a stay-at-home mom. She then waited for the next question. As Meeker explained, the HCP "stopped right there" after her mother answered the initial question concretely. Meeker shared her observations and reactions:

"he's asking her about her background and where she went to school. My mother's a college grad. She majored in chemistry back in the day. Yes, she's a very, very, very intelligent woman. Then she got married and she worked at a Sears because that was the only job she could get. Then, once she started having children, she was a stay at home mom. She said she was a stay at home mom for a while... he totally dissed her. Like she wasn't even worth talking to anymore... My mother answered the immediate thing that happened after college, he didn't even ask about any of the 45 years that she was in the workforce that were all of these other jobs. He just stopped right there... you would think that he would have developed skills, personal skills, that you could employ. It was just so awful. "

-- Meeker

Meeker's perception, that her mother was not "known" or appreciated for her accomplishments and experiences over time, contributed to lack of appreciation for the neurologist's skill and worth. Her vehemence when she commented about the neurologist's perceived lack of personal skills spoke to the dismay and outright anger that she felt on her mother's behalf. Notably, Meeker and her mother did not have a second
appointment with the neurologist described in the interaction. Instead, Meeker searched for, and found, a different HCP.

In a similar scenario, Rachel, too, told of an experience with a group of HCPs at a NH who did not seem to understand the importance of taking time to obtain information about her mother's history. The HCPs' collective lack of awareness and appreciation for her mother's history had, in Rachel's opinion, dramatically affected her mother's adjustment to the NH environment and her interactions with staff. Rachel described her mother's somewhat idiosyncratic response to colors, a response that led, unfortunately, to negative interactions on the NH unit. Rachel explained:

"She happens to have a fear of colors, bizarre as it is. If you're wearing white, she's not going to like you. Unless you've lived with her, you wouldn't know that... Weird as it is. But you know what? This is about her... (it's about) communication and how do we accomplish her basic needs, isn't that what the nursing home is for? To make sure that they're safe and cared for?"

-Rachel

While Rachel acknowledged that her mother's actions and reactions were unusual, she also pointed out that "this is about her." Better communication, Rachel suggested, would have alleviated at least part of the problem and helped staff to understand and work with her mother differently and perhaps, more effectively.

Rachel, Sky, Stan, Meeker and Aubrey all shared stories about interactions with HCPs that highlighted the importance that the PWD to be seen, acknowledged and understood---that they be "known." Knowing the person, not just person-who-happens-to-be-diagnosed-with-dementia, was identified as a key factor affecting perceived quality of care.
Show Me That My Person Matters. Participants whose identified family member (the PWD) resided in long term care often shared descriptions of interactions between staff and residents at the LTCF. As part of those descriptions, many participants alluded to (what they perceived to be) respectful or disrespectful interactions between front-line staff and their own family member. The impact of observed interactions on participants was profound and highlighted the importance of being able to witness respectful, person-centered interactions between staff members and PWD. The presence or absence of such interactions contributed to participants' assessment of whether their own loved one "mattered" to staff as a "unique in all the world" person and not just one more body with dementia.

In the descriptions of staff: resident interactions that follow, much of what was shared by participants involved simple everyday courtesies. Specific examples of these courtesies included the importance of calling a person by name, speaking to a resident when passing, or ensuring that basic activities of daily living were attended to in a way that was representative of what the person, before dementia, would have wanted. As "Amy" stated:

"Everybody here is so patient and so kind. I remember...(even when) she had only been here just a very short time. They know everybody's name. They don't just walk by and say" hi." They say hi and the name of the person."--Amy

Something as simple as a name carried great power for Amy and contributed to her belief that her mother was known, respected and mattered. Amy's awareness that staff had "named" her mother contributed to her belief that her mother was being cared for in a warm and person-centered environment. She alluded to how quickly she had
noticed and registered, in her mind, the actions of staff when she pointed out that her evaluation of the facility and the care provided had been made when her mother had only been a resident at the facility for a short while.

"Silsbee," too, spoke of the need to observe respectful interaction between his wife and those caring for her. As he spoke about his wife, who was in an advanced stage of dementia, he shared two specific experiences that carried great weight in his evaluation of whether his wife mattered to either staff or other residents. The first interaction took place in a dialogue with staff, in which Silsbee explained that he wished the staff would stop and interact with his wife. Silsbee shared:

"I said, I wish they would stop and interact with her... That somebody would pay attention. (And they said) We don't when you're there because you're there with her. If you hadn't been there then we have and we met her walking down the hall, of course we'd stop. And we talk to her. I'm not at all sure that was the case. Maybe they did once in a while. Certainly they don't now."

—Silsbee

The difference between Silsbee's observation that staff is not interacting with his wife is in direct contrast to the second interaction, which took place between the Silsbee and his wife's roommate. During the telling of this second excerpt, his voice became reedy and weak. Silsbee explained:

"...and I remember she shared a room with some other woman and the woman said you know in the evenings your wife comes and sits on my bed and talks to me. She said, I don't always understand what she said. But it was very pleasant."

--Silsbee
After making the statement above, Silsbee began to cry. The importance on knowing that someone was interacting with his wife, was knowing her and treating her with respect, was significant and powerful as he reflected on his wife's care.

The importance of treating the PWD with respect was also highlighted by Martha, who reflected on time spent with her husband on an in-patient geriatric psychiatry unit. The depersonalization and lack of attention to personal care was enormously difficult for her to observe.

"It seems minor, but it was important to me that his razor, I took an electric razor, and nobody helped him shave. And that was one personal thing I could do with him, so I did, when they could find the razor. But most of the time, they couldn't find the razor. He was unshaven. He was very conscious of that. His clothes were an issue. It was very complex for me to try to persuade an aide to get clean clothes up in the closet somewhere, had to go. So he sometimes, he didn't have his own clothes on. I felt having his own clothes was terribly important for his identity." --Martha

Martha's experience of watching her husband, a formerly meticulous man, go unshaven and wearing clothes that were not his own, distressed her for multiple reasons. While she stated that shaving her husband was something she could do (and in fact often did), the staff was apparently often unable to locate the electric razor in question. Her ability to perform this simple task, then, was compromised. The issue of seeing her husband in clothing that was not his own was also traumatic, because, as Martha explained, her husband's clothing "was terribly important for his identity." As in the description of the missing razor, Martha's ability to ensure that her husband wore his own clothes was outside of her control. Her knowledge of what her husband would have wanted prior to his illness dictated the standard and the attention to particular details that were pertinent
to honoring her husband's personhood.

Martha later disclosed that her husband had been aggressive on the unit and that additional personnel, including Security staff, had been needed to control his behaviors. While she indicated that she understood that portions of what she witnessed on the unit were perhaps unavoidable, the reality of witnessing him in a state that he would not have tolerated or wanted prior to his dementia was extraordinarily painful and was reflected in her evaluation of his care during the hospital stay.

A similar observation came from Rachel, who shared a story of observing a resident interact with her mother at the conclusion of a shower. As Rachel explained, she walked onto the unit and watched the aide "wheel her around with just a couple of towels draped on her in the plastic wheelchair." Rachel didn't comment on whether her mother was aware of what was occurring, yet her tone, during the telling of this event, was one of incredulity. Rachel's own distress was evident as she turned her palms upward and then pushed her hands out as she stated during the telling of this story:

"treat people like you would want to be treated. Like you want to treat your mother. " Give them a little bit of, I don't know...You get to the point where you just numb off because you've screamed and you're the noisy one."

--Rachel

The need to respect the person behind the illness was a critical part of "knowing my person and showing that the person mattered" for participants. Each participant, when describing interactions with HCPs across settings, spoke of the need for HCPs to both have knowledge of the PWD's history and to honor that history by treating them with respect. Moments in which participants witnessed "the little things" that demonstrated respect and awareness of what mattered were held close to the heart and
shared with clear fondness for those involved. For those participants who shared "what was missing," their distress and awareness that what they were witnessing felt wrong was conveyed clearly, yet some of the participants struggled with finding a balance between advocating for respect for the PWD and with the awareness that they didn't want to be seen as problematic, themselves.

**Know What is Important to Me ...Include Me.** Embedded in participants' interviews were moments in which they conveyed a need to be seen, heard and included, themselves. Again, the words of Aubrey rang true, as she expressed something similar to what was described above about respect for the PWD, but in this excerpt, stated outright that the attention to detail was important to her as a caregiver. Aubrey described the morning ritual at the NH:

"Her aide who has been there for 11 years, she'll get them all up, I work with (the aide) to make sure her clothes, I'll ask where she is at with clothes and underwear and socks and stuff like that, she knows I like her to be dressed. Yesterday she had makeup on and her little fake jewelry, she looked phenomenal..."  

--Aubrey

As with Aubrey, both "Sam" and "Silsbee" explained that they wanted basic information about daily life and functional levels of their respective family members. Each explained that the moments that were important often came from the aides and that the simple things were often the most important:

"they're the ones actually taking care of her... It's the aides who get her up, and put her to bed, change her and feed her and so forth. They make a tremendous difference. The good ones...are wonderful... they seem to take more interest. Talk to me about her and how she is....and they know she ate a good breakfast..."  

--Silsbee

"(I wanted to know).... Is she continent? Does she know? More of the
daily life stuff. What is she eating? Is she interacting... those questions..."
The aides all knew the answers...and they were delightful. They were really nice. Nice, nice ladies....incredibly kind.. more hands-on. They would involve us. They’d ask, did I want to help...to do anything? Do I want to help feed her? Did I want to help with walking? They were much more apt to ask those questions. ...they just seemed to have more of an interaction with Mom." ---Sam

Amy described a need to be included in her mother's days and to be a part of her care during NH visits. She explained:

"(the physical therapist) talked about) how to walk with her how to hold the back of the belt. Just not stop her from falling but if she starts to go down just to make going down easy easier. So that she doesn't go straight down....and the activities director, sometimes. Which is helpful because if they go on a trip or something you want to hear that side of it if you're not there. How did they do? How did they respond? --Amy

The appreciation shared by Amy for both the physical therapist and the activities director was evident. The interaction with the physical therapist was particularly important to Amy, who wanted to be able to ambulate her mother safely. Amy's confidence in her own ability to walk with her mother was evident as she shared that the therapist had instructed her not to prevent her mother from falling, necessarily, but to make the descent "easier."

Though the majority of participants' focus was interactions between staff and the PWD, several participants alluded to a need that they (the participants) be known and respected as a family member. Their wish to be included, to the extent that it was possible, in their loved one's lives was evident in their words and the tenor of their voices.

