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Hurricane Preparedness of Community-Dwelling Dementia Caregivers in South Florida

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Hurricane Preparedness of Community-Dwelling Dementia Caregivers in South Florida

by

Janelle J. Christensen

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy
Department of Anthropology
College of Arts and Sciences

and

Master of Public Health
Department of Global Health
College of Public Health
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Key Words: home and community-based care, informal caregivers, disaster preparedness, health literacy, risk fatigue

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Dedication

I dedicate this work to anyone providing medical services and care for people in their community. And the Governor of Florida, who said, “Florida does not need any more anthropologists” while I was completing my research in 2011.
I am deeply grateful to my dedicated committee members. I cannot glow enough about the support provided by advisor, Dr. Heide Castaneda, who was attentive, forever diplomatic, deeply insightful, and patient. My gratitude also goes to Dr. Linda Whiteford and Dr. Kevin Yelvington. I specifically thank Dr. David A. Chiriboga for helping me to set up my partnership with Alzheimer’s Community Care, Inc. I am grateful for both his insights and assistance. Dr. Lisa M. Brown has been critical to my training as an academic, teaching me the art of research and peer-reviewed publications. Dr. Jaime W. Corvin has been essential to disaster management research from a public health perspective. My parents, John and Donna Christensen, never wavered in their support. I thank them, and my brother, Erik Christensen, Cousin Rachel, Aunt Vicki, and John Stewart, and Grandpa Ernie, for their understanding and their growing enthusiasm. Heartfelt thanks to long-time friend Sarina Steinbarth (and her mother Susie). My husband, David Rodenfels kept me (relatively) sane through this process. Teddy and Jim Rodenfels have shared with me their own stories and assisted us through the changes in our lives. Thanks to Aunt Melanie Mouras has edited major parts of this dissertation. I would also like to thank my adopted family, my friends, and fellow-graduate students: Jennifer Syvertsen, Elizabeth Cooper, Carylanna Taylor, Besty Danforth-Richey, Rohan Jeramiah, Racine and Heather Brown, and Cindy Grace-MacCasky who went ahead of me or along side of me in the dissertation and graduation process and shared their experiences. I also would like to thank Maressa Dixon, Bridget Cotner, Melissa Pope, Mabel Sabogal for being amazing colleagues, and friends. My partnering organization, Alzheimer’s Community Care, and the staff, Mary Barnes, CEO, Patsy Oram, COO, and Ron Radcliffe VP of CCS, Kathryn Hosaflook, Janet Zweiback and JoEllen Smith, Danielle Worley, and Thomas Leitzsch gave an impressive amount of assistance.
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Abstract

The aim of this dissertation is to explore how informal caregivers for people with dementia (PWD), who are community dwelling (i.e., not in nursing homes), prepare and plan for disasters. The research site is a particularly hurricane-prone region of Florida, second only to New Orleans in its vulnerability. An underlying assumption of this research is that caregivers for PWD have to plan and anticipate problems that are unique to their role. The rationale for the study described here is that disaster planning and mitigation save lives (Tengs et al. 1995), but there is little or no literature on disaster planning for the frail elderly and their caregivers.

Mixed methods design which includes: 1) participant observation; 2) staff interviews (n=8); 3) preliminary caregiver interviews (n=5); 4) baseline chart/disaster plan review (n=290); 5) intervention (presentation to staff and administration) and form revision; 6) follow-up chart/ disaster plan review (n=259); 7) caregiver survey(n=253); 8) final caregiver interviews (N=15- total number of caregiver interviews 20); 9) disaster literacy testing (n=20); 10) final group interview with ACC administration.

This work documents the way that caregivers talk about disaster planning and say they will do if a hurricane strikes and reflects on their past hurricane experiences. Major findings include gaps in the county run Special Needs Shelter services available in Florida for people with dementia. The response and difficulty that caregivers might face can depend on the stage of the disease.
Chapter 1: Introduction

The aim of this dissertation is to explore how informal caregivers for people with dementia (PWD), who are community dwelling (i.e., not in nursing homes), prepare and plan for disasters. The research site is a particularly hurricane-prone region of Florida, second only to New Orleans in its vulnerability. An underlying assumption of this research is that caregivers for PWD have to plan and anticipate problems that are unique to their role. An estimated 5.4 million Americans had a diagnosis of Alzheimer’s disease in 2011 (450,000 of whom live in Florida), and there are 1.4 million unpaid caregivers providing for their needs (Alzheimer’s Association 2011). Though most caregivers are women (60% of all caregivers for PWD in the US are female), they are not a homogenous group and, therefore, their levels of disaster preparedness are likely to vary.

The rationale for the study described here is that disaster planning and mitigation save lives (Tengs et al. 1995), but there is little or no literature on disaster planning for the frail elderly and their caregivers. In many states, authorities expect individuals to prepare and carry out their own personal disaster plans. This can be problematic for people who are unaware of this responsibility and/or have income restrictions (Mack, Spotts, Hayes and Warner 2006). Individuals with disabilities, as well as the frail elderly and their caregivers, are especially vulnerable because, as illustrated by Hurricane Katrina, they bear the greatest burden of morbidity and mortality when a hurricane strikes (Green 2006; Brunkard, Namulanda and Ratard 2008; Jenkins, Laska, and Williamson 2008). Nonetheless, large sections of the public remain unprepared (FEMA Citizen Corps
Several factors contribute to this lack of preparation, including: 1) people may lack information about risk or how to prepare for it (access); 2) they may not understand the information or how to use it (comprehension); 3) they may not have the means to properly prepare (socio-economic factors); or 4) they may not trust the people or entities that are providing them information about risk (risk perception) (Sorensen and Vogt Sorensen 2007).

Regardless of discipline, McEntire and Meyers (2004) point out that most research is done in the aftermath of a disaster (for excellent examples of anthropological post-disaster research, see Gladwin 1997, and Yelvington 1997). In contrast, preparedness is less emphasized even though it is recognized as a key component of emergency management. This has major implications for public health research, as there is not much baseline pre-disaster data (Whiteford 2004) which makes it difficult to measure the direct impact of the disaster on a population’s health (Noji 2005). Gathering baseline data might seem less attractive because disasters are relatively unpredictable. The current study represents an example of pre-disaster research and thus addresses a topic in the disaster literature that has not received as much attention.

**Anthropological Contributions to the Study of Alzheimer’s and Disasters.**

Anthropology is a holistic discipline, which means that in addition to its own theoretical and methodological tradition, it draws upon those from other fields such as biology, psychology, sociology, history, political science and philosophy. Medical anthropology and gerontological anthropology, especially, have an especially strong history of working alongside other disciplines (Gubrium and Holstein 1999). A key feature of anthropological research is ethnography, or long-term fieldwork with intensive
participant observation (Agar1996). Long-term fieldwork and ethnography remains a central feature of the discipline of Anthropology. Participant observation involves immersing one’s self in a way of life that is different from one’s own, actually participating in the activities under study in order “intellectualize about what you have seen and heard” (Agar 1996:344). Ethnography and participant observation allow the researcher to straddle the line between an “insider” or “outsider” point of view. For instance, in this study, I participated as an “outsider” because I am a researcher (and not, for example, a nurse or case manager) volunteering at the adult day centers. On the other hand, I was able to play the role of an insider because I volunteered in these centers, working alongside nurses, assisting in whatever ways I could: passing out meals, playing group games like bingo, and learning how to gently redirect disruptive behaviors. I met with administration regularly, accompanied caregivers and staff on advocacy trips to Tallahassee, and assisted with educational conferences. Through all of these activities, I forged human connections with the people I worked for and worked with.

Anthropologists also have a commitment to studying epistemology – that is, a critical examination of the construction (and limits) of knowledge – and how power is exercised through seemingly mundane, everyday bureaucracies. An anthropological orientation allows researchers to place phenomenon within its historical and social context. Additionally, they are committed to hearing their subjects’ stories, opinions and interpretation of events, even if it varies from dominant explanatory models (Button 2006). It is a gathering of differing perspectives and experiences and an attempt to weave these stories together into an understanding of how people operate (or how they think things ought to be operating).
Anthropologists have played a large role in understanding approaches to health and healing (Whiteford and Bennett 2005). They have considered the impacts of disasters on social networks and health (Oliver-Smith 1996; Henry 2005). Furthermore, they have examined how elderly populations fare in medical systems, and how frail elders, as a population, have responded to disasters (Gladwin and Peacock 1996). In the late 1990s, anthropologists began to examine dementia as a social phenomenon (Cohen 1998). Anthropologists have continued to examine Alzheimer’s disease within a bio-social framework (Hertskovits 1995; Poveda 2003; Leibing 2006; Kaufman 2006; Fry 2007; Taylor 2008; Hashmi 2009). As yet, however, these different themes – the medical system, disasters, and people with dementia – have not been synthesized.

**Justification for Research.**

Currently, there is very little academic documentation of how caregivers learn about risk, or where they receive their disaster planning information. Furthermore, it unknown how well caregivers understand the risk communication materials available to them (such as information about special needs shelters). There is little information on caregiver preparedness levels for disasters in general. The topic of dementia specific disaster preparedness does not exist in the anthropological or public health literature. My research attempts to bridge the gap between the existing anthropological findings and theories in, first, disasters and, secondly, dementia. Furthermore, it will provide baseline data on this vulnerable group’s preparedness. This information serves an applicable service whereas it can be used in the near future should a hurricane or related disaster strike the Treasure Coast area.
Overview of Chapters.

In the following chapter (Chapter 2), I present the history and background of the research setting in Southeast Florida, with particular attention to the history of hurricanes in this area. The chapter explores the extensive history of hurricanes in Florida, with a special emphasis on how they have affected vulnerable populations. Of particular note is the 1928 hurricane, which devastated the Lake Okeechobee area. This is noteworthy because many of the vulnerabilities that existed in 1928 remain in place today. This area is considered to be the second most vulnerable area in the United States, right after New Orleans (International Hurricane Center 2007; Zhang, Xiao and Leatherman 2006).