Keep the PWD at the center. Several participants spoke of occasions when it appeared to them that the focus of care became facility needs, HCP needs or simply got
lost altogether. The suggestion to put the patient "at the center" of treatment planning and care delivery was made explicitly by "Rachel," though similar suggestions were made by others. As she spoke, Rachel acknowledged that each member of the team was important and an expert in a specific area, but that working together while keeping her mother at the center of treatment planning was crucial. Rachel described her idea:

"really put her at kind of the center of it and not whatever. Like I say, she could have so much more if they communicated better and really saw what's going on... think of a wheel. She's at the center and we're all experts in one area. It's not going to move until we all come together and focus on her."

--Rachel

Rachel's statement, that "it's not going to move until we all come together and focus on her" communicated her awareness of the importance of communication and teamwork. Her hope, as she later expressed, was that HCPs would become more focused, in the era of health care reform, with putting the patient at the center of the wheel.

The impact of a team approach and ensuring that the team focused on the residents was echoed by "Susan," who spoke in very positive terms about the staff at her father's current Memory Care ALF.

They get to know the residents, which I think really makes a difference. Like the receptionist does a baking class with them... they all interact, even if it’s not their job, it gives them that human connection, and you can really, again, it’s just back to human dignity, because that’s really the most important thing for my dad. For me, with my dad. And with my family, that’s what we’re looking for. We know he’s going to be getting worse. We know that."

--Susan

Keeping the patient as the focus was mentioned as part of "a broken health care system" and indirectly in the "partnership" sections of this work. While each example of
highlighting the need for collaboration has a slightly different tenor, the repetitive nature of the comments was notable.

**Summary.** Across the theme of "knowing what matters" participants shared their need to have their "person" be known and respected, to be known and included, themselves and to know that the PWD's needs were guiding treatment decisions. Examples provided by participants of meaningful moments included negative and positive experiences. Each experience highlighted, in its own way, the need to have the PWD and the caregivers, themselves, be seen as "unique in all the world."

**How Providers Can Help**

All participants were asked, during the course of their interviews, to offer suggestions about how HCP could better meet needs of caregivers. Some participants responded rapidly with suggestions, others pondered the question for some time before answering. Often, answers were situation-specific and given in the midst of interviews after describing a particularly challenging personal experience. In those moments, participants simply pointed out what would have helped them, in that exact situation, at that exact time. At other times, participants offered more sweeping suggestions aimed at changing the health care delivery in a more systemic way. Suggestion proposed, whether situation-specific, systemic, seemingly simple or complex, offered insight into ways that HCPs could improve practice, ensure more productive interactions with caregivers and ultimately, improve the care provided to PWD. Suggestions offered by participants were grouped into the following categories:

1) provide support and education for caregivers,
2) address communication problems,

3) reevaluate (your) roles and reclaim responsibilities as HCP, and

4) adopt a business model of health care delivery that stresses customer service.

**Provide support and education to help prepare caregivers for their roles.**

Several participants suggested that HCPs develop caregiver education materials and supports for caregivers of PWD. Specific suggestions offered included leveraging the use of technology, assigning a point person or coordinator for each PWD (and their family member), providing basic caregiver training manuals and offering specific tutorials on legal questions, Medicaid and selection of long term care facilities.

In one example offered, "Barb" suggested that HCPs develop an 'information and communication notebook for caregivers of PWD. The notebook would be given to each caregiver at the first meeting of the HCP and caregiver. Caregivers, she explained, would be asked to review information at home and write down questions for follow up. HCPs, in turn, would allocate designated follow-up time during appointments to review information, discuss questions and discuss a plan. Barb described her idea in the following excerpt:

"...it’s the doctor’s first meeting, hands them a booklet, short sweet and to the point, hands them a booklet and says look, I’d like you to read this and next time you come in, I would like you to write down your questions and what you need some answers to. I want you to read this first, and if it is something pressing, call me. Other than that, I want you to write, there is a sheet in the back here, write all of your questions. Write them all down and next time you come in, we will... give you extra time so we can actually answer those questions.

*They are doing most of the work by reading it, all they have to do is compile something like that, there are tons of things out there already that they could utilize. Have the person read it, do the feedback, the family could sit down, it would be a great family exercise. Sit down and read it all through, or maybe*
there is a video... this is what is going to happen, this is the progression that is
taking place, this is what we are going to do. Maybe it is something the
family sits down and learns about what to expect from what is happening."--Barb

Barb's suggestion incorporated both a HCP: caregiver contract for care and a
model for education and feedback in which both caregiver and HCP have "action items"
for follow up. Ultimately, three areas of need were addressed: education for caregivers,
a systematic structure to guide dialogue and time for interactive dialogue and an
emphasis on collaboration.

"Emery" also addressed the need for education, but added a different mechanism
for obtaining consistent guidance and support. Emery suggested that a contact person
should be assigned to each caregiver (or family) at the time of diagnosis or testing. A
"point person," she explained, could tailor information that was appropriate to each
caregiver and dispense that information over time. Suggested topics to be covered by the
point person included proactive strategies around problem prevention, completing legal
paperwork, and information about resources. Emery explained:

"Even if you were given a contact person and that person were familiar with the
Alzheimer's... that person can say these are the kinds of things that can become
problematic...? Or, another good thing to check for is if this happens, maybe the
next time it happens, you could do X, Y, Z. Or is this happening in addition to
that? Just like to talk about the process a little bit. The person, first of all feels
like they're being heard, but also that...whole process of like if you could catch
them sooner...do all of their paperwork.... So, there's lots of little things along the
way that if someone's helping you locate them and identify them, it could change
the whole process along the way...it would have been helpful if somebody had
some sort of generic guideline on the process... If you are worried about their
driving, this is where you can have them tested or what you can do or who to
call... because a lot of people don't even know that... Which the Alzheimer's
organization does quite nicely, but who would know? And why would you go to
that Alzheimer's organization if...you're just trying to figure out do they even (hae
Alzheimer's and what that means...it doesn't kick in soon enough...I also think
that that should automatically kick in a person that starts coordinating care
because there's too many others, there's all those other doctors, all those five million appointments that my mother ...

"Sam" and "Meeker" echoed the sentiments of Emery and Barb when they shared their respective observations. Sam stated:

"the more education they have at the beginning as far as what this road is like ... OK, I see your mom’s not eating well. That’s part of the disease process. This is part of it. It’s very disconcerting. We understand that. But educate them as far as what exactly that means so that they don’t all of a sudden say, oh my god, my mother’s lost ten pounds....."

--Sam

Meeker, in turn, observed that

"it would have been helpful to know what the appointment was going to be like. To say to my mother he’s going to ask you memory questions, which might be very simple or very difficult. He might hold up a penny and ask you what it is. Just so that she wouldn't have been, once she was insulted then she's just like not wanting to interact. Maybe even just know that. We're going there. He's going to ask you specific memory questions. That would have been helpful."

--Meeker

Barb, Emery, Sam and Meeker each highlighted the need for caregiver education early in the trajectory of dementia. Providing education and support proactively, they suggested, could prevent or lessen problems as PWD progressed in their illness and the caregiver role became more demanding.

In addition to addressing more global needs for education around the caregiver role and specific symptomatology of dementia, several participants provided very specific recommendations around regulatory or legal issues. The need to provide assistance and direction around Medicaid eligibility and policies were addressed by "Stan," who suggested developing a primer, of sorts, related to Medicaid. Stan's suggestion came in the midst of speaking of his own difficulties with getting a problem
rectified with his mother's Medicaid eligibility. His suggestion was short and to the point and his consternation with the system evident when he said:

"...do a one-pager (on Medicaid) to make it easier. I mean, how long does that take? --Stan"

Stan's frustration arose from an experience in which he spent long periods of time phone "trying to get a live person." After failing to resolve the problem using Medicaid's automated phone system, Stan sought guidance from an attorney, who discovered one question that was answered incorrectly. The attorney pointed out the question to Stan and told him, "they’re not really asking that, they’re asking something else." As Stan told this story, he looked at the interviewer, grimaced, then extended his hands, palms up, and open and said, "How would I know that? It’s in English." The idea for a Medicaid primer was a direct result of the experience.

"Aubrey" too, provided a suggestion that came from an experience that continued to haunt her. Aubrey explained that she made what seemed, at the time, to be a sound decision in selecting a LTCF for her mother. In retrospect, she realized that a different choice might have been better suited to her mother's needs. Aubrey described her experience and her wish to rewrite history, then suggested that having a tutorial or counseling session for caregivers would have helped:

"she (was) ten minutes closer to me, it seemed like the sun, moon and stars were aligning to say, this is the right move. ...it just was a nightmare, just a nightmare. She didn’t even last there 30 days...If somebody had counseled me and said.... you know, because my mother wasn’t blessed with riches, so when we she fell, hospital, rehab, can’t go home...(that facility)was in (a town close to me)... I was doing it for financial reasons, but nobody pulled me aside and said, I understand the financial reasons, but understand that where she is in her dementia, this might not be the best thing for her. If somebody had said that to me then, I might have reconsidered. I would have had to fight a family member to do it, but
God knows, I think family members are always that way anyway. In hindsight, yeah, it was the best and worst move for her. —Aubrey

Suggestions from participants highlighted needs for improved caregiver support, education and dedicated time with some type of HCP. Educational needs highlighted included both "basic training" for caregivers and more specific needs such as navigating issues with Medicaid and approaching the task of selecting a LTC facility. Each suggestion, whether it was birthed from a particular experience or came from looking at educational needs using broad strokes, offered insight into ways that HCPs can better support caregivers in their roles.

**Improve Communication between HCPs and Family Caregivers.** Several participants made suggestions about ways to improve communication within a long term care facility. Ideas proposed included setting up a caregiver "Bill of Rights for Long Term Care," having a structured agreement around communication and care planning that allowed for alternatives to in-person attendance at meetings, and a guide for what to expect during the first two weeks or month of a PWD's LTCF stay.