Though over 70 years have passed, the Lake Okeechobee area is still highly vulnerable to hurricane damage because of failing infrastructure. More recent hurricanes are presented to illustrate the development of need for a theory of “risk fatigue” presented in Chapter 4. It also sets the stage for the contributions to the anthropology of health policy, as applied to the use of special needs shelters in Florida.

In Chapter 3, I present a history and background on of Alzheimer’s disease and related dementias. In the first part of the chapter, I explore how diseases, including dementia, are socially constructed. AD is a biological process, however, its impact is not only biological in nature; it also has social ramifications and can change identities and roles. The diagnosis of a dementia can carry stigma, which changes how people (family, friend, medical professionals and legislators) relate to a person (Goffman 1968). A PWD often loses their “adult” status – if not immediately, then as the disease progresses. The medical establishment has created a series of tests and measures to codify the changes that take place in a PWD over time. There are different measures for staging the
progression of dementia, and while these are socially constructed, they may be useful in relation to disaster planning. I explore the different measures of the stages of dementia such as the Global Deterioration Scale (GDS), the Functional Assessment of Staging Test (FAST) and the concept of retrogenesis. It is important to note, however, these tests are specific to the Alzheimer’s type dementia and may not be applicable to other types, such as vascular dementia or Pick’s disease. The chapter also addresses specific risks associated with dementia, such as wandering behaviors and vulnerabilities during disaster events, as well as current programs and mechanisms to reduce these risks (such as the Alzheimer’s Association’ Safe Return program).

The second part of Chapter 3 focuses on the provision of informal care for a PWD. Caregivers must shift from one social role, such as spouse or adult child, to another – that of caregiver. There are a number of stressors and health risks associated with these changes. Furthermore, as most informal caregivers are female (60%, nationally), the feminization of dementia care is addressed. I then discuss the concept of “home and community-based care” – namely, the decline in support for institutional care, in favor of care by family members in the community. The emphasis on community-based care, while favorable, is not without its challenges, especially if the shift is not adequately supported by resources for family caregivers. Finally, as there is very little literature on how caregivers for PWD plan and prepare for disasters, I address what is known about how older populations (especially frail elderly) and families plan and respond to disasters.

Chapter 4 presents a literature review on disaster research. First, the essential concept of vulnerability, or differential risk, to disasters is presented. Concepts drawn
from anthropology, such as the pressure and release (PAR) model is introduced to explain how vulnerability acts to create differential risk. I explore the disaster cycle, focusing on preparedness and mitigation strategies for hurricanes, and explain the measurement of hurricanes using the Saffir-Simpson Wind Scale as a way for experts to predict and communicate hurricane risk to the general population. The concept of a “risk society” is an important framework for understanding the relationship between the scientific experts and the lay population. Theorists such as Giddens (1991) and Beck (1992) have posited that, a condition of modernity is that lay populations are less likely to trust expert opinion, such as weather forecasters, when assessing risk. I illustrate the progression of this concept, which was refined by anthropologists and public health scholars, such as Nichter (2003) and Lupton (1999), for its use in medical anthropology. I further apply these concepts to high-risk populations in disaster response.

Chapter 5 presents essential anthropological concepts as applied to both disasters and dementia. First, I present a brief introduction to the anthropology of health policy and critical medical anthropology, as outlined by Castro and Singer (2004). I review Whiteford and Tobin’s (2004) application of critical medical anthropology to the anthropology of disasters. I then review theoretical concepts from the anthropology of disasters that are most closely related to my research: namely, anthropology of aging in disasters (Adams, Kaufman, Van Hattum and Moody 2011) and the anthropology of disabilities in disasters (Fjord 2007; Fjord and Manderson 2009). In particular, I review Fjord’s critique of the vulnerability concept which has been used heavily in disaster studies. While she argues that this concept can be used to justify “expected” causalities from vulnerable populations, I posit that the vulnerability concept is still relevant.
Finally, I review theoretical concepts from the anthropology of dementia, specifically considering the ways in which medical anthropologists have conceptualized the loss of personhood (Taylor 2008).

Chapter 6 outlines the methodology used to address my main research questions using a mixed-methods design. This chapter explains the purpose, procedure, analysis and limitations of each of the ten different methods employed over the course of a year. First, participant observation occurred throughout the course of the study. Second, I conducted interviews with staff and caregivers. Third, I reviewed the disaster plans that ACC kept on file for each of the caregivers and PWD who accesses their services. Fourth, I provided an educational intervention for the staff, based on my findings from the chart audit, which was followed by another disaster plan review. A fifth component was the caregiver survey. The latter was developed with the aid of ACC staff and designed to further explore risks faced by the caregiver population. I then completed the final caregiver interviews, which included disaster literacy testing. The sixth and final method employed was a group interview with three members of the ACC administration.

In Chapter 7, I present the results yielded from each of the methods. The staff interviews revealed the staff perception that people who live alone at home (without immediate family or close friends to care for them) may be most vulnerable to the deleterious impacts of a hurricane. Unfortunately, these were not the target of this study; fortunately, they are not the largest proportion of PWD. Families in which both the PWD and the caregiver are frail elderly were also cited as particularly vulnerable to disasters. Income was also a concern, since those without financial resources were less likely to be able to afford an extended evacuation or stockpiling food and supplies. There was also
deep concern for communities in the Lake Okeechobee area because of socio-demographic disparities. Overall, however, staff felt that the majority of the caregivers they served were relatively well prepared for a disaster, and that participation in ACC improved disaster planning. The interviews revealed an uncertainty about who should sign up for special needs shelters and under what circumstances.

The baseline chart review confirmed the high number of female caregivers (3:1 ratio) and revealed a low number of recorded disaster plans. A large number (though not the majority) of caregivers (46%) did not provide an evacuation plan; of those who did provide an evacuation plan (54%), the most common response was simply that they would drive out of the area (n=55, 35%). The review also revealed that, despite ACC’s goal to have all participants enrolled in their Safe Return program, only 58.3% actually enrolled. After a presentation of this data to staff, I completed a follow-up chart review, which revealed several improvements. First, the Safe Return enrollment increased by 16.7%. Furthermore, the revised form, which asked for different disaster plans based on the strength of a hurricane (determined by the Saffir-Simpson Wind Scale), yielded more complete results. More caregivers responded with a disaster or recovery plans.

The caregiver survey provided insight into caregiver burden and home safety. It drew upon a different population than the disaster plan reviews (people who did not use the adult day centers were included) and revealed facts that the chart review could not. The vast majority of the caregivers lived with the PWD (94.5%, n=239), and most reported that they received help from family or friends (41%, n=100). However, a large number had no support (other than ACC) either formally or informally, and even those that reported that they received help most commonly had less than three hours of help a
week (40.1%, n=101). These factors might explain why they most commonly reported feeling overwhelmed by their work at least “sometimes” and, very commonly, “quite often”. The survey also provided insight into the level of disaster preparedness and factors that might influence disaster recovery. Overall, it seemed that most caregivers are prepared. Most claimed to have a disaster kit (67.6%, n=171); however, caregiver interviews revealed that term “disaster kit” is often interpreted loosely (if they have any supplies stocked, even if not in a designated location, caregivers often considered it to be a kit). While most lived in free-standing homes (61.7%, n=156) made of cinderblock (73.5%, n=186), had hurricane shutters or impact resistant glass (73.9%, n=187), and felt that they would be able to afford repairs if their home sustained damage (64%, n=162). However, less than half had access to a generator (41.9%, n=106). While most caregivers had home or renters’ insurance, and nearly half had a wind protection policy as part of their plan, most did not have flood insurance.

The caregivers selected for interviews matched the demographic trends found in the baseline disaster plan review, so that inferences could be made about the results. Caregivers who had been providing care to a PWD during the 2004-2005 hurricane season (six years prior to this research) emphasized the marked difference between the stage of the PWD disease then and now. More specifically, caregivers suggested that disaster response was more difficult during the early stages of the disease because PWD were more resistant to evacuation (if necessary). However, during the early stages, PWD were often able to help with preparation (such as hanging hurricane shutters). In the later stages, PWD were judged to be less able to help, however, caregivers felt they were also more compliant with the caregivers’ decisions.
Disaster literacy tests revealed that most caregivers were unfamiliar with special needs shelters (SpNS). Even after reading a pamphlet, most caregivers were unable to distinguish the differences between the SpNS services and a regular disaster shelter (average score was 1.8 out of a total of a possible score of 3).

The final interview with ACC administration helped to synthesize findings and theory that are presented in Chapter 6.

Chapter 8, the discussion chapter, places demographics and disaster preparedness within state and national trends. Other overarching themes include: 1) the stages of dementia over time and how they might impact a family’s disaster plan; 2) how Alzheimer’s disease is defined and recognized in the social and policy arenas, which includes issues of personhood and citizenship; 3) the function of special needs shelters for people with dementia in the treasure coast, 4) vulnerability and structural violence, especially in the Lake Okeechobee area; 5) risk society and the media; and, finally, a discussion of disaster planning and risk fatigue.

The final part of this chapter includes conclusions and recommendations. The major conclusion of this research is that caregivers who faced hurricanes while providing care for a PWD had different experiences depending on the stage of the disease. These differences, I argue, can complicate disaster planning.

Finally, several suggestions are made to improve caregiver disaster planning at the Federal, state, county, organizational levels and caregiver levels. Government subsidized housing, I propose, ought to include hurricane shutters to better protect citizens and government property. The state of Florida should implement a regulation that provisions for PWD be made in SpNS at the county level. Both federal and state
governments need to support the transition to home and community-based care by financially backing programs, such as ACC, which make the transition possible. My research found that many caregivers seem unclear of the purpose of SpNS, even after reading the pamphlet. For this reason, materials need to be clearer about how their services differ from regular, Red Cross-run shelters. County governments ought to collaborate with organizations, such as ACC to provide appropriate services for PWD in SpNS. Several suggestions that I made to ACC were adopted during the course of this study, including a change in the disaster plan intake forms that they keep on file. Continued education of staff about the importance of disaster planning for frail elders might help increase the quality of the disaster plans obtained by the staff.

Caregivers (or organizations supporting them) can create disaster kits that are specifically tailored to meet the needs of caregivers and people with dementia. These disaster kits will include items that are geared toward the safety of the community dwelling caregiver and the person they care for, specifically including items that will prevent dehydration and heat stroke. Since environmental changes can cause agitation in people with dementia, including activities that can help focus and entertain them should the power go out or if they have to relocate. Suggestions for items to be included in the dementia specific disaster kit and suggested activities are listed in the recommendations.

**Notes on Terminology.**

In many long-term care settings, such as nursing homes, people receiving services are not called “patients” but are instead “consumers”. This consumer language is believed, in these settings, to be more empowering because it reminds both the staff and
person receiving care that they have agency, that is, they are purchasing a service. ACC does not adopt a consumer-oriented language, but instead uses the term “patient” when referring to a person with AD or a related dementia who is accessing their services. This biomedical terminology is thought to be less alienating than the language of consumerism, such as “client” or “consumer” now often employed in long-term care settings (McLean 1995; McLean 2000).

Here, I use the term person with dementia (PWD) when referring to someone with a diagnosis of Alzheimer’s disease (AD) or a related dementia-causing disease, such as Parkinson’s, Hutchinson’s, or Pick’s (to name a few). While I acknowledge that “dementia” is not a clinical diagnosis listed in the DSM-IV, I use the term in the generic sense, to encompass people who manifest symptoms of dementia as part of the causal disease. I frequently refer to AD specifically because it is the most common cause of dementia in PWD.

When I discuss “older” populations, unless otherwise specified, I am referring to “frail elderly” which is defined as “individuals aged 65 or older with physical, cognitive, social, psychological, and/or economic circumstances that will likely limit their ability to perform one or more Activities of Daily Living (ADLs) or Instrumental Activities” (Fernandez et al. 2002: 71).
Chapter 2: Research Setting

This proposed research is located at the intersection of two distinct, yet interrelated, issues: disasters and dementia.¹ The state of Florida provides the ideal conditions for examining what could be termed a “perfect storm” of circumstances, as it is: 1) particularly vulnerable to hurricanes and 2) a haven for individuals over 60 years of age, which consequently makes it 3) more likely to have residents with Alzheimer’s disease and related dementias.

Frail elderly people, in particular, may be unable to prepare their homes when a disaster threatens, and are less likely to have access to resources such as money, supplies, a car, and social networks (Hutton, 2008). This is especially a concern in Florida’s coastal counties, which were struck by hurricanes approximately 57 times between 1900 and 2007 (NOAA 2009). There is a high concentration of individuals of retirement age in Florida: 17.3% of the entire Florida population was over the age of 65 in 2010. As a population ages, the risk for Alzheimer’s disease and other dementias increases. According to the Department of Elder Affairs, 11.4% of Florida residents over the age of 60 have Alzheimer’s disease (2008). The elderly and the disabled are considered vulnerable populations at risk for higher injury, illness and death rates during and after a hurricane (Wisner, Blaikie, Cannon, and Davis, 2004).

In light of these synergistic risks, policies, agencies and organizations that support vulnerable populations are crucial for mitigation. A disaster event, such as a hurricane,

¹ The most common cause of dementia is Alzheimer’s disease; however, this is not the only cause. Other causes, such as Lewy body dementia and vascular dementia are discussed later in this chapter.
may increase the stress placed on family caregivers (Ironson et al. 1997). Several programs in Florida seek to support elderly individuals with Alzheimer’s disease and their caregivers, and many incorporate basic disaster planning into their services. Viable disaster plans can aid families through all phases of a disaster event. Little is known about: 1) where caregivers receive their disaster planning/risk information; 2) how well they understand risk communication materials; 3) caregiver preparedness levels; or 4) caregiver risk perceptions. Furthermore, very little research is available on dementia specific disaster planning needs for people with dementia and their care caregivers. This research will seek to bridge this gap for this vulnerable population in the high-risk state of Florida.

This dissertation research focused on the Treasure Coast, which is located in southeast Florida and encompasses Palm Beach, Martin and St. Lucie counties. This includes the Lake Okeechobee area in Palm Beach County, considered the second most vulnerable to hurricanes in the United States, behind only New Orleans (IHC 2007; Zhang, Xiao and Leatherman 2006). The partnering organization for this study, Alzheimer’s Community Care (ACC), is based out of Palm Beach County but provides services throughout the Treasure Coast area. It acts as a safety net for families caring for a PWD, so that PWD can be cared for in the community, rather than in an institution.

History and Background: Hurricanes in Florida

*My dad used to call me the Hurricane Kid. I was born during a hurricane, you know. If you are born in Florida during the summer, you have a good chance of being born during a hurricane.* 2011 ACC Adult Day Center Client
Hurricanes have left their mark on Florida’s history. They have not only changed the physical environment, but they have shaped many people’s lives. This section discusses the socio-political history of hurricanes, particularly in South Florida. I place emphasis on how hurricanes have impacted vulnerable populations. First, I describe early hurricane history in the state of Florida, including the 1928 storm of Okeechobee. Secondly, I will present more contemporary hurricane experiences, beginning with Hurricane Andrew in 1992. Thirdly, I discuss the most recent direct hurricane impacts occurred during the 2004-2005 hurricane season, wherein hurricanes struck Florida on six occasions within a 14-month period. Four of these six made landfall in South Florida, directly affecting the residents of the Treasure Coast (which includes St. Lucie, Martin and Palm Beach counties).

**Early Hurricane History in Florida.**

The first storm that appeared in western history books was the “great storm” of 1559, which destroyed a fleet of Spanish explorers attempting to settle Pensacola, Florida (Barnes 2007). Before this account, countless storms had likely crashed against Florida’s shores for millions of years. There are no known recorded hurricane experiences of Florida’s indigenous populations. The name these storms bear in the Western hemisphere, which is likely derived from the Mayan storm god “Hurukan,” suggests an impressive history (Barnes 2007). Linguistically similar words, found throughout the Caribbean, translate to “evil spirit” or “big wind” (Barnes 2007). Linguistic continuity suggests that people had been impressed by the destructive nature of these powerful storms; however, little else is known about how past civilizations prepared, survived and recovered from the storms of the area.
Stories of intense storms found in sailor’s journals or documents from Spanish settlers provide scattered records, however the precise number of hurricanes that have hit Florida is uncertain (Barnes 2007) until the United States created a Weather Bureau in the 1870s and established a more systematic record. These records indicate that from 1900 to 2005, 67 hurricanes have made landfall on Florida’s shores (Barnes 2007: 3).

Few Westerners occupied Florida until after 1906, when Henry Flagler built a railroad and a luxury resort. The rapid development that followed also meant that there would be more property to be lost in the event of a hurricane. The 1920s, in particular, were a profitable time for farmers, who had discovered the rich soil or “muck” in the flood plains of Lake Okeechobee (Kleinberg 2003; Mykle 2006). The 1926 hurricane season was an active one that largely impacted the southeast of Florida and deeply damaged the city of Miami (Mykle 2006). It was the 1928 season, however, that wrought the greatest devastation for area that is now Palm Beach County.
Okeechobee Hurricane of 1928.

*Her soil is her fortune.* Belle Glade City Motto

Louder and higher and lower and wider the sound and motion spread, mounting, sinking, darking. It woke up old Okeechobee and the monster began to roll in his bed. Began to roll and complain like a peevish world on a grumble. The people felt uncomfortable but safe because there were the seawalls to chain the senseless monster in his bed. The folks let the people do the thinking. If the castles thought themselves secure, the cabins needn’t worry...

A huge barrier of the makings of the dike to which the cabins had been added was rolling and tumbling forward. Ten feet higher and as far they could see the muttering wall advanced before the braced-up waters like a road crusher on a cosmic scale. The monstropolous beast had left his bed. The two hundred mile per hour wind had loosed his chains. He seized hold of his dikes and ran forward until he met the quarters; uprooted them like grass and rushed on after his supposed-to-be conquerors, rolling the dikes, rolling the houses, rolling the people in the houses along with other timbers. The sea was walking the earth with a heavy heel. (Zora Neale Hurston 1937)

Anthropologist, Zora Neale Hurston, wrote her novel, Their Eyes Were Watching God, based on the black farm workers in the Lake Okeechobee area. The story meets its crescendo during the 1928 hurricane that devastated the area and has left a lasting effect on the populations in the area to this day.

After the expulsion of the Calusa Indians, most of the early residents surrounding Lake Okeechobee were drawn by the rich soil. The richest soil was in the floodplains of Lake Okeechobee, which would occasionally flood the crops leaving behind a rich “muck” (Barnes 2007; Mykle 2008). According to Mykle (2008), farmers lobbied to have a dike built to preserve the farm land available. Dredges were commissioned to drain part of the lake and construct a dike out of the newly revealed mud at the bottom of the lake.

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22 Hurston was trained under Franz Boas, who is considered to be the father of American Anthropology.
Once the Herbert Hoover dike was completed in 1925, farmland was protected by a 9-foot levee, mostly made out of silt. The dike was cross-cut by canals that ran through farm lands and into the Atlantic Ocean. Locks were built out of concrete to control the flow of water through the canals. Unfortunately, when struck by a Category 5 hurricane, it would not be strong enough to hold Lake Okeechobee back from the communities that had begun to flourish on its banks: Belle Glade, Pahokee and Chosen would sustain significant damage.