Recognition of his own challenges and the emotional upheaval that accompanied his mother's placement in a LTCF led "Stan" to suggest that:

"...they (the HCPs at the LTCF) could sit down and they could say, OK, sometimes, you know, because first of all, the day you're bringing someone in is very traumatic and difficult, right? Nobody wants to bring their parent or loved one to a nursing home. So OK, within the next two weeks, whenever you're ready, you know, we're here at some time blocks. We'd like you to come and we want to just sit and chat. This is what we're doing, blah, blah, blah." —Stan

Rachel addressed communication needs and the importance of the HCPs and designated family caregiver having an agreement for both pre-set appointment times to
discuss ongoing care needs and an understanding about notification related to changes in status, benefits or resident needs. In recognition of the challenges inherent in scheduling such meetings, she suggested that using Skype technology might be an option to allow those who were not physically present to participate. She went on to propose an using online tool that would allow caregivers to access information about their family member's daily activities:

"Probably a minimal once a month (there should be a care planning meeting or communication meeting), being realistic. Then, of course, when there's a problem. Figuring out exactly what she needs. Having every member of her team there. The psychiatrist... Have a plan together. Have something so that this is what the goal is, to get her so that she has her physical needs taken care of... have a plan together. Have something so that this is what the goal is, to get her so that she has her physical needs taken care of... "... say this is what your family member needs and this is what we can provide. There's a gap... say to me as a caregiver Medicare's cutting out or whatever. She's chronic and we cannot pay for a physical therapist. She needs it however...you may want to consider hiring somebody privately. Or something. It would be nice if it was in person but if that can't happen, then Skype.... It would be nice if I could actually pull up and see has she had or has she eaten today? Did she have her shower today?"

--Rachel

As with Rachel, Harry identified opportunities in which technology could be leveraged in a way that would assist HCPs in their work, promote communication and lessen anxiety of caregivers waiting for case managers to find a bed for PWD who needed a step-down from a hospital stay:

"I worked in computers and I could see no reason why there wasn’t a conventional database somewhere where they would actually know which beds are available and where, rather than picking up the phone and calling 10 or 12 locations, playing telephone tag. That got me a little nervous..."

--Harry

Sam also addressed the issue of communication with HCPs in LTCF. She did not propose a specific suggestion of how to actualize her request for "more conversation"
between HCPs at LTCFs and family caregivers, but expressed how difficult it was to walk a line between advocacy and aggressiveness in getting a family member's needs met. Sam explained:

"More conversations, more keeping up with what was going on. It took a lot of aggressiveness on my part to get them to call me when something was going on."

---Sam

**Take ownership for your roles as professionals.**

Throughout interviews, a number of participants referenced dissatisfaction with HCPs and spoke of their own perceptions that HCPs were not fulfilling their duties in an optimal fashion. Suggestions that directly addressed this perception were made by "Sam," Malala" and "Emery." Arguably, these suggestions could also fall under the "health care system" challenges, however both Emery and Sam referenced HCPs needing to do specific things differently, eg. "change their lists," get more involved, " or address an issue that "should be on your doctor thing." Items mentioned were directly related to job performance and expectation, so were included here.

Malala and Emery suggested actions related directly to addressing PWD at time of diagnosis. For Malala, the focus was on explaining to both the PWD and the caregiver, what the diagnosis of Alzheimer's disease meant and how it might affect her functioning. She explained what would be helpful to both the PWD and the caregiver:

"I think it would have been helpful to first of all if he described to her that she had Alzheimer's, that she had mild to moderate or whatever he was deciding she had. And how that could show up in her everyday life, which would have been helpful to her, not that she would necessarily remember. But it would certainly have been helpful to us to know what that means. There's all sorts of things beyond can't remembering. I mean there's perception issues and all these other things that you never hear about until someone thinks to tell you that... He just basically said have this medication. I'll see you in three months." --Malala
Malala's closing statement, "He just basically said have this medication. I'll see you in three months" captured the frustration that arose when a HCP failed, in her opinion, to fully carry out what she believed were his duties as a professional.

Emery, too, stressed the importance of the HCP speaking directly to the PWD, but went one step further when she suggested that in addition to providing explanation, the HCP needed to provide actual direction about the need to designate someone to be an official contact, representative or health care proxy. In the example provided, Emery was explaining what she believed HCPs needed to hear:

"I think at that point you need to say to my mother and to us this is serious thing. This can affect your ability to make decisions. This can affect your ability to do X, Y, Z. And say to her if you have decisions, you should be consulting with them. They should be on your doctor thing. They should da da da da da da. Because in retrospect, she nearly canceled or changed her health insurance. .. There's just so many things that can go down the drain before you even know that your family member has this very serious thing that can impact all over the place." --Emery

Sam's offering, in contrast, related to involvement of HCPs and rethinking of goals and priorities, particularly around the issue of "goals of care" discussions and end of life treatment. Sam's perception of both a strong focus in healthcare of simply checking off a "box" on a list of specified actions and what she perceived to be a focus on "prolonging the inevitable" led her to offer the following suggestion:

"get social work involved and get nursing more active...as far as proactive. . Help people change their “lists” It seems like the goal is so heavy towards prolonging an inevitable situation. So when it reaches a point where someone’s got no quality, or not the quality of life they’re looking for, then we need to support to say, OK, let God take over now. Let God take over... I think we need to start helping people plan for death on diagnosis ... involve hospice...It’s kind of like discharge planning on admissions. You start your discharge planning when somebody comes in. With Alzheimer's, you need to start thinking maintenance,
yes, how do we do this, but not to be afraid of what’s coming up and helping them know what’s normal, what’s not normal.” — Sam

Several participants suggested areas of focus for HCP which, if addressed would improve HCP interactions with caregivers and care of PWD. Suggestions from participants addressed discussion and education of PWD about the realities associated with the diagnosis of dementia and the need for HCPs to become more involved in goals of care discussions.

Use best business practices to develop better customer service. Many participants addressed a distinct lack of focus in healthcare on both the caregiver experience and the experience of a PWD. "Stan," who had a background in business, indicated that in healthcare, overall and in NH, specifically, the focus needed to be shifted from what is easier for HCPs to what is better for consumers. Stan had had both negative and positive experiences in NH settings over a period of a year. As a businessman, his observations of the flow of operations in several NHs led to the following suggestions:

"I think this place (the NH) could act like a professional service organization, ...at the very beginning, say, 'here’s what the next seven days are going to look like, here’s what the next 14 days... And by the way, you know, we have a care meeting. If you have any questions, you can always call this person, blah, blah, blah. You know, I mean, to me that’s just normal, like, you know, that’s like, even the equivalent of the manager at the restaurant coming and saying, Lesley, we’re so glad you and your friend are here, you know, the scallops are the hot thing tonight, and if there’s anything I can do, just ask for you, you know? You immediately feel better, even if you never complain or ask for anything, you think, wow, that’s kind of cool. The manager cares enough. I think nursing homes are missing that, because I think they, as much as they try not to be, we’re talking about a product, and the product is people who are old and dying.

Nobody does this. I just don’t understand it. They don’t want outliers. They don’t want somebody to come in and say, OK, on the second day I want you to do this
with my dad. They want to be able to, and I understand that. They want to be able to say, this is what we're doing...I had a good friend who taught me about, you know, about the idea of when you have clients, having a unique client experience. So that the experience at one place, you know, how do you win clients? The experience has to be so much better." --Stan

The observation made by Stan, that health care, in general, lacked a customer service focus led him to suggest that business practices be incorporated into healthcare, overall and LTC, specifically. His belief was that providing consumers with a clear set of guidelines about what to expect and changing the focus to one of the consumer experience could lessen or eliminate future problems in the NH setting.

**Summary.** A number of participants offered suggestions for HCPs about how they could better meet the needs of PWD and their caregivers --how they could "do it better."

Suggestions included incorporating caregiver education, improving HCP: caregiver communication and adopting best business practices so that health care has more of a consumer focus. Suggestions, for many, stemmed from particularly problematic encounters and were aimed at solving very specific problems. Other offerings were more global or systemic, and accordingly, more complex.

**Conclusion**

Meaningful interactions with HCPs were described in both negative and positive terms and occurred across the trajectory of illness in a variety of settings. Central themes included the presence or absence of partnership with HCPs, the importance of knowing what mattered and retaining personhood, identification and utilization of resources and navigation of a complicated health care system that was not designed for PWD.
Suggestions offered by participants for improving the caregiver experience centered around changes needed in the health care system and recommendations for HCPs, themselves.
CHAPTER FIVE

Discussion

In Chapter Five, I present a brief overview of the study, provide interpretation of the findings within the study and compare findings to relevant existing literature. I then discuss limitations of the research and identify implications for practice, education and policy and scholarship.

Introduction

The primary purpose of this qualitative descriptive study was to describe characteristics and content of meaningful interactions between HCPs and family caregivers of PWD as seen through the collective participant lens. A secondary purpose was to understand ways in which family caregivers obtained information or resources that facilitated preparedness for managing uncertainty associated with providing care for persons with moderate to severe dementia. The theory of social justice provided by Powers and Faden (2006) served as the moral foundation upon which the study was grounded.

The study addressed a gap in our understanding of the caregiver experience of interacting with and obtaining knowledge from HCPs throughout the caregiving process and provided knowledge about what creates a meaningful interaction from the perspectives of family caregivers of PWD. Findings were reported using everyday language to ensure allegiance to the words and tenor used by participants during interviews. HCPs in this study had the opportunity to address and impact many, if not
all, of the six core dimensions of well-being outlined by Powers & Faden (2006) through meaningful interactions with caregivers. The degree to which core dimensions of well-being were affected depended upon the relative positive or negative impact of the interaction on the caregiver.

**Major Findings**

Three themes stood out as central in family caregivers' accounts of meaningful interactions with HCPs. These themes permeated interviews in which participants described both negative and positive meaningful interactions with HCPs. The themes were: 1) challenges of obtaining care for a PWD in what was perceived, by participants, to be a broken healthcare system; 2) relationships with HCPs and the impact of partnership; and 3) the importance of knowing what mattered to each caregiver: PWD team. Each of the three themes played a role in impacting caregiver well-being in one or more of domains identified by Powers and Faden (2006) and are addressed in the sections that follow.

Interactions that carried negative emotional valence often resulted in participants expressing fear, abandonment, sadness, loneliness and anger. Positive interactions, in contrast, resulted in certainty, trust and a sense of stability. Although most participants experienced a combination of negative and positive interactions with different HCPs and in settings across the health care system, some participants were able to have “corrective experiences” in which negative experiences were replaced by more productive and helpful interactions with HCPs. In this way, positive interactions acted to reset the dial on HCP: caregiver relationships and allowed participants to identify moments in which
needed information or support made a substantive difference in outlook, preparedness or ability to manage the caregiving role.