In 1928, the prediction and records of the Weather Bureau were not exact; they had to rely on first-hand accounts of hurricanes transmitted by telegraph. Once a storm hit a reporting area, communication was almost immediately lost. Storms were not easy to track and, therefore, accurate warnings were difficult to issue. Additionally, false alarms could cost Florida a large amount in tourist dollars. Before the 1928 hurricane hit, the Palm Beach Post printed that the storm was likely to head south to Cuba.

The storm hit on September 16 (Barnes 2008). The eye of the storm crossed Lake Okeechobee, sucking up the water and creating a storm surge that disintegrated the mud dike and swallowed the surrounding communities. Mykle writes that, “The rural roadbeds and dikes were littered with bodies -- mostly black migrant farmhands” (2008:188). Most of the black farmhands that worked in the fields did not have cars with which to evacuate. Segregation was in full effect, so farmhands were unable to shelter in safer structures with the white families. Most unidentified black bodies were buried in mass graves, 674 of them in West Palm Beach alone. In Pahokee and other Everglade towns, surviving black farmhands were forced to gather and load bodies at gunpoint (Kleinberg 2003: 187). Mykle estimates that the total number lost (black and white) was probably around
3,000 in the Palm Beach County area surrounding Lake Okeechobee (2008: 212-213). Property was defaulted on. People abandoned the state in large numbers, and the great market crash in 1929 exacerbated the economic decline. In the nearly 90 years since this storm, prediction and warning systems have improved. People now have several days to prepare and respond to an oncoming storm.

However, some of the vulnerabilities have remained. For instance, the newly built dike is still weak, and the towns of Belle Glade and Pahokee are still isolated and largely segregated. The majority of the local population is black, at 62.5% (the statewide average is 15.4% of the population). Educational attainment in people aged 25 and older is low; 15.6% have less than a 9th grade education level. Another 17.5% have 9th grade -12th grade educations. This means that a full third of the population does not have a high-school diploma. The percentage of people in Pahokee who have acquired at least a high school education is significantly lower than the state of Florida (at 66.9% ) and the US in general (84.6%) (U.S. Census Bureau 2009).

The number of families living below the poverty level in this area is 21.5%, over twice the number of impoverished families in Florida at 9.5% or the US (9.9%). (U.S. Census Bureau 2009). Though the city of Pahokee is located on the edge of a failing dike, 20% of the population lives in mobile homes, compared with 10%in the state of Florida and 7% in the US, in general) (U.S. Census Bureau 2009). Mobile homes are notoriously vulnerable to hurricanes, and suffer greatly from floods and high winds. The International Hurricane Research Center has rated the Lake Okeechobee area the second most vulnerable to hurricanes in the United States, behind New Orleans (IHC 2007; Zhang, Xiao and Leatherman 2006).
As will become clear in the following chapters, participants in this study frequently referenced the 1928 storm when talking about hurricane experiences in the region.

**Contemporary Hurricanes.**

**Hurricane Andrew, 1992**

Hurricane Andrew hit Biscayne Bay, Dade County, Florida on August 24th, 1992 as a Category 5 storm (Barnes 2007). The Hurricane Center in Coral Gables braced itself as the hurricane directed itself toward the forecasters. Though Andrew was a “dry” storm, its winds were very powerful, at 175mph, destroying entire neighborhoods in Dade County. There were 32 deaths associated with Hurricane Andrew (CDC 2011). According to the Center of Disease Control (CDC), these deaths were caused by flying debris (causing blunt or penetrating trauma), suffocation from collapsed buildings, and drowning.

Though 64 years had passed since the 1928 storm, some structural inequalities persisted in differential losses from the storm. Though racial segregation was no longer in effect, Gladwin and Peacock (1997) found that ethnic minorities (Black and Hispanic) were less likely to evacuate than white populations, probably because of disparate economic conditions than a direct reflection of race and ethnicity (Gladwin and Peacock 1997: 65).

**Hurricane Charley.**

Hurricane Charley, a Category 4, was the first 2004 hurricane to hit Florida on August 13th (Barnes 2007: 308). Originally, Charley was predicted to hit the Tampa Bay area, but it instead turned and made landfall over Sanibel Island on the West Coast (100 miles south of Tampa). Lake Okeechobee levels increased up to three feet above normal along the north and northeast shores (NOAA Charley 2011). Charley was responsible for
an estimated $15.4 billion (2004 USD) in damage throughout the US, though the majority of this damage was in Florida (Barnes 2007). The Florida city of Naples had the greatest amount of damage with numerous power poles, trees and signs blown down, and a few roofs damaged (NOAA Charley 2011). An estimated 130,000 customers in Collier County lost power. About 2,500 people took refuge in six shelters (NOAA Charley 2011).

**Hurricane Frances.**
Frances hit Florida on the border of Martin and St. Lucie counties on September 5th, 2004 (Barnes, 2007). When it made landfall, it was listed as a Category 2 storm on the Saffir-Simpson Scale. However, it was a “wet” storm with torrential rain and storm surges (Barnes 2007). Florida Power and Light reported power outages to 659,000 customers in Palm Beach, 590,000 in Broward, 423,000 in Miami-Dade, 39,200 in Collier, 2,500 in Hendry and 1,700 in Collier counties. An estimated 17,000 persons sought refuge in public shelters in Palm Beach County and nearly 7,000 in Broward County (NOAA Frances 2011). Hurricane Frances caused an estimated $12 billion (2004 USD) in damage (Barnes 2007).

**Hurricane Ivan.**
Hurricane Ivan hit the Florida Panhandle on the Alabama border on September 16th, 2004. Though Ivan had fluctuated between a Category 3 and 5 during its life, it was a Category 3 on the Saffir-Simpson scale when it hit (NOAA; Barnes 2007). In total, Hurricane Ivan was directly responsible for 91 deaths in the Caribbean and 25 in United States. Most of the US deaths were due to the tornadoes associated with the hurricane.
Hurricane Jeanne

On September 25th, 2004, Jeanne hit Florida as a Category 3 hurricane on the Saffir-Simpson scale. It hit on the Martin/St. Lucie county border, five miles from the location where Frances had hit only weeks earlier (Barnes 2007). Like Frances, it was also a “wet storm”, with rainfall accumulations totaled 231 mm (9.1 in) in Palm Beach (Hurricane History 2011). All 167 schools in Palm Beach County sustained some damage (Isger 2004).

Only three deaths were directly attributed to Jeanne in Florida (NOAA Jeanne 2011). According to the Palm Beach Post, emergency response after Hurricane Jeanne was faster than during Hurricane Frances. They noted, however that, “there were stark exceptions” and pointed out that, “Most of Belle Glade [near Lake Okeechobee] lacked power and water. The relief supply of ice was gone within two hours” in part because the Belle Glade Fire Station had to “share its partial truckload of ice and water” with two other rural towns off of Lake Okeechobee: South Bay and Pahokee. They also noted that, “[w]ater pressure was a trickle at Glades General Hospital, where portable toilets were set up outside the emergency room”. Both the Glades General Hospital and the Hospital in Pahokee are now permanently closed and remain vacant.

This same article also reported that thirty-five special needs patients were moved from the special needs shelter to a hospital in Lantana (Palm Beach County), joining at least 65 patients from St. Lucie County, which had no special-needs shelter (Isger 2004). There were several reasons for the transfer of special needs patients to a hospital: 1) their previous location at the fairgrounds was turned into a supply distribution center; and 2) many homes were still without the necessary electricity to run equipment, such as medicine pumps or dialysis machines (Isger 2004). My research uncovered the ongoing
theme of the isolation of the Lake Okeechobee area and continual concerns surrounding special needs shelters in all three counties (which will be presented in the discussion chapter, Chapter 8).

**The 2005 Hurricane Season.**

**Hurricane Dennis.**
Hurricane Dennis hit the Florida Panhandle on July 10th, 2005. It made landfall at Santa Rosa Island, Florida as a Category 3 storm. It paralleled Hurricane Ivan in both intensity and location, however, according to Barnes “almost everyone agreed that Ivan was far, far worse” (2007: 346). There were $1.8 billion dollars’ worth of property damages and the storm resulted in three U.S. deaths. As Dennis dissipated, Tropical Storm Katrina formed in the Atlantic.

**Hurricane Katrina.**
When Hurricane Katrina crossed South Florida on August 25th, 2005, she was only a Category 1 on the Saffir-Simpson Scale. In fact, Katrina reached official hurricane status while only 15 miles off the coast of Fort Lauderdale in Palm Beach County (Barnes 2007). There were very few evacuations in Florida before she struck.

However, Hurricane Katrina would go on to become one of the deadliest storms in United States history (Barnes 2007). The images resulting from Katrina’s impact in Louisiana (and the resulting levee breaks) would leave lasting impressions on the minds of Floridians. It, like Hurricane Andrew, highlighted the disparity between populations. For these reasons, I will describe this storm in more detail.

When Katrina hit Louisiana and Mississippi, she was a Category 3 storm, generating “record breaking storm surges” up to 27 feet in some areas (though some measurements are unreliable due to damage to tide gauges) (Barnes 2007:353). In the city
of New Orleans, the levee and dyke system failed. Since much of the city of New Orleans was below sea level, large portions of the city flooded.

Katrina was responsible for a total of 1,833 deaths (Barnes 2007). These deaths were not random. Though the elderly population made up 11.7% of New Orleans’s population, over 64% of Katrina’s deaths were over 65 years old (Brinkley 2006; Brunkard et al. 2008; Jenkins et al. 2008). This disproportionate burden illustrates that the elderly population was far more vulnerable than younger populations. Some elderly may have been unwilling to evacuate, however, others may have simply been unable to leave their homes.