Strategies used to obtain information and manage uncertainty associated with the caregiving role included attempts to access both formal and informal resources. Attempts to access resources and obtain information were most often described as occurring in moments of crisis or transition and were often aimed at addressing specific issues or gaining emotional or social support. As participants described their experiences, many offered suggestions aimed at improving the quality of interactions with HCPs or at improving the health care delivery system, itself, as it related to care of PWD and family caregivers.

**Obtaining care for a PWD in a broken healthcare system.** All participants referred, at some point during the interview, to the difficulty of obtaining information from or interacting with HCPs in a system that was simply not designed to accommodate the needs of PWD or their caregivers. Challenges identified by participants included ineffective communication with HCPs across settings and disciplines, rules aimed at care designed for the majority of health care consumers accessing care rather than attention to individual needs, and HCPs who were perceived to be emotionally and physically unavailable and as lacking adequate training for providing care to PWD and the caregivers.

Meaningful interactions, in the context of a broken healthcare system, were most often described using negative terms. Interactions were described as being unsatisfactory in frequency, scope, practicality or delivery of information and centered predominantly
around physicians. Equally important, however, was the near-total absence in this section of reference to nurses, nurse practitioners, social workers or other providers. The absence of nurses in descriptions of meaningful interactions suggested not only fragmentation of the health care delivery system, but also a lack of focus by nurses on the endorsed aims of the discipline.

Often, meaningful interactions described by participants centered around moments of crisis or transition. Examples included the diagnosis of dementia, a need to address specific issues such as driving or living independently, treatment of medical issues, hospitalization, code status or long term care placement. Participants who described such examples often referred to HCPs as being unwilling or unable to spend time in conversation about treatment or treatment options, unwilling to generate referrals, avoidant of difficult conversations with the PWD or failing to fully execute and communicate needed information. Accordingly, interactions in this context were identified as meaningful because of emotional repercussions for participants. Participants verbalized feelings of anger, hurt, disillusionment, worry that PWD would receive inadequate or unneeded treatment, or that their own attempts to advocate for their PWD would lead to negative consequences for either the PWD or themselves.

A subtheme within this category that caused particular ire for participants was "rules for the many versus attention to specific, individualized care." Ironically, the issues raised by participants centered around practices that had been put in place to ensure that safe, evidence-based care was provided in a standardized and complete fashion. And, as participants pointed out, those practices made sense ...unless the care
recipient was a PWD. Specific examples highlighted included pre-surgical teaching, preventative testing, and a requirement for confirmatory lab work before providing treatment for urinary tract infections. HCP: caregiver interactions around the above issues were seen as problematic because HCPs were seen as unwilling to deviate from established guidelines in order to address needs of a PWD in a way that, to participants, made sense.

Core dimensions of well-being (Powers & Faden, 2006), including health, self-determination, respect, attachment, and reasoning were affected in negative ways as caregivers interacted with and attempted to gain support from HCPs in what was perceived as a broken health care system. Each of the domains is addressed separately for purpose of explication, however, domains of well-being are interactive and must be seen as part of a whole.

As many participants described previous interactions with HCPs, the negative impact of the described event on the emotional well-being (health) of caregivers was often visibly apparent. Some participants shared the impact of interactions through outward displays of tears, physical gestures such as gripping the arms of chairs or punching the air and told of interactions using quavering voices. Others verbalized fear that their own actions or anger displayed during specific interactions with a HCP would result in repercussions for their respective PWD. Self-determination was affected as caregivers met with challenges or barriers to enacting either their own wishes or the known wishes of their PWD. Respect was compromised when efforts to engage HCPs in discussion were dismissed or when participants spoke of feeling unseen or unheard.
Finally, the impact of negative interactions on the ability to engage in reasoned decision making was impacted as participants attempted to make decisions without needed information or support.

**Relationships with HCPs and the impact of partnership.** Some participants identified strong partnering relationships with HCPs that rose above any challenges that were system-related. Characteristics of participants in self-described partnerships with HCPs included any or all of the following: a background in a medical or human services role, prior experience of seeing a collaborative partnership with a health care provider played out in a positive way, and self-identification as an information-seeker. HCP characteristics, in comparison, included willingness to be accessible, to respond to queries or concerns in a timely manner, to engage in respectful and interactive dialogue and to engage in mutual goal setting aimed at effectively and comprehensively meeting the needs of the PWD.

Partnerships often began when a HCP demonstrated receptivity to inquiries by the participant or when HCPs addressed issues of social or emotional support. Corrective emotional experiences occurred when participants experienced their own needs being met and when needs of PWD were acknowledged and addressed. Participants who were able to participate in partnering relationships expressed appreciation, satisfaction and trust in HCPs providing services for the PWD.

When both HCP and caregiver were committed to creation of a partnership role, caregivers owned responsibility for keeping providers informed and often, for following up on specific details. Trust, respect and collaboration also created a relationship in
which HCPs did not need to be perfect in either their professional skill or interactive style. Instead, HCPs with whom a partnership had been built simply needed to be competent, genuine, honest and willing to refer to other providers when help was needed. The presence of partnership allowed inclusiveness and interdependency for caregivers as active members of the health care team, collaboration between caregivers and HCPs and mutual responsibility for meeting the needs of the PWD.

The impact of partnership on domains of caregiver well-being was an almost exact opposite from what occurred in the broken health care system. Participants verbalized the positive effect of partnership by indicating that they felt respected, informed and engaged with the identified HCP in meeting the needs of the PWD together. In this way, partnership addressed domains of respect, decision making and self-determination, contributing to overall well-being of participants. The impact on health, while not measured, was observed as participants made eye contact, smiled, verbalized trust and stability in the knowledge and visibly relaxed as they indicated that they had partners upon whom they could depend.

**The importance of knowing what matters to each caregiver: PWD team.**

All participants described both negative and positive meaningful interactions in which it became apparent that HCPs knew (or did not know) what "mattered" to participants and PWD. What mattered to participants in this study was that HCPs demonstrated an understanding and appreciation for personhood of the PWD, knowledge of the treatment goals of both caregiver and PWD, respect for the PWD and willingness to include their respective caregivers. The idea of being "known" was one that was of
primary import to all participants. When participants perceived that the PWD was not seen or appreciated in a holistic manner, they expressed anger, disgust and sadness. When describing such moments in interviews, they often lashed out, figuratively and with gestures, at the invisible HCP. The importance of having HCPs know, understand, appreciate, honor and respect the individuality, needs and wishes of each caregiver and PWD team was identified as a critical need for participants. As with partnership, positive interactions between HCPs and participants that centered around knowing what mattered had the power to act as corrective experiences. When caregivers believed that they were seen and acknowledged as individuals and, perhaps more importantly, that the PWD was acknowledged as unique and honored as a whole person, the level of trust and spoken level of satisfaction with care increased dramatically.

As with the themes of partnership and the broken health care system, multiple domains of well-being were affected when providers knew what mattered to PWD and their caregivers. As with partnership, well-being was impacted in a positive fashion, particularly in domains of self-determination and respect.

**Strategies used to manage uncertainty.** Participants attempted to manage uncertainty by accessing both formal and informal resources. Formal resources described by participants included a variety of interdisciplinary HCPs and the Alzheimer's Association. Participants who accessed formal resources did so most frequently, though not exclusively, in the context of a crisis, or with regard to a specific question or event. Reasons provided for accessing formal resources included specific attempts to gain information that would further their understanding or guide them toward next steps. The
Alzheimer's Association was singled out as being particularly helpful and as having a wide variety of resources ranging from a 24 hour telephone support service to educational materials and support groups for PWD and their caregivers.

Proactive (non-crisis oriented) guidance was actively sought from formal resources by only a small number of participants. Interestingly, those participants were self-described "information seekers" and were most often the same individuals who described being in partnerships with HCPs. In addition, those individuals were often employed (or had been employed) in health care settings or were actively involved in running their own businesses. The comfort level and proactive approach demonstrated by participants who proactively sought out information was attributed, by participants who worked in health care, to knowledge about the workings of the health care system, a history of collegial relationships or simply lack of fear or worry about interacting with HCPs across disciplines. For participants who came from business backgrounds, the familiarity with thinking proactively and strategizing about potential problems rather than reactive measures was a learned skill. This finding suggests that HCPs may need to coach or teach family caregivers to proactively anticipate and plan for change. Additionally HCPs may need to help caregivers learn about navigation of the healthcare system and actively outline ways in which they, as potential resources, can be helpful.

Informal resources identified by participants included literature, internet resources, lay community supports, friends and other family members. Family members, friends and community supports were most often accessed when participants either needed social support or when they wanted to provide support for a peer. Specific
literature was used by participants to try to find likenesses to their own situations and thus "normalize" their roles as caregivers. Most participants utilized informal channels exclusively until they found themselves in a health care setting at a time when a specific question or crisis arose.

**Participant reflections: How HCPs can help.** As part of the interview process, participants were asked for suggestions about how providers could be more helpful in supporting caregivers in their roles. Participants offered many suggestions, ranging from ways that educational tools could be incorporated in regular appointments with HCPs to ways in which HCPs could address their interpersonal and interactive styles of communicating.

As was the case when participants answered overarching study questions, the focus was on systemic issues and communication. Particular suggestions included incorporation of and focus on customer service measures as part of health care delivery, including time for dialogue in HCP appointments with caregivers and a renewed commitment by HCPs to reclaim their professional responsibilities to engage with caregivers and PWD around topics such as goals of care, diagnosis and changes in autonomy.

**Findings Related to Existing Literature**

The review of existing literature indicated that family caregivers, as a group, are unprepared for the emotional, physical and practical challenges associated with caregiving (Alzheimer's Association, 2011a; Birch & Draper, 2008; Caron, et al., 2005; Ducharme, et al., 2011; Family Caregiver Alliance, 2009; Givens, et al., 2009; Hebert, et
Systemic challenges of the health care system that contribute to lack of preparedness for caregiving have been cited across a broad span of studies and time (Alzheimer's Association, 2011a; Birch & Draper, 2008; Caron, et al., 2005; Ducharme, et al., 2011; Givens, et al., 2009; Hebert, et al., 2009; Maizes, Rakel & Niemiec, 2009; Mitchell, et al., 2009). Additional contributory factors affecting preparedness include uncertainty about the caregiver role, inadequate preparation for decision-making, lack of knowledge of the disease process and potential treatment outcomes, feelings of isolation, and infrequent, ineffective communication with HCPs (Dreyer, et al., 2009; Givens, et al., 2009; Hebert, et al., 2009; Kiely, et al., 2008; Reinke, et al., 2008; Samia, Hepburn & Nichols, 2012; Shanawani, et al., 2008; Strachan, et al., 2009).