Minorities also bore a disproportionate burden during Hurricane Katrina. Elliott and Pais (2006) explored the issues of race and class as differential vulnerability during Katrina. The areas in which race and class (termed “axes of variation”) were most salient were in 1) timing of evacuation and 2) lack of job security during recovery. They found that poor inner-city residents, often falling along racial lines, “are the least likely to heed formal evacuation warnings, some because they lack transportation and others because they fail to take such warnings seriously” (2006:318). They also found that black workers in the city were four times more likely to lose their jobs after the storm than whites, even after economic differences were accounted for.

Katrina was closely followed by Hurricane Rita, which barely missed the Florida Keys and did considerable damage to many of the same areas previously brutalized. **Hurricane Wilma.**

Hurricane Wilma hit Florida on October 24th, 2005, as the aftermath of Katrina was still unfolding. Wilma transformed from a tropical storm into a Category 5 hurricane within 24 hours (Barnes 2007). It entered the state of Florida in Everglades City as a
Category 3 storm. It crossed Big Cypress National Preserve and then exited in Palm Beach as a Category 2. Though six people in Florida died as a direct result of the hurricane, Hurricane Wilma is most remembered for the damage to infrastructure (NOAA 2011). Wilma caused the largest electricity loss in Florida history, leaving six million people without power (Barnes 2007). The outage lasted nearly a month in some areas (Salisbury 2010) and delayed recovery in several critical areas.

**Special Needs Shelters (SpNS)**

When a hurricane threatens an area, the American Red Cross establishes and administrates several shelters to house people who might otherwise not survive the storm. These shelters are for people who live in flood zones, mobile homes, or those do not have family or friends available to house them. These shelters are not equipped to provide for people with medical needs and, while structurally sound, are not guaranteed access to electrical power. Special needs shelters, however, are managed by the local county government and are designed to accommodate people who use oxygen, c-pap machines, are on dialysis or any other machine that requires electricity. They are staffed with medical personnel and can assist with administering medications.

In 2004, the SpNS in Ft. Pierce (in St. Lucie County) began to break down and leak during Hurricane Frances. In response, approximately 100 patients were transferred to another location (Channel 10 News 2004). St. Lucie county officials reported that no one was injured at the special needs shelter or during the transfer; however, it is likely to have been a frightening experience for most.

When Jeanne began to threaten the area, the special needs shelter was still not repaired (Reeder, 2004). On September 24th, a St. Lucie Newspaper headline read “St.
Lucie Can't Give Shelter To Infirm” (Reeder 2004). To resolve this issue, people with special needs were bused to an alternative shelter in Palm Beach County (DiPietre 2004). This alternate shelter was at the Palm Beach County Public Health Department, which was separate from the Palm Beach County Special Needs Shelter. St. Lucie public health officials accompanied patients on the bus and assisted them throughout Hurricane Jeanne. The perspectives of the patients were not explored in this ordeal. The following year, St. Lucie County collaborated with the school system to better provide alternative SpNS (Panoff 2005).

A more personal account of the 2004 hurricane season offered is by Susan E. Green, a sociologist at the University of South Florida, who wrote explicitly about emotional toll that the multiple hurricanes took on her and her family in an article entitled “Enough Already!’: Caregiving and Disaster Preparedness—Two Faces of Anticipatory Loss” (2005). She recounted how a pregnant family member had evacuated to Green’s home, while the baby’s father continued to work at a special needs shelter:

“Our nephew’s pregnant wife held her year-old baby in our boarded-up house and watched as the Weather Channel reported that the roof of the special needs shelter in which her husband was working had been ripped off during the night—forcing an evacuation of the shelter while Jeanne’s winds still raged (Green 2005: 203).

Concern for loved ones and property can cause an increase in stress and emotional strain. The emotional trauma of a natural disaster can lead to further public health concerns, including post-traumatic stress syndrome and depression (Galea, Tracy, Norris, and Coffey 2008; Norris, Kaniasty, Conrad, Inman, and Murphy 2002; Ironson et al. 1997. These factors, in turn, might make it difficult to respond in the face of concurrent disaster. These issues are discussed further in Chapter 5, in Theory. Furthermore, the use
of SpNS is a contested issue, which is described in the results (Chapter 7) and discussion (Chapter 8).

**Summary of Research Setting**

The Treasure Coast, consisting of Palm Beach, Martin and St. Lucie counties, has been impacted by multiple hurricanes during the past two hundred years. As more people move to and develop this hurricane prone area, the more people are at risk for experiencing the negative effects of a disaster (Cutter 2003). The history that I recounted here highlights the difference between the number of deaths that took place in Florida during the 2004-2005 and the death toll of Hurricane Katrina in Louisiana. This suggests that Florida has been more successful in its disaster mitigation and planning than some other coastal states. It might also suggest that Florida has simply not been hit in the “right place at the right time” since Florida is home to four of the top ten most vulnerable areas in the United States (#2: Lake Okeechobee Area, #3: Florida Keys, #5: Miami and Ft. Lauderdale area, and #10: The Tampa/ St. Petersburg area) (IHC 2007; Zhang, Xiao and Leatherman 2006). The multiple hurricanes of the 2004-2005 hurricane seasons highlighted some weaknesses in Florida’s disaster plan, which become important themes in my results: 1) there is an ongoing segregation and marginalization of people living in the Lake Okeechobee area; 2) special needs shelters are not always safe. As will be revealed in the results, there are many pitfalls in the current special needs shelter systems in Florida that directly impact the well-being of people with dementia and their caregivers.

In addition, this historical recounting of hurricanes sets the stage for theoretical developments posed in Chapter 5. During these back-to-back hurricanes in Florida,
experts, politicians and journalists alike commented on the decreased response to these hurricanes over time. Multiple explanations were posed for this lack of response, including “hurricane amnesia” and “hurricane fatigue”. In chapter 5, I will reference these hurricanes again to explain a term that is more useful: “risk fatigue”.
Chapter 3: Literature Review of Alzheimer’s disease and Caregiving

This chapter is divided into two parts. The first discusses the social construction of Alzheimer’s disease and related dementias, while the second focuses on caregiving for persons with dementia (PWD). The core theoretical concerns for the construction of Alzheimer’s disease and related dementias focus on the anthropological concepts of personhood and recognition. Biomedical measurements, such as the progressive stages of the dementias, are also considered within a socially constructed framework. The measurement of loss and the staging of AD have profound social significance for the individuals to which they are applied. Furthermore, they have important implications for disaster planning (which is revealed in the Results and Discussion chapters).

The primary theoretical concerns for Part II are the nature of familial caregiving social roles, the feminization of caregiving, and caregiver burden. In this second part of the chapter, I introduce the concepts of home and community-based care for PWD and why it is preferred by caregivers and legislators alike. Though home and community-based care is considered favorable to institutional settings, there remain concerns that need to be problematized; Critical medical anthropology (Castro and Singer 2004) emphasized the need to reflect on the historical and political-economic mechanisms that influence health disparities. I adopt this critical stance when examining the feminization of dementia care. Women bear the greatest burden of caring for community dwelling and institutionalized elder’s alike (Henderson 1994; Colello 2007). The social and political-economic pressures which are currently privileging home and community based care over
skilled nursing, often fail to account for the lack of training for community based caregivers. These caregivers rarely have training on dementia or in techniques for responding to associated behavioral disorders, which puts both the caregiver and the PWD at risk for injury and other stressor (which frequently translate into caregiver burden). Caregiving can carry many risks. People who provide care for another demonstrate an increased morbidity and mortality rates (when compared to the non-caregiving population). While not every PWD has a family member that is both willing and capable to provide labor intensive care in their home, emphasis continues to be placed on this method of care provision. The defunding of Medicaid beds in skilled nursing homes can be problematic for these people and must be considered in policy planning. I attempt to place these demographic trends in caregiving within the push for home and community-based care, and compare concerns with the deinstitutionalization that took place for people with psychiatric needs in the 1980s.

I tie caregiver burden and risk assessment to the theoretically rich concepts of personhood and social roles; I argue that there is a shift in social roles when someone takes on the identity of caregiver rather than “wife”, “husband”, “son”, or “daughter”, which ultimately, can impact disaster planning decision. Finally, I present anthropological literature on family “older adult” decision-making during hurricanes. I use literature on “older adults” and people with disabilities because there is a paucity of research on PWD before, during, and after hurricanes. Since old age is the greatest predictor of an AD or related dementia, this literature is used to approximate issues and concerns for PWD and their caregivers during disasters.

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3 As documented by Federal Emergency Management Administration and Citizen Corps surveys.
In March 2011, I walked into a Florida State Representative’s office in Tallahassee with two caregivers of persons with dementia (PWD), a Lutheran pastor, and an Alzheimer’s Community Care (ACC) representative. Our goal was to explain the importance of the Silver Alert Bill, which would provide law enforcement with resources to aid in locating and returning missing elders. Our secondary goal was to lobby for the continuation of funding for adult day care programs and caregiver support offered through ACC, since funding had been cut every year for the past four years. The representative listened politely, and then asked, “Shouldn’t we be prioritizing funding to find a cure for Alzheimer’s, not just on maintaining the status quo?” My jaw dropped, and I made a clumsy attempt to explain the difference between healing and curing; a critique of biomedicine, which often failed to address the actual suffering of individuals as it pursued a cure… but I stopped myself. We only had five minutes of face time with the representative, and I quickly realized I had been operating under one set of assumptions about the disease and he another. To ask someone to, in five minutes, reflect upon and critique the assumptions he has carried for approximately fifty years was simply too much. It was beyond the scope of our meeting to address disparate worldviews.