Sadly, the experiences described by participants in this study do not indicate that significant progress has been made in addressing many of the factors affecting preparedness for caregiving for a PWD. Instead, findings from this study provided confirmatory evidence supporting the work of the many previous authors cited, particularly around systemic issues including lack of provider availability, lack of person centered care and rules governing practice that failed to meet the needs of PWD. Challenges related to HCP: caregiver communication were also specifically addressed by participants in this study and again, findings were congruent with prior literature.

This study extends previous knowledge by offering specific suggestions from participants about ways to address systemic barriers and ways that HCPs can better prepare family members of PWD for the caregiving role, improve the caregiver
experience of working with HCPs and support them through development of collaborative partnerships aimed at effectively managing ongoing care of PWD. Each of those items will be addressed in sections that follow.

This study also supports the claim that communication and an understanding of caregiver needs are key elements of meaningful interactions between caregivers, PWD, and HCPs (Mitchell, et al., 2009; Shega, et al., 2008; Washington, Meadows, Elliott & Koopman, 2011). Findings from the study provide a new lens for examining meaningful interactions between HCPs and family caregivers by offering descriptions of caregiver perspectives on what they define as meaningful interactions.

While in the original studies, "meaningful" was interpreted to be positive, findings from this study demonstrated that when caregivers were asked specifically about meaningful or significant interactions, they included both positive and negative interactions and included examples from multiple HCP interactions. In addition, although most participants had experienced multiple negative interactions, many demonstrated, in telling their stories, a willingness to effectively "give HCPs another chance" and open the door to the possibility of a corrective experience in which a negative experience could be replaced with a positive one. Corrective experiences, in turn, allowed participants new opportunities to connect with HCPs, develop positive working relationships and to experience additional levels of support and guidance as they moved forward in their caregiving roles.

Despite recent focus on health care reform and passage of the Affordable Care Act, it appears that few inroads have been made in addressing issues of communication
between HCP and caregivers of persons with dementia (Alzheimer's Association, 2011a; Naylor, et al., 2012). While individual HCPs were cited as being particularly effective, the experience of negotiating care in broader system remained largely unchanged. The importance of continuing efforts of health care reform focused on care collaboration, Accountable Care Organizations and person-centered medical homes is evident in the light of participant experiences in the current health care environment.

The value of developing HCP: family caregiver partnerships around care of PWD has been discussed by researchers in long term care settings (Bramble, Moyle and Shum, 2011) and in a collaboration between the Veteran's Administration and the Alzheimer's Association (Bass, et al., 2013). In both examples, partnerships between caregivers and HCPs or groups of providers were instrumental in improving caregiver outcomes. Specific areas of improvement included increased knowledge, decreased stress and improved satisfaction with care (Bramble, et al., 2011) and a decrease in depression scores along with increased use of support services (Bass, et al., 2013). While the two studies mentioned offer examples of intervention studies in which short-term gains were obtained, this study builds on both works in that it provides clear direction about specific elements of partnership that participants found to be meaningful.

Finally, this study validates and provides an opportunity to extend the conceptual model of preparedness proposed by Hebert and colleagues (2009) as a tool to guide clinical practice. In the model, caregiver life experience, uncertainty and communication are depicted as affecting caregiver preparedness for bereavement. Caregivers manage uncertainty by seeking information and assimilating that information into existing
working knowledge. Communication, in the conceptual model of preparedness, includes both content (knowledge) and relational aspects of interaction. A bidirectional link between communication and uncertainty suggests an iterative process, in which dialogue occurs between individuals involved. The element of life experience, while not directly modifiable by HCPs, provides information about previous coping strategies and decision making experience around treatment choices. The conceptual model was supported by findings in this study through several pathways. In the first, a participant explained that modeling of the partnering relationship with a HCP had been provided by her mother. In the second pathway, caregivers explained that multiple family members had been affected by a form of dementia or other progressive illness. In both of these scenarios, participants described themselves as better prepared to navigate the health care system and more familiar with ways to interact with HCPs.

It is important to note that the model by Hebert and colleagues (2009) was not constructed explicitly for caregivers of PWD, but rather developed as a tool for understanding caregiver preparedness for death of a loved one with a terminal illness. The findings of this study are supportive of the exploratory work, but extend it to include impact of HCP: caregiver communication throughout the caregiving trajectory.

Specific areas of expansion or extension of the model proposed by Hebert and colleagues (2009) include replacing the communication element of the model with the more comprehensive construct of partnership, adding the construct of well-being to the model, and including assessment of caregiver needs and response to care as an overarching element that spans the entire conceptual model.
Replacement of communication with the construct of partnership expands the model to include interactive and respectful dialogue, mutual goal setting and availability of the HCP to provide guidance. Expansion of communication in the model is needed to address the experience of caregivers in this study who suggested that isolation can exist even when dialogue occurs. The isolation or loneliness experienced by caregivers in this study is congruent with accounts of caregivers cited in NAPA report, who reported being confused and left "without a road map" (Alzheimer's Association, 2011a, p. 26) to decide on next steps in care or address problems. The partnership construct moves the communication element in the existing model forward and addresses the need for connection and availability of a perceived ally in the caregiving experience.

The need for ongoing assessment of caregiver knowledge, support and response to care was illustrated in participant descriptions of interactions with HCPs over time. Participants in the study expressed a variety of needs, including the need for explicit directives, emotional support, generalized information about dementia, guidance toward additional resources and intervention with the PWD around issues related to autonomy. For many participants, needs changed over time and circumstance. The ongoing changes in both breadth and depth of needs described by participants suggest that individual tailoring of interventions is needed, not only for individual caregivers and PWD, but also for those same caregivers at different points in time.

Assessing response to care provides a feedback loop to ensure that needs of caregivers were understood and met. In addition, the feedback loop provides a mechanism for evaluating caregiver response to HCP interventions or guidance.
Well-being of caregivers was not a direct measure in this study, however, the qualitative reports and affect demonstrated by participants in this study as they described both negative and positive meaningful interactions suggests that a link between communication, preparedness and caregiver well-being exists. Well-being, as described by Powers & Faden (2006), is evaluated across multiple domains. Deficits in one area impact well-being in related domains. The broad measure of well-being, then, is evaluated comprehensively. The exact mechanism for evaluation of well-being is not yet defined, however given the importance of the construct, an assessment tool, including both subjective and objective caregiver data, is needed. Design of such a tool should include input from caregivers and from HCPs.

The findings above give additional substance and direction to the priorities and recommendations highlighted in current policy initiatives put forth at the Ware Educational Summit (Naylor, et. al, 2012), in the NAPA report (Alzheimer's Association, 2011a) and in the National Strategy for Quality Improvement in Health Care (U.S. Department of Health and Human Services (DHHS) (2013a). Each of those reports highlights a critical need for improved training for HCPs aimed at providing compassionate, person-centered care for PWD and their family members. Additional recommendations include focus on developing partnerships between HCPs and family caregivers, the need to implement evidence-based best practices and need for a "responsive" care delivery system for PWD and their families that addresses individual needs across settings and contexts (Naylor, et al., 2012; Alzheimer's Association, 2011a; USDHHS, 2013b).
**Study Limitations**

Although this study yielded new insights in caregiver experiences and perceptions of meaningful interactions with HCPs, several limitations were present. The study sample size was adequate to allow saturation to be reached, however the study settings, located in and around one of the country's largest medical communities, potentially impacted study findings. Additionally, the sample consisted of only English-speaking, Caucasian participants. Additional study is indicated to include both ethnically diverse populations and rural populations.

As with any study using only one component of a treatment dyad, a limitation exists due to the absence of perspectives of HCPs. The goal was to obtain participant experiences and truths, however obtaining the perspectives of both HCP and participants would have allowed a broader lens to be used in evaluating results. The disconnect between HCP and caregiver perspectives is best understood when the words of both parties are heard at similar points in time.

**Implications for Policy**

Findings from this study have implications for policies that revolve primarily around redesigning care to better meet the needs of PWD and their caregivers. Participants in this study described a fragmented health care system that is not designed to meet the needs of PWD or their caregivers. Designing a system that is better equipped to provide care for PWD and their caregivers is the first step toward changing the culture of dementia care. Accordingly, several specific recommendations emerge.
A Dementia-Ready or Dementia-Focused System of Care. The move to design a dementia-ready or dementia-capable system of health care accelerated when the Department of Health and Human Services (DHHS) and the Administration on Aging (AoA) released a recent request for funding proposal entitled Creating and Sustaining Dementia-Capable Service Systems for People with Dementia and their Family Caregivers (UDDHHS, 2013b). The proposal is focused on designing a home and community based system that better meets the needs of PWD and their caregivers. The request-for-funding proposal represents a critical juncture in beginning to change the way that care for those with dementia is delivered.

In continuing to expand on the idea of "dementia-ready" system of care, stakeholders in Wisconsin convened in October, 2013, to discuss ways to improve care across community settings. Priority recommendations from that group included: increasing community involvement and support, implementing a coordinated care effort using professionals trained in care of PWD and familiar with the needs of caregivers, addressing regulatory issues related to managing of challenging behaviors in facility settings, creating incentives for best practices specific to dementia care, creation of crisis teams to address emergent needs and creation of a special facility aimed at caring for especially complex and behaviorally challenging individuals (WDDHS, White Paper 00563, 2013, October). Notably, both of the initiatives described above are congruent with recommendations made at the Ware Invitational Summit (Naylor, et. al, 2012) and the NAPA report (Alzheimer's Association, 2011a).
While both of the initiatives represent enormous steps forward in redesigning dementia care, neither fully met the criteria for creation of a dementia-ready system as highlighted by the findings of this research. In order to meet the goal of a truly dementia-capable system, primary, secondary and tertiary medical care settings must be included in care design. While the current focus of many interventions is to support PWD and their caregivers in home settings, that goal is often not achievable or is intermittently interrupted when exacerbations of medical comorbidities occur.

PWD living in home settings, even in the context of extended community supports, eventually require 24 hour supervision to ensure safety. For many family caregivers, external demands of both work and private life, combined with fiscal realities, simply do not allow for ongoing care in a home setting to exist. Community supports are unlikely, given the fiscal climate, to be available for 24 hour care. Factors influencing the ability to remain at home include behavioral dysregulation, increasing medical needs, and health of the caregivers themselves. In addition, the exclusive concentration on community settings risks alienating caregivers who are unable to keep PWD at home and has the potential to create real or perceived moral judgments about family caregivers who are not able or do not choose to care for a PWD in a home setting.