In the following pages, however, I will take the time to discuss the historical framing of the disease known as Alzheimer’s (and related dementias). I will attempt to explain the (medical) anthropological underpinnings of concepts like, “old” and “senile,” “sick” and “well” (Kleinman 1980; Lock 1993). I, like other medical anthropologists, such as Cohen (1998) Leibing (2006), Taylor (2008), and Hashmi (2009), argue that...
“senility,” “dementia,” and “Alzheimer’s disease” are socially constructed concepts. However, this does not imply that they are “not real,” but rather that their content depends upon particular historical and social contingencies and may shift over time, location, and cultural context (Kleinman 1980). As a result of these socially contingent definitions, we make assumptions about what illnesses are and how people with these conditions ought to be treated. In order to understand these issues, I will first deconstruct or “unpack” these concepts in order to critically contextualize my findings. This also has implications for applied solutions, since a problem based on a set of social assumptions often require a shift in perspective and definitions to resolve conflict.

**Core Theoretical Concerns.**

For the first section of this chapter, the two primary anthropological theoretical frameworks guiding the research are: 1) the loss of personhood, adult status, social roles, and “citizenship” when one has a cognitively-debilitating and chronic illness (Estroff 1993; Estroff, Penn, and Toporoek 2004), such as AD; and 2) issues associated with “recognition,” not only on the interpersonal level, but on the political as well. As I discuss below, the first framework – the loss of one’s personhood or adult status – has been examined in studies of both mental and physical disabilities. It has been used to critique assumptions about equating “productivity” (the ability to work, have an income) with being a valuable citizen. The second framework, of “recognition,” has been recently applied in medical anthropology (Taylor 2008) to explore the shift in a PWD’s ability to recognize family and friends, as well as (similar to the above framework) a person’s recognition within socio-political arena. The loss of recognition means that the PWD is less able to reciprocate, express affection, and have a voice. A result of both frameworks
is what has been referred to as the point of “social death”, when people around the PWD stop recognizing them as “fully human” or “fully alive” (Hertzkovits 1995; Poveda 2003; Leibing 2006; Fry 2007; Taylor 2008; Hashmi 2009). Instead, they are frequently described as a “shell” that no longer contains the full person.

Like Taylor (2008) and Kaufman (2006), I will consider alternatives to the dehumanizing assumption often applied in biomedical approaches and reinforced in popular media. To offer context, I provide background on constructions of age and what it means to be “old” and at risk for acquired disabilities.

Time and Age

*Humans have ‘domesticated time’ by making it a subject of cultural interpretation.* (Fry 2007:11)

A human universal is that societies stratify themselves by age. However, there is variation in how “age” is defined and measured (Hendricks and Hendricks 1976). Not all societies’ measure age against the number of rotations the earth has made around the sun since they were born; this measure (incorporated into the Gregorian calendar) is a relatively recent invention. More general markers, such as changing seasons, might be used as an indicator for change over time. Another way to conceptualize age is to categorize people into generations (or generational life courses), life stages (staged life courses) or age-classed life courses (Hendricks and Hendricks 1976; Fry 2007). In modern western societies, age -- measured from the time of birth -- has become an important biomarker that is codified in legal and medical documents and assumed to correlate with certain stages in human development, which denote “citizenship” (Fry 2007). Chronological age can be divided into a “tripartite” life course, which divides citizenship into three stages: 1) childhood, 2) adult citizenship, and 3) post-adulthood or
old age (Fry 2002). Conceptions about age-specific roles and responsibilities can vary across societies; for example, while people are considered to have the capacity to consume alcohol in Germany at the age of 16, people in the United States must wait until 21. In modern time, adulthood is when a person is capable of “full citizenship” (Fry 2007), as demonstrated by roles taken on in family relations and work (or the provision of goods). As a result, when one reaches “post-adult” status, a person often relinquishes responsibilities such as working full time. Thus, there are different social roles and responsibilities (or lack thereof) associated with different stages of the human life. Older age is the strongest correlate and risk factor for Alzheimer’s disease and related dementias; the most common form appears after the age of 60 (Bludau 2010).

Medical anthropologists have sought to understand the perspective of the PWD, whose perceptions of time and reality vary from others. PWD frequently experience age and time “disorientation”, in which he or she believes she is decades younger than the actual age lived. Shomaker (1989) argues understanding how time disorientation is experienced by a PWD might aid in handling problematic behaviors (such as repeated attempts to go to work, even when the PWD has been retired for years). There have been two primary approaches to time disorientation: 1) reality orientation and 2) validation therapy (Fiel 1985; Fiel 1993; Morton and Bleathman 1991). With reality orientation, a PWD is consistently reminded of the “actual” time and place (Feil 1985). Validation therapy, conversely, verbally affirms the PWD’s (dis)orientation, thereby reducing stress and conflict between the caregiver and PWD (Feil 1985). With affirmation, caregivers can redirect or distract a PWD from problematic behaviors, such as attempts to leave the home unaccompanied. According to Downs (1997), this approach can help preserve a
sense of dignity and personhood in the PWD. In the following sections, the themes of
time and personhood reoccur throughout the research about AD and related dementias.

**Social Construction of the Dementias.**

*We simply take this nearly silent, ludicrously powerful electrochemical engine for
granted. We feed it, try not to smash it too hard against walls or windshield,
and let it work its magic for us. Only when it begins to fail in some way, only then are
we surprised, devastated, and in awe.* Shenk on the human brain in *The
Forgetting* (2001:12)

According to critical medical anthropology, understanding dementia within a historical
context is vital to illustrate how it has been socially constructed. Debates that posit
dementia as a “normal” part of aging have been pitted against those that conceptualize it
as a disease distinct from the aging process. These debates provide context in which
dementia and Alzheimer’s disease, specifically, began to be medicalized. *The naming of
the disease* (and the identification of the organic structures associated with its signs and
symptoms) created a jumping point from which the medical field could begin to measure
and diagnose the illness (Kaufman 1980). Perhaps the most important aspect (for the
purposes of this research on disaster planning and response) is the “staging” of
Alzheimer’s type dementia, which I discuss in detail below. Staging is a way of grouping
signs and symptoms into recognizable and measurable periods as the disease progresses
over time. As a result of the progressive nature of the disease, disaster plans need to be
constantly reevaluated to appropriately respond to the needs of the Person with Dementia
(PWD).

While the biological processes of Alzheimer’s and other dementias (such as
vascular dementia) may have always been present in human populations, most people
simply did not live long enough for the expression of these diseases. Nonetheless,
references to the deterioration of the human mind with age have existed since humans first began to use writing as a tool for recording history. Egyptian pyramid texts (dated from more than 4,000 years ago) refer to the sun god Ra, who eventually aged, became feeble, and showed signs of senility (Shenk 2001). About 2,700 years ago in ancient Greece, Pythagoras, a physician, described old age and mental decline (Berchtold et al. 1998). Roman writers, such as Juvenal and Virgil, also allude to the mental decline in old age (Falkner 1989; Schenk 2001). However, the phenomenon of mental decline was associated with the relatively rare occurrence of living beyond the age of 60 years. It was not until the late 19th century, when societies began to undergo epidemiological transitions and fewer people died of infectious diseases and began to live into old age, that dementias became more common (Kinsella 2009).

“Normal Aging” and Naming a Disease: A Bio-social Endeavor.

Every disease needs a name. As a matter of social reality, no disease exists until it has one (Shenk 2001:278).

Dementia has long existed under the name of senility, which was assumed to be a normal part of aging until the late 19th century. Alzheimer’s disease, now understood to be the most common cause of dementia, exists as a social construct because of the events surrounding the death of Frau Auguste D. in 1906. Frau D.’s doctor, Alois Alzheimer, noticed a subset of unusual behaviors (progressive “psychic disturbances in the absence of epileptic fits”) (Shenk 2001:22). Upon her death, he examined her brain under a microscope and first documented the infamous tangles and plaques in the tissue. In 1910, his boss, Emil Kraepelin, referred to Morbus Alzheimer (Alzheimer’s disease) in his published Handbook, officially coining the name (Cohen 1998; Shenk 2001).
Alzheimer thus contributed to a shift in the way that aging itself was constructed in the Western world. His identification of the pathology related to cognitive decline provided the field of psychiatry with an organic link to the associated behaviors (Shenk 2001). With the distinction of dementia as a disease process separate from normal aging, a biomedical war could be waged upon it (Shenk 2001). This was the beginning of the constructed understanding of Alzheimer’s disease.

According to anthropologist Sharon Kaufman, historically, people assumed that senility was a normal (and therefore inevitable) part of growing old, until the idea came under scrutiny in the late 1880’s (Kaufman 2006: 25). A physician, I.L. Nascher, argued that memory loss was not, in fact, a normal part of aging (Kaufman 2006:25). People who experienced senility, he said, had a disease. Even with Alzheimer’s evidence, the debate over whether the “softening of the brain” was a normal part of aging, and whether aging itself was a pathological or a chronic illness, continued through 1930’s and the “aging as a disease” paradigm continued to be taught in medical schools (Kaufman 2006; Cole 1992).

Indeed, in many ways, the debate continues to this day (Blumenthal 2003). In the modern era, even with the use of scientific measurement, the boundaries between normal aging and disease remain blurred. As Kaufman points out, “the idea of age-related disease muddies the waters” about whether there is a difference between “normal aging” and “aging as disease” (2006:26). The case of arteriosclerosis is a good example of this, since it is “normal” to have age-related hardening of the arteries “until it progresses to a point at which they lead to diseases, such as heart attacks” (Blumenthal 1993:1272 as quoted in Kaufman, 2006). Once a person has a heart attack, the hardened arteries are no
longer “normal”- they are considered “pathological”. Similarly, forgetfulness is now considered to be a normal part of aging, until it reaches a point when a person can no longer complete their activities of daily living (ADLs). The Diagnostic and Statistical Manual of Mental Disorders (DSM IV) codifies the point at which “forgetfulness” becomes a disease. Thus, while aging is associated with several “normal” conditions, once they progress to a certain (socially and medically defined) point they become age-related diseases. In the decades since the identification and naming of AD, the debate continues.