As participants in this study described, care in acute care medical hospitals is far from dementia-capable or dementia-ready. A key policy initiative that builds on the current proposal by the USDHHS and the AoA must be pursued to ensure that HCPs across settings are educated and skilled in care of PWD and attentive to the needs of their caregivers. Ideally, taking the initiatives proposed for outpatient and community care and
adding complementary acute care initiatives can begin to ensure that a seamless blanket of care exists for PWD and their caregivers.

**Recovery-focused Treatment.** The current treatment modality upon which dementia care is executed is based on a medical model of illness. Revising that approach to one of a recovery-focused model, while initially counter-intuitive, is one approach to empowering consumers and developing collaborative partnerships between HCPs, PWD and their caregivers.

The recovery-focused model, developed for use in mental health nearly a decade ago, was initiated as part of an ongoing initiative to the change culture of care in mental health. It is endorsed by both Substance Abuse and Mental Health Services Administration (SAMHSA) and the U.S. Department of Health and Human Services (DHHS) and has slowly infiltrated mental health treatment across the country.

Although dementia care is not generally thought of in terms of a recovery-based model, the principles of the model are easily applicable to care of PWD and their caregivers (Murray & Boyd, 2009). Core principles identified in the recovery model, include: holistic, person centered care, a focus on balancing independence and interdependence, choice, growth, empowerment and hope (Farkas, Gagne, Anthony & Chamberlin, 2005). Involvement of caregivers and PWD in recovery-focused care encourages participation, responsibility for personal growth, choice, focused learning and self determination (Murray and Boyd, 2009), which in turn, contribute to well-being across the domains of well-being described by Powers and Faden (2006).
Given the multiple challenges outlined by participants in this study and ongoing communication and systemic challenges of the health care system, adoption of a recovery model may well be a key element in refocusing efforts to empower and include caregivers and PWD in designing care for those affected by dementia. Notably, included in this process are specific requirements of HCPs to meet with identified clients and participate in lock step with them throughout the care planning process. Additionally, connection with a peer who is familiar with the stressors and challenges of dealing with dementia, procuring additional resources and negotiating various systems provides normalization and support to what is undeniably a difficult process.

Implementation of a recovery-based model is undeniably a culture change. As such, a first step is introducing HCPs focused on care of PWD and their caregivers to a recovery model. The most natural evolution of such a culture change is to begin with HCPs in psychiatric hospitals or outpatient psychiatric settings, as those providers are most likely to be familiar with the model as proposed for use with persons living with other psychiatric diagnoses. As part of an initial surge, including organizational leaders at hospitals, outpatient centers and respective State Departments of Mental Health (DMH) in discussion likely adds to the ease of information dissemination, as has been the case with other initiatives in psychiatric care (e.g., decreasing restraint use, increasing use of sensory interventions).

Implications for Practice

Results of this study suggest that meaningful interactions with HCPs, whether negative or positive, impact caregiver well-being and that challenges exist for caregivers
attempting to manage uncertainty related to the caregiving role. While multiple findings provided insight into the caregiver experience, two findings in this study were particularly surprising. The first surprising finding was interpretation by participants of the word "meaningful." The second was the near-complete absence of nurses in participant accounts of meaningful interactions. Both findings have implications for nursing practice.

In the original conception of the study, the word "meaningful" was chosen as a descriptor of significant or important interactions between HCPs and family caregivers. For many, if not most participants, interactions with HCPs that stood out as significant or important were meaningful in a negative sense. The method of qualitative description was chosen specifically to ensure that findings would be portrayed from an emic perspective and clearly represent participants' truth. Participants’ truth, that meaningful interactions were often negative, provides nurses and other HCPs with needed information to guide care delivery, develop interventions and evaluate interactions going forward.

As descriptions of meaningful interactions with HCPs were described, the emotion attached to negative interactions was exemplified as powerful and lasting. In some cases, the emotional valence of negative interactions overshadowed the content of words spoken by either HCP or caregiver. This finding speaks to the need for evaluation of caregivers’ experiences of both past and ongoing interactions. All HCPs share the need to understand the impact of interactions on the well-being of those receiving care, but nursing, with it's focus on empowerment, collaboration and meaning-making (Tarlier,
2004; Willis, et al., 2008), is in an ideal role to facilitate interventions aimed at caregiver evaluation of past experiences with HCPs. The first step in developing an intervention aimed at evaluation of HCP: caregiver interaction is to create templates or guidelines that will improve interactions going forward.

One example of such a template centers around purposefully linking written descriptions of interactions to caregiver reactions through an evaluative process that occurs as part of registered nurse (RN): caregiver treatment planning. Caregivers would be asked to identify elements of communication that are important and explain ways in which actual interactions have been helpful or could be tailored to be more useful. Through ongoing discussions and completion of this process, caregivers would have opportunities to act as scriptwriters, identifying and sharing way in which HCPs can provide support and guidance in a semi-tailored fashion. As the process evolves, first steps in development of a RN: caregiver partnership are taken. Caregivers are able to experience RNs as being available, able to engage in respectful dialogue and as contributing to mutual goal setting around future interactions. The completed tool can then be included in discussion with the health care team and used by members of the team as a guideline for HCP discussions going forward.

While the example above is simply a hypothetical model, the benefits of using a template similar to the one described above are threefold: 1) active dialogue between the professional nurse and the caregiver provides an opportunity to begin a partnering relationship and develop a tailored care plan to address effective methods and styles of communication for interactions; 2) the opportunity to re-script negative interactions
offers caregivers the opportunity for corrective experiences as their suggestions are heard and as they are able to impact change going forward; 3) active engagement and participation in creating positive outcomes would be a step towards positively impacting overall caregiver well-being. Tailoring communication style to include those methods of communication that are perceived as valuable and effective to individual caregivers is one step that can be taken to improving HCP: caregiver communication by adapting to individual caregiver styles and modes of learning.

The second surprising finding of this study related to practice was the limited identification or discussion about nurses as resources for caregivers. Nurses were rarely mentioned in participant experiences across primary, secondary or tertiary care. When nurses were mentioned, they were described as being "too busy," "unavailable" or "aloof." The reasons for this are unclear, however the need for action is evident.

Nurses have long endorsed a commitment to form collaborative relationships with clients, to empower clients to move toward maintaining, restoring or improving health and to assist them in making meaning around illness and subsequent return to health (Tarlier, 2004, Willis, et al., 2008). If the experiences of participants in this study are representative of the larger caregiver population, then the absence of nursing representation in identified meaningful interactions with participants indicates that nurses strayed considerably from the endorsed aims of the discipline. Addressing many of the issues identified by participants in this study, then, will require nurses to re-engage with the aims of nursing and re-emerge as leaders of the health care team.
The focus of the discipline of nursing has been identified by Willis, Grace & Roy (2008) as "facilitating humanization, meaning, choice, quality of life, and healing in living and dying (p. E28)." Nurses embracing this focus are well equipped to address issues of injustice related to unsatisfactory health care delivery for PWD and their caregivers. A first step in addressing issues of injustice is for nurses to attend, in a relational way, to those receiving care. Such a step requires a return to basic roots of collaborative treatment planning, organizing care delivery around identified values, choices and meaning and addressing quality of life and well-being of care recipients.

Salient findings from this study addressed the importance of connection between HCP and caregivers of PWD. Caregivers expressed the need to be identified and respected as partners in care, to be included in care of PWD and to "matter" in an existential sense as holistic human beings. A key focus, then, for nurses working with PWD and their caregivers, is to re-assess and revise current practice and evaluate how to incorporate identified needs into nursing practice on a regular basis.

One example of a way to incorporate knowledge of what caregivers need into practice includes working with nursing leadership to develop organizational practice guidelines that provide ongoing education for nurses about caregivers' needs and stipulate the expectation that nurses have regular dialogues with caregivers about concerns and include them in care planning meetings on a regular basis. Importantly, nursing leaders also hold a responsibility for educating non-nursing organizational leaders about the importance of ensuring that staffing ratios and environmental realities allow for such dialogues to occur. Several participants in this study noted that nurses did not have space
or time to privately interact with caregivers, thus discussions, if any, happened in
hallways or across doors or countertops and were of short duration. Nursing leaders can
take the step of stipulating what "should" occur in daily practice, however they must also
be instrumental in procuring some degree of organizational commitment to ensure that
nurses have time and space to engage in private, interactive discussion with caregivers.
While to some degree, power to accomplish this aim lies in the collective hands of
organizational leaders, the duty to educate those leaders about needs of caregivers falls to
nurses, themselves.

When health care for PWD and support for their caregivers is evaluated in the
context of this study, the importance of implementing a dementia-capable system cannot
be overstated. Nurses can and should serve as lynchpins around which the wheel of a
dementia-capable health care delivery is designed. Professional nurses, working to the
full extent of their training and education, serve in roles across health care. Whether
serving in front line care delivery, advanced practice roles, research, education or policy
development, nurses are able to collaborate with each other, with health colleagues from
other disciplines, and with care recipients to define and implement elements that make
our health care system more able to care for PWD and support associated caregivers.

**Implications for Education**

Educators and students of nursing must be aware of how changes that have
occurred in recent years within the health care system may have resulted in task-focused
actions rather than attention to the core mandates of nursing. Increased utilization of
technology, including electronic documentation, bar coding and scanning of medications
and focus on standardized care in the form of checklists and dictated protocols for practice offer increased patient safety but ironically, take much of the humanization and interaction that has been a hallmark of nursing away from the bedside and from front line care. Educators, then, must provide new nurses with skills aimed at mastery of technology, understanding of tools aimed at increasing patient safety and a firm grasp on the need to retain humanization and individualization of patient care as a core value of nursing.

In addition, educators must heed the directive given in the *Future of Nursing* report (2010), in which nursing educators and leaders were tasked with the goal of expanding opportunities for nurses to lead. As educators, we must focus on ensuring that nurses have an opportunity to develop skills and innovative thinking to develop team models aimed at providing care that is client-centered and better meets the needs of the persons we serve (IOM, 2010).