Thus, in one respect, “naming the disease brings order out of chaos” (Womack, 2010) and offers the possibility of resolution. This allows, e.g., a concerned spouse to "see" the disease in order to fulfill a general psychological need to define and order a chaotic experience, and to provide clear expectations for the future, which, though bleak, are more secure than the unknown (Gubrium 1986:69; Hertzkovits 1995; Whitehouse, Gaines, Lindstrom and Graham 2005). Once named, a disease is defined by its signs and symptoms. The severity of the signs and symptoms can then be measured, and a search begun for causes and ways to reduce them. Diagnosis also brings with it legitimacy (Cohen 1998; Solimeo 2009). “[W]hatever the patient’s experience of pain, disability, or illness might be, this experience must be validated by a health care practitioner in order for a patient to legitimately be sick” (Solimeo 2009:9). Establishing the legitimacy of an illness can result in desired social acceptability as well as resources for the suffering person. For instance, in Florida, dementia must be diagnosed by a medical professional in order to obtain financial support for medical and social services. The medical professional evaluates the physical signs and symptoms with a number of tests and
measurements. The severity of the cognitive impairments is ranked to determine the types and amounts of formal support that can be offered. Nonetheless, anthropologists emphasize that the process of naming and defining a disease is culturally driven. As explained by Whitehouse et al. 2005:

> although AD and other subdiagnoses are considered discrete categories for which specific therapies are sought, in actual fact, the boundaries that might delineate the various dementias, and distinguish between normal and abnormal cognitive functioning, are unclear and are constantly debated within the medical professions.

Beyond biomedical explanations, alternative explanatory models (Kleinman 1980) might be employed by patients to cope with an unfamiliar disease, many of which have been documented by medical anthropologists. For example, Cohen (1998) found that, in India, the locus of Alzheimer’s disease is believed to lie in “a bad family” (read broken, scattered, inattentive and neglectful family). People, who lived with intact, “good” families, it was believed, did not become senile. In another anthropological study, Leibing (2006) found that many families believed that the true cause of Alzheimer’s disease was a “hard life” that the afflicted person could no longer process (241). Ikels (2002) in a study in Guangzhou, China, illustrated that while people might display the same physiological and behavioral features of dementia, their experience of the disease is very different than those with dementia in the United States. These differences lay within the social make-up of the societies, and in “meaning attributed to these changes and in the caregiving arrangements” (Hashmi 2009).

While both bio-medical and other explanatory models have helped people make sense of senility, dementia and Alzheimer’s disease, being formal recognition of the

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4 The Department of Elder Affairs of the State of Florida requires a “Prioritization Assessment Form; DOEA Form” 701A (10/03) to be completed if a PWD requests funding for social services. This is discussed further later in this chapter.
disease potentially transforms a person, their relationships, and social roles.\textsuperscript{5} It is important to note that when anthropologists discuss illnesses as social constructions, they are not implying that a disease does not exist. Rather, “[a]nthropologists underline how scientific activity is not always about uncovering ‘nature’. It is a fierce fight to construct reality” (Graham 2006:83-84). Alzheimer’s disease is a bio-social process, in that there are sociocultural manifestations in addition to physical ones. Anthropologists distinguish between disease (the objective, biological symptoms) and illness (the socially defined significance and response to the disease) (Kleinman 1980). To put it another way, “[m]edical anthropologists do not dispute that biological disease occurs, but are more interested in the reasons why scientifically demonstrable physical pathology should appear and be treated in such different ways around the world” (Hashmi 2009:207).

Underlying the discovery of scientific facts are social frameworks that influence where and how scientists look for answers. Whether dementia is a “normal” part of aging or not is one of these influential frameworks. Other dominant factors in the United States are the market-driven and bio-medical paradigms, which influence how AD and the related dementias are identified, diagnosed, measured and how people with the diagnoses are treated (both medically and on an interpersonal level). When determining the worth of a person in a market-driven system, self-sufficiency and independence are key values. When a people are diagnosed with AD or a related dementia, questions are raised about their ability to provide for themselves. These questions begin a shift in how families, friends and medical professionals perceive the diagnosed person.

\textsuperscript{5} When symptoms are not categorized and legitimized, people with the symptoms are in a liminal place and become stigmatized. Others might see them as “lazy” or “stupid” and potentially “worthless” These connections will be discussed further later in this chapter.
Measuring Loss: Diagnosis, Testing, and Stages

If dementia is entirely a pathological entity caused by neuronal and neurotransmitter loss, then why should there be a question about the cross-cultural validity of dementia? (Hashmi 2009:210)

One thing that has not changed since Alois Alzheimer first observed the deceased Frau D.’s plaques and tangles is that the only way to definitively diagnose the disease is through biopsy (e.g., to operate physically on the brain) or autopsy. The former is an invasive and potentially dangerous procedure, so instead screening tests, such as the Mini Mental Status Examination (MMSE) (Folstein and Folstein 1974), the Global Deterioration Scale (GDS) (Reisberg et al. 1982), and Functional Assessment Staging (FAST) (Reisberg et al. 1988) are increasingly used in tandem with neurological testing and magnetic resonance imaging (MRI) to measure potential shrinkage in the brain. Alzheimer’s type dementia follows a relatively predictable pattern of decline in functioning, which is largely explained by biomedical processes.

Biomedical Processes.
Alzheimer’s disease usually begins its attack on the brain in the hippocampus, “a curved, two-inch-long, peapod-like structure in the brain’s temporal lobes” (Shenk 2001:37). The hippocampus is the part of the brain that allows the mind to process and create new memories. Consequently, the first cognitive abilities to decline in people with the disease are their grasp on recent occurrences (learning and memory). Current biomedical explanations of the damage to the hippocampus point to several factors: 1) the presence of intracellular neurofibrillary tangles (NFTs) (made of a protein called tau); 2) neuronal loss, 3) the formation of extracellular senile plaque (made of amyloidbeta-peptide or “A [beta]”) and 4) the occurrence of cerebral amyloid angiopathy (CAA) (De Strooper 2010; Chang et al. 2011). Essentially, the neurons and synapses are blocked and
strangled by the tau (tangles) and amyloid beta-peptide (plaques), thus becoming unable to send electromagnetic signals to each other or receive an adequate amount of blood (and therefore, die) (De Strooper 2010; Chang, et al. 2011). Though scientists have identified the composition of the plaques and tangles, their cause remains unclear.

Though the plaques and tangles first begin in the hippocampus, over time, the cells in the surrounding area in the cortex begin to be affected (Scahill, Schott, Stevens, Rosser and Fox 2002). As the disease progresses, the area of the brain that controls thinking and planning begins to deteriorate. Next, speech, and the ability to understand speech, declines. Eventually, the plaques and tangles begin to choke off the brainstem, which regulates reflexes such as breathing. The end stage of Alzheimer’s type dementia, therefore, is death. Importantly, as each part of the brain is affected, there are corresponding functional deficits.

This progressive nature of AD allows for a degree of measurement and inference; it can be broken down into stages to mark the progression of the disease. However, there are some exceptions to the staging process. First, not all forms of dementia are of the Alzheimer’s type (there is also Lewy Body disease, vascular dementia, Parkinson’s, Huntington’s, and Pick’s, disease, which can cause dementia). Most dementias, however, do become worse over time and none can be “cured”. Second, there are variations even within the AD diagnosis. For example, there is a visual variant of the disease wherein visual disturbances emerge before other signs (Santano et al.2011). In the following

7 The measurements discussed later in this chapter (i.e., GDS and FAST) apply specifically to Alzheimer’s type dementia and may not be applicable to the other types.
section, I will discuss the formal diagnostic process used to assess a person presenting with signs and symptoms of dementia.

**DSM-IV (Diagnostic and Statistical Manual of Mental Disorders (2000))**

The Diagnostic and Statistical Manual of Mental Disorders (2000) provides criteria for professionals to use when diagnosing Alzheimer’s type dementia. Explicitly, the DSM-IV is assessing signs and symptoms that are predicated on a biological function. Implicitly, the DSM-IV is codifying socially constructed assumptions about what are “normal” and “abnormal” behaviors. The criteria included to diagnose Alzheimer’s type dementia are as follows:

1. Memory impairment- impaired ability to learn new information or recall previously learned information; and one or more of the following impairment in cognition:
   a. Aphasia- difficulty in language comprehension or production, manifested in difficulty in finding the right words and marked by the presence of frequent word substitutions, breaking off mid-sentence, and repetition;
   b. Apraxia- difficulty performing movement in response to verbal commands despite intact motor function;
   c. Agnosia- difficulty recognizing familiar faces, objects, places in spite of intact sensory function; or
   d. Executive function- difficulty in planning or sequencing activity, or difficulty completing a task in the presence of interference from another task.

It is assumed that these deficits “must be severe enough to cause significant impairment in social or occupational function and must represent a significant decline from a

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8 The DSM-V is expected to be released May, 2013: [http://www.psych.org/dsmv.aspx](http://www.psych.org/dsmv.aspx)
previous level of functioning” (Albert 2001:139). The person carrying this diagnosis must, therefore, display disabling factors. The subtext of this assumption is that the person with the diagnosis is less able to contribute meaningfully to society. Scholars have begun to question some of the underlying assumptions “about normal behaviour that relate to productivity, unity, moderation and rationality [sic]” (Crowe 2001:1). The DSM-IV has been critiqued for focusing on the individual without taking into account the social or cultural context in which behaviors occur (Crowe: 2001). In other words, in some societies or social situations, an “abnormal behavior” might be considered appropriate or at least “normal” among elders. Variation in the response to biological functions, again, illustrates how disease is socially constructed. This begs the question, is the way in which Americans respond to the illness, really the best way? Are there ways that our conception of the disease can be improved? These questions will be addressed further in the discussion chapter (Chapter 8).

The Three-Stage Alzheimer’s Disease Model

As a chronic illness, Alzheimer dementia is characterized by an ‘uncertain course,’ but explaining the illness in terms of a time structure and stages enables the experience to be organized and improves the caregivers’ ability to predict and supervise the development of the illness. Poveda 2003: 26-31

In addition to the naming of a disease, its definition (as seen in the DSM-IV text above) and measurement are also socially constructed. The measurement or staging of a dementia reflects the progressive nature of the disease; as the disease progresses, behaviors, risks and caregiver concerns also change. Caregiver concerns and risk assessments ultimately influence disaster planning. For these reasons, the staging and some of the primary tools used to determine the stages of dementia are outlined below.
The Folstein Mini-Mental Status Exam (MMSE) has been widely used to measure the progression and severity of the disease. It is a 30-point assessment “of orientation, memory, attention, language, calculation and visio-spatial construction skill, typically used as a screening test” (Albert 2004: 140). A score below 24 is considered impaired and an indication of dementia; a score of 15-24 is ranked as mild to moderate impairment and a score of less than 15 is definite impairment (Albert 2001: 140). It is important to note, however, that how a person performs on the MMSE is influenced by socio-cultural and economic factors, such as age and level of formal education (Albert 2004). Those with more education, for example, tend to have higher median scores regardless of dementia status, suggesting that these influences must be considered when interpreting scores (Albert 2004: 140; Stern 2006). Lower education levels are often linked with lower socio-economic status and higher morbidity rates in general (Muller 2003). Education as a confounding factor highlights one of the many bio-social aspects of dementia and highlights the difficulties in measuring interactions between biological processes, social factors and disease (Stern 2006). Nonetheless, researchers have used the MMSE to measure the severity of dementia. They have found that psychiatric symptoms, such as wandering and fecal smearing (scatolia), vary with the severity of dementia with probable AD (Lopez et al. 2003; Scarmeas et al. 2007; Ata et al. 2010).

As mentioned, the score on the MMSE correlates to a ranking within three stages of dementia. The Three Stage Dementia Model is a generalized grouping of signs, symptoms and behaviors that might be observed over time.
### Table 3.1 Three Stages of Dementia Model

<table>
<thead>
<tr>
<th>Dementia Stage 1:</th>
</tr>
</thead>
<tbody>
<tr>
<td>The person becomes aware that she is not thinking and remembering as she did in the past. At this stage, she is pretty good at covering up gaps and lapses in memory. Family members and others may see a troubling lapse once in a while but will likely attribute it to the person having a bad day or the normal memory changes that occur with aging. Tools such as making notes, using a written calendar and keeping lists can help her stay on track.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Dementia Stage 2:</th>
</tr>
</thead>
<tbody>
<tr>
<td>At this stage memory lapses and confusion become more obvious and the person can no longer hide her memory gaps from family and friends. Her short-term memory is very impaired and she may ask a lot of repetitive questions and be anxious about when events are happening. Her ability to manage her day-to-day life is affected. A formerly neat person may become messy. Hobbies that previously provided enjoyment may be abandoned. She may withdraw socially, finding that she is uncomfortable in group situations. Friends may drift away when your family member can no longer participate and respond as she did before.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Dementia Stage 3:</th>
</tr>
</thead>
<tbody>
<tr>
<td>At this stage, she is highly impaired by her dementia. It is obvious to anyone speaking to her for more than a few minutes that something is wrong with her ability to think. Her dementia may also limit her ability to communicate. She requires daily supervision, if not constant supervision, to make sure that she is safe. She needs assistance with the activities of daily living such as bathing and dressing and can no longer live independently.</td>
</tr>
</tbody>
</table>

Table adapted from [http://www.understanding-dementia.com/stages-of-dementia.html](http://www.understanding-dementia.com/stages-of-dementia.html)

**Seven Stage Dementia Models**

Other tests, such as the Global Deterioration Scale (GDS) (a.k.a. the Reisberg Scale) and the Functional Assessment Staging (FAST), break down the mental decline into seven distinct stages. Each test has different possible outcomes. The GDS evaluates stages in cognitive function, while the FAST emphasizes functional abilities.

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It is important to note that these measures are specific to the Alzheimer’s type dementia only.
<table>
<thead>
<tr>
<th>Global Deterioration Scale</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Stage 1:</strong> No Cognitive Decline</td>
</tr>
<tr>
<td><strong>Stage 2:</strong> Very Mild Cognitive Decline</td>
</tr>
<tr>
<td><strong>Stage 3:</strong> Mild Cognitive Decline</td>
</tr>
<tr>
<td><strong>Stage 4:</strong> Moderate Cognitive Decline</td>
</tr>
<tr>
<td><strong>Stage 5:</strong> Moderately Severe Cognitive Decline</td>
</tr>
<tr>
<td><strong>Stage 6:</strong> Severe Cognitive Decline (Middle Dementia)</td>
</tr>
<tr>
<td><strong>Stage 7:</strong> Very Severe Cognitive Decline (Late Dementia)</td>
</tr>
</tbody>
</table>

(Reisberg et al. 1982)

Table adapted from [http://helpguide.org/elder/alzheimers_disease_symptoms_stages.htm](http://helpguide.org/elder/alzheimers_disease_symptoms_stages.htm)
Functional Assessment Staging (FAST)
Another staging method for dementia, the Functional Assessment Staging (FAST), focuses more on an individual's level of functioning and activities of daily living versus cognitive decline. Of note, a person may be at a different stage cognitively (GDS stage) and functionally (FAST stage).

Table 3.3 Functional Assessment Staging (FAST)

<table>
<thead>
<tr>
<th>Stage</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stage 1</td>
<td>Normal adult. No functional decline</td>
</tr>
<tr>
<td>Stage 2</td>
<td>Normal older adult. Personal awareness of some functional decline.</td>
</tr>
<tr>
<td>Stage 3</td>
<td>Early Alzheimer's disease. Noticeable deficits in demanding job situations.</td>
</tr>
<tr>
<td>Stage 4</td>
<td>Mild Alzheimer's. Requires assistance in complicated tasks such as handling finances, planning parties, etc.</td>
</tr>
<tr>
<td>Stage 5</td>
<td>Moderate Alzheimer's. Requires assistance in choosing proper attire.</td>
</tr>
<tr>
<td>Stage 6</td>
<td>Moderately severe Alzheimer's. Requires assistance dressing, bathing, and toileting. Experiences urinary and fecal incontinence.</td>
</tr>
<tr>
<td>Stage 7</td>
<td>Severe Alzheimer's. Speech ability declines to about a half-dozen intelligible words. Progressive loss of abilities to walk, sit up, smile, and hold head up. (Reisberg et al. 1988)</td>
</tr>
</tbody>
</table>

The GDS and the FAST assessments are more useful for explaining the variation in behaviors over time than the MMSE, since they capture the clusters of behavioral symptoms likely to be encountered at each “stage” of dementia (Reisberg et al. 2009).

Stages 6 and 7 each have sub-stages (Reisberg 1983; Shenk 2001). Reisberg likens this stage to a reversal with childhood development, terming it “retrogenesis” (Reisberg 1980; Shimada et al. 2003). The decline in the functions associated with AD matches, almost marker by marker, the phases of cognitive child development:
### Table 3.4 Comparison of Child Development and AD Stages

<table>
<thead>
<tr>
<th>Child Development</th>
<th>Alzheimer’s Disease (Last stages to first)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>Acquired Ability</td>
</tr>
<tr>
<td>1-3 months</td>
<td>Can hold up head</td>
</tr>
<tr>
<td>2-4 months</td>
<td>Can smile</td>
</tr>
<tr>
<td>6-10 months</td>
<td>Can sit up without assistance</td>
</tr>
<tr>
<td>1 year</td>
<td>Can walk without assistance</td>
</tr>
<tr>
<td>1 year</td>
<td>Can speak one word</td>
</tr>
<tr>
<td>15 months</td>
<td>Can speak 5-6 words</td>
</tr>
<tr>
<td>2-3 years</td>
<td>Can control bowels</td>
</tr>
<tr>
<td>3-4.5 years</td>
<td>Can control urine</td>
</tr>
<tr>
<td>4 years</td>
<td>Can use toilet without assistance</td>
</tr>
<tr>
<td>4-5 years</td>
<td>Can adjust bath water temperature</td>
</tr>
<tr>
<td>4-5 years</td>
<td>Can put on clothes without assistance</td>
</tr>
<tr>
<td>5-7 years</td>
<td>Can select proper clothing for occasion or season</td>
</tr>
<tr>
<td>8-12 years</td>
<td>Can handle simple finances</td>
</tr>
<tr>
<td>12+</td>
<td>Can hold a job, prepare meals</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(Adapted from Shenk 2001: 122-123)

The above table documents physical development/decline. Each of these markers, such as the ability to smile, also carries deep social meaning. The ability to smile indicates recognition and a basic acknowledgement, and can be a simple form of reciprocity. Each loss in function might be considered to be a loss of personhood within the social context.
There have been several critiques of this model, because it explicitly equates the PWD with a child (Castleman 1999). Salari (2005) argues that conceptualizing people with dementia as children is inappropriate and can lead to abusive behaviors “in the form of age inappropriate speech and behavior patterns, activities, and physical environments which disregards a lifetime of experiences and adult status” (55). Central to her argument is that people should be treated as adults with full citizenship, regardless of what capacities are lost (or what the PWD might find soothing) (Salari 2001). Other researchers use the above framework to explain the use of child-like toys, such as dolls, as successful therapeutic