**Future Directions for Scholarship**

Findings from this study point to multiple opportunities for ongoing scholarship. This study described the experiences and perspectives of Caucasian caregivers of PWD in a resource and research-rich geographical area. Replication of this qualitative study is needed to include perspectives of racially and ethnically diverse family caregivers of PWD and caregivers living in rural locations. Obtaining perspectives of a more diverse group of participants will provide information to guide intervention development aimed at improving interactions between HCPs and family caregivers and ensure that needs of a broad population of caregivers are considered.
Additional inquiry is also needed to evaluate HCP: caregiver concordance in accounts of information exchanged during non-crisis-related interactions. Opportunities exist for education, assessment of caregiver needs and advance care planning during non-crisis-oriented appointments with HCPs, yet few participants in this study spoke of obtaining knowledge or direction from HCPs outside of crisis situations. HCPs' perspectives of interactions were not obtained in this study. As such, it is unclear whether HCPs' accounts of interactions would be congruent with caregivers' experiences.

A mixed methods study focused on evaluation of the concordance of HCP: caregiver perceptions about information requested and exchanged during non-crisis oriented interactions is needed to better understand ways that information flow can be improved and evaluated. In such a study, information about both caregiver and HCP perspectives of interactions can be evaluated qualitatively. Content of interactions can best be captured using both qualitative and quantitative measures. Results of such a study can be used to identify types of interactions that most often lead to discordant responses between HCP and caregivers, to develop HCP training modules focused on improving HCP communication skills, and to develop assessment tools that incorporate ongoing opportunities to evaluate HCP: caregiver interactions.

The final recommendations for scholarship relate to the need for construction and evaluation of a dementia-capable system. Several specific priorities for research emerged from this study that directly relate to issues within the healthcare system itself. Each is crucial to designing of a system to meet the needs of PWD and their caregivers.
One critical priority in designing a dementia capable system is to evaluate, qualitatively and quantitatively, the functional knowledge base of HCPs who interact with PWD and their caregivers in acute care settings. Caregivers in this study identified situations in which hospital-based HCPs across a variety of disciplines demonstrated a lack of awareness of the challenges faced by persons with dementia and lacked knowledge of appropriate interventions for addressing issues of assessment and care. This lack of knowledge affected (or had the potential to affect) quality of care for PWD who were admitted to the hospital for issues not directly related to the dementia diagnosis and impacted HCP: caregiver interactions about delivery of care. Additionally, perceived lack of knowledge and awareness of HCPs impacted the emotional well-being of caregivers by affecting levels of trust and certainty that appropriate care was being provided.

A mixed methods study, designed to include assessment, intervention and evaluation phases will guide evidence-based intervention development and provide opportunities for ongoing evaluation. In such a study, the first phase might include quantitative evaluation of HCP knowledge related to dementia and qualitative recording and evaluation of simulated experiences with PWD and their caregivers. HCP strengths could then be identified along with information about deficits in knowledge. This phase can be followed by development of tailored interventions that provide education about dementia and dementia care and foster skills development around providing that care. In the final phase of the study, effects of the intervention can again be measured using quantitative and qualitative evaluation of both knowledge and skill in addressing specific
needs of the population. The outcome of such a study will provide opportunities for interdisciplinary training in addition to discipline-specific education. Increased knowledge and skills about the needs of PWD and their caregivers will lead to improved care for PWD and their caregivers.

A second key area of research related to design of a dementia-capable system is to create paths for obtaining care that minimize challenges and better serve PWD and their caregivers. Caregivers in this study verbalized many challenges to obtaining appropriate care for their loved ones with dementia. These challenges were often related to having multiple transitions in care, across which limited communication took place and during which multiple providers “touched” or had contact with the patient, but few had working knowledge of the comprehensive picture of care needed or planned. One study to address the challenges in providing dementia-capable care in acute care settings, is to design, with caregiver input, entry, treatment and exit from the emergency room to inpatient units with a goal of minimizing the number of providers, easing anxiety and minimizing the impact of a chaotic emergency room environment. A second study in the same trajectory of research involves designing the patient care experience after arriving on an inpatient unit with the same goals in mind. A third study in the series looks toward the discharge arena and reducing unneeded readmissions.

In each of the above areas of scholarship, longitudinal studies will be needed to provide ongoing feedback about ways in which care is changing over time and across health care settings. Studies aimed at evaluation of caregiver needs, HCP: caregiver interactions, technical and functional knowledge of HCPs caring for PWD and their
caregivers and methods for providing appropriate, person-centered care will offer continuing opportunities to improve the care and well-being of PWD and their caregivers.

Conclusions

This qualitative descriptive study addressed a gap in our understanding of the caregiver experience of interacting with and obtaining knowledge from HCPs throughout the caregiving process and provided knowledge about what created a meaningful interaction from the perspectives of family caregivers of PWD. Interactions with HCPs experienced by participants as meaningful often centered around moments of crisis or transition and were described in both negative and positive terms. Although family caregivers were closely attuned to the technical quality of care provided, the descriptions of meaningful interactions focused primarily on the presence or absence of an interactive dialogue or relationship with the HCP and included emotional or social support that was either present or absent. Accordingly, the need for emotional and social support and relationship emerged in each of the three interconnecting and recurrent themes that emerged from interviews with participants. Corrective experiences, in which negative interactions with HCPs were replaced with more productive dialogues offered an opportunity for HCPs to re-engage family caregivers in collaborative working relationships in which HCPs were viewed as partners and resources for information.

Themes that emerged across participant interviews included the challenges of obtaining care for a PWD in a health care system that was not designed to meet the needs of those PWD or their caregivers, the importance of relationship with HCPs and the
impact of partnership, and the importance of HCPs knowing what mattered to each caregiver: PWD team.

Although participants looked to both formal and informal resources for information and support as they attempted to obtain information and manage uncertainty associated with the caregiving role, few participants sought out information or support in a proactive or planned fashion. Instead, efforts to obtain information most often occurred in response to direct events or needs. Only a small number of participants, those identified as "information seekers," did attempt to obtain information from HCPs about course of disease, additional resources or emotional support in the absence of a direct, identified need or emergent situation. Information seekers most often had experience working in some aspect within the health care industry or acted in leadership roles in a business setting and attributed their comfort level in addressing issues as a learned skill.

Results of this study suggest that HCPs must turn their focus toward development of relationships and partnerships with consumers rather than focusing on only the technical aspects of providing care. Doing so will allow HCPs to meet the ethical mandate shared across disciplines to provide comprehensive and holistic care and support caregivers ongoing emotional, physical and spiritual well-being. In conjunction with development of partnerships and collaboration around care, issues within the health care system that affect the ability to provide or obtain person-centered care itself must be addressed and corrected. Nurses, with the history of a discipline steeped in social justice, are particularly well-suited to embrace the challenge of fostering partnerships and meaning-making experiences between HCPs and family caregivers. Accordingly, nurses
have an obligation and responsibility to work with both caregivers and their own health care peers to address the many challenges of creating a dementia-ready system.

This study provides new knowledge about meaningful interactions with HCPs from the perspectives of family caregivers of PWD within a social justice framework. Additionally, the study provides insight into ways that family caregivers obtain resources aimed at managing uncertainty of caring for PWD. Implications for improving caregiver: HCP interactions and the effective and timely use of resources help focus next steps in efforts to create a more dementia-capable system across the trajectory of care. This study is the first in a program of research aimed at ensuring that PWD and the caregivers, themselves, receive the care they deserve and need.
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Appendix A. Boston College IRB Approval

BOSTON COLLEGE
Institutional Review Board
Office for Research Protections
Waul House, 3rd Floor
Phone: (617) 552-4778, fax: (617) 552-0498

IRB Protocol Number: 12.304.01e

DATE: June 4, 2012

TO: Lesley Adkison

CC: Ellen Mahoney

FROM: Office of Research Protections

RE: Descriptions of Meaningful Health Care Provider Interaction: Perspectives from Family Caregivers of Persons with Moderate to Advanced Dementia

Notice of Evaluation – [Exempt 45 CFR 46.101(b)]

The Office for Research Protections (ORP) has evaluated the project named above. According to the information provided, you intend to conduct interviews to learn about what family caregivers of persons with moderate to severe dementia experience when they talk with health care providers. This is a minimal risk study.

This study has been granted an exemption from Boston College IRB review in accordance with 45 CFR 46.101(b) 2. This designation is based on the assumption that the materials that you submitted to the ORP contain a complete and accurate description of all the ways in which human subjects are involved in your research.

This exemption is given with the following conditions:

1. You will conduct the project according to the plans and protocol you submitted;
2. No further contact with the ORP is necessary unless you make changes to your project or adverse events or injuries to subjects occur;
3. If you propose to make any changes in the project, you must submit the changes to the ORP for IRB review; you will not initiate any changes until they have been reviewed and approved by the IRB;
4. If any adverse events or injuries to subjects occur, you will report these immediately to the ORP.

The University appreciates your efforts to conduct research in compliance with the federal
regulations that have been established to ensure the protection of human subjects in research.

Date of Exemption: Monday, June 04, 2012

If you are conducting research using an online survey (e.g. Survey Monkey, Qualtrics), the IRB requires that the approval dates appear on the online consent page of your survey. Please copy and paste the statement below onto your survey:

The Boston College IRB approved this protocol on June 4, 2012.

Sincerely,

[Signature]

Stephen Erickson
Director
Office for Research Protections
Appendix B.   Informed Consent

Boston College Wm. F. Connell Graduate School of Nursing
Informed Consent to Participate in a Research Study:

"Descriptions of Meaningful Health Care Provider Interaction: Perspectives from Family Caregivers of Persons with Moderate to Advanced Dementia"

Researcher: Lesley E. Adkison, RN, MSN, PhD(c)
Adult Consent Form

Introduction
- You are being asked to be in a research study. The study is about what family members of persons with moderate to severe dementia experience when they talk with health care providers.
- You were selected to be in the study because you have identified yourself as a family caregiver for someone with moderate to severe dementia.
- Participating in the study involves one interview. The interview lasts about an hour.
- This form tells you important information about the research study. Please read it carefully. If you have any questions about the research or about this form, please ask me to explain.
- Taking part in this study is up to you. I will not tell anyone whether you decide to participate. If you decide to be in the study, I will ask you to sign this form. The form shows that you want to participate. I will give you a signed copy of this form to keep.

Purpose of Study:
- The purpose of this study is to learn more about what family members of persons with moderate to severe dementia experience when they talk with health care providers. I hope to understand more about what moments or events stand out as important to you when you think about interactions with health care providers.
- 20 - 30 people are expected to be in this study. The people who participate are from different locations around Boston.

What will happen if you decide to be in the research study:
- You and I will meet at a location and time that you choose. It could be at this location or at another place where you feel comfortable.
- We will go over this form together. I will answer any questions you might have about the form or the study.
• I will ask you to sign two copies of the consent form. You will keep one copy of the form and I will keep the other.

• I will ask you to select a pseudonym (a fake name) for yourself and any other person you mention during the interview. During the interview, I will use your pseudonym when I talk to you. The goal of using a pseudonym is to keep information private.

• I will ask you to complete a brief demographic form. The information on the demographic form will allow me to describe the group of people participating in the study. When you fill out the form, you won't use your real name.

• After the forms have been completed, you and I will talk for about an hour. Our discussion will be tape-recorded. The reason I use a tape recorder is to make sure that our discussion is documented accurately. I will ask questions and ask you to answer them using as much description or explanation as possible.

• Sometimes, I may ask you to say more about particular statements. I may also ask questions to make sure I understand you correctly. The interview will be over when you have finished talking about the topic. If you feel uncomfortable with a question, you can skip it.

• At the end of the interview, I will ask whether you want me to send you a written copy (transcript) of our interview. I can send a copy of the transcript by regular mail or email. It will not have your name on it. It will have your pseudonym on it.

• If you want to receive a written copy of our discussion, you can write your email or street address in the space on the last page of this form. If you disagree with anything in the transcript, you can contact me by email or by phone. You can tell me about any information that you think needs to be removed or changed. I will make the changes and send you a new copy.

Study Findings

• Study results may be published in a health care journal or used to teach others. Most of the findings will be reported as group data. This means that ideas or themes from the interviews are combined together. Grouping themes is one way to protect your privacy. No real names or real locations will be used when I report the data.

• In this type of research, specific words used by people in the study are very important. Actual words or phrases are sometimes included in study findings as quotations. If this happens with a statement that you have made, the pseudonym you chose will be used, not your real name.

Boston College IRB
JUN 04 2012
Exempt

Subject’s Initials ___
Risks and Discomforts of Being in the Study

- The greatest risk in an interview study is confidentiality. I have designed this study in a way that protects your privacy as much as possible.
- Another risk of being the study is that you might get upset or uncomfortable when you are talking with me. If you get uncomfortable, we can take a break. We can also decide to meet at another time. We could even stop the interview completely. If you decide at any point that you need to stop our discussion, I will use the information already recorded unless you ask me not to use it.
- I have listed the known risks of participating in this study. As with all research, however, there may be unknown risks of participation.

Benefits of Being in the Study:

- The purpose of the study is to describe interactions with health care providers from the point of view of family members of persons with moderate to severe dementia.
- There is no direct benefit to you for participating in this study.
- The information you provide may help health care providers understand more about what family members experience during interactions with health care providers. This, in turn, may help other family members in similar situations.

Payments:

- You will not receive any payment for participating in the study.

Costs:

- There is no cost to you to be in this research study.

Confidentiality:

- The records of this study will be kept private. All research records will be kept in a locked file in my office.
- The consent form will have your signature on it. It will also have your pseudonym. That is the only document that will have both your real name and your pseudonym. The consent form will be kept in a different location from the transcripts of interviews.
- The electronic copy of your interview will be kept in a password-protected file on my personal computer. My computer is protected to prevent anyone other than me from being able to use it.
- The only individuals who could see your name on the consent form are members of the Institutional Review Board (IRB) at Boston College. The IRB is an ethics board that monitors all research projects at Boston College. From time to time, IRBs audit

oston College IRB

JUN 4 2012

Exempt

Subject’s Initials___
research projects to ensure that ethically sound research is being conducted. Consent forms are sometimes reviewed in an audit by the IRB.

- Members of my dissertation committee may review copies of interviews. The committee members have oversight of the research process. All members of my committee are professors at Boston College in the Connell School of Nursing. No identifying information will be shared during discussions about the data.

Choosing to be in the study:
- Choosing to be in this study is voluntary. If you choose not to be in the study, no one will know. Study participation will not affect your current or future relationship with a treatment provider, organization or facility.
- You are free to withdraw your consent at any time, for any reason.
- There is no penalty or loss of benefits for not being in the study.
- There is no penalty for withdrawing from the study.

Contacts and Questions:
The Principal Investigator of this study is Lesley Adkison. Questions or concerns about this research study may be directed to me or to my academic advisor, Dr. Ellen Mahoney, at Boston College. Our phone numbers and email addresses are listed below.

Lesley Adkison (339) 368-1425
adkison@bc.edu

Ellen Mahoney (617) 552-4262
ellen.mahoney@bc.edu

If you want to speak with someone not directly involved in this research study, you may contact the Director of the Office for Research Protections, Boston College at (617) 552-4778, or irb@bc.edu.

Copy of Consent Form:
- You will be given a copy of this form to keep for your records and future reference.
Statement of Consent:

- I have read (or have had read to me) the contents of this consent form. I have been encouraged to ask questions. I have received answers to my questions. I give my consent to be in this study. I have received (or will receive) a copy of this form.

Study Participant (Print Name): ___________________________ Date: __________

Participant Signature: ___________________________ Date: __________

Pseudonym Chosen: ___________________________

☐ I have explained the research to the study participant.
☐ I have answered all questions about this research study to the best of my ability.
☐ The participant has received a copy of the consent form.

______________________________ Date/Time

Lesley Adkison, Principal Investigator

---

Boston College IRB

JUN 9 4 2012

Exempt

Subject’s Initials: __________
Receiving a Copy of the Transcript

I want to receive a copy of my transcript  Yes  No
(Circle One)

Please send my transcript to me by email at: ____________________________

Please send the transcript to me by regular mail at the following address:
____________________________________________________________________

Participant Signature  Date

Investigator Signature  Date:

Boston College IRB
JUN 04 2012
Exempt

Subject’s Initials
Appendix C. Demographic Form

Demographic Form

Please select a pseudonym (false name or code name) for yourself. Please select a different pseudonym for the family member who has been diagnosed with Alzheimer's disease or another form of dementia.

Your Pseudonym: __________________________

Pseudonym for Family Member: ________________

What year were you born? _______________

Race: ______________

Ethnicity: ______________

What kind of health care providers do you and _______ see now to address issues related to ______'s memory problems?

☐ Primary Care Doctor      ☐ Geriatric Psychiatrist
☐ Nurse Practitioner       ☐ General Psychiatrist
☐ Social Worker            ☐ Neurologist
☐ Other ___________________

What kind of memory problems does your family member have?
Has your family member been hospitalized recently for any reason?

☐ No

☐ Yes
  ☐ once in the last 3-6 months
  ☐ once in the last 6-12 months
  ☐ my family member has had multiple hospitalizations in the last year.

Please list some of the ways that you have needed to provide help for your family member.
## Appendix D: Global Deterioration Scale

### GLOBAL DETERIORATION SCALE (GDS)

<table>
<thead>
<tr>
<th>Stage</th>
<th>Deficits in cognition and function</th>
<th>Usual care setting</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Subjectively and objectively normal</td>
<td>Independent</td>
</tr>
<tr>
<td>2</td>
<td>Subjective complaints of mild memory loss. Objectively normal on testing. No functional deficit</td>
<td>Independent</td>
</tr>
<tr>
<td>3</td>
<td>Mild Cognitive Impairment (MCI) Early clear-cut deficits. Functionally normal but co-workers may be aware of declining work performance. Objective deficits on testing. Denial may appear.</td>
<td>Independent</td>
</tr>
<tr>
<td>4</td>
<td>Early dementia Clear-cut deficits on careful clinical interview. Difficulty performing complex tasks, e.g. handling finances, travelling. Denial is common. Withdrawal from challenging situations.</td>
<td>Might live independently – perhaps with assistance from family or caregivers.</td>
</tr>
<tr>
<td>5</td>
<td>Moderate dementia Can no longer survive without some assistance. Unable to recall major relevant aspects of their current lives, e.g. an address or telephone number of many years, names of grandchildren, etc. Some disorientation to date, day of week, season, or to place. They require no assistance with toileting, eating, or dressing but may need help choosing appropriate clothing.</td>
<td>At home with live-in family member. In seniors’ residence with home support. Possibly in facility care, especially if behavioural problems or comorbid physical disabilities.</td>
</tr>
<tr>
<td>6</td>
<td>Moderately severe dementia May occasionally forget name of spouse. Largely unaware of recent experiences and events in their lives. Will require assistance with basic ADLs. May be incontinent of urine. Behavioural and psychological symptoms of dementia (BPSD) are common, e.g. delusions, repetitive behaviours, agitation.</td>
<td>Most often in Complex Care facility.</td>
</tr>
<tr>
<td>7</td>
<td>Severe dementia Verbal abilities will be lost over the course of this stage. Incontinent. Needs assistance with feeding. Loss ability to walk.</td>
<td>Complex Care</td>
</tr>
</tbody>
</table>


Boston College IRB
JUN 04 2012
Exempt
Tell Your Story
Experiences in Communicating with the Health Care Team
A Research Study for Family Caregivers

Who Can Participate? Adults who have provided support for a family member with moderate to severe Alzheimer’s disease or other form of dementia.

What is Involved? One interview, lasting about an hour

Why? To share information about what caregivers experience when they talk with health care providers.

Where? At the location of your choice.

Who is Doing it? Lesley Adkison, Boston College School of Nursing, Ph.D. program

How do I sign up? Call Lesley at (339) 368-1425 to find out more or set up an interview.

This study has been approved by the Boston College Institutional Review Board.
Appendix F. Interview Guide

Interview Guide

Thank you for agreeing to meet with me today. I'm interested in understanding what is important to family caregivers in interactions with health care providers, specifically what makes a difference in terms of whether you have found an interaction to be helpful or useful.

Opening Question: I'd like to ask you to tell me what it has been like to act as a support person / caregiver for someone with memory problems and describe how the role has changed as ______ has moved through stages of the illness. (This request is intended to give some background information and allow the caregiver to become comfortable in the interview setting. It will help me to know more about how long the caregiver has been in the role and will provide some information about what is required of the caregiver on a daily basis).

Central Question: When you think about interactions that you have had with health care providers about dementia or caregiving, what stands out as important or significant to you now?

Subquestions and Probes:

What do you think would be the most helpful thing for healthcare providers to know about the needs of family caregivers? How can we do better?

Describe for me what information has been important for you to have in your role as a ______’s caregiver?

What sources of information have you used and how did you tap into those sources of information?

When you go to an appointment with a health care provider, how do you and the health care provider work together to figure out what might be the most helpful or useful at that time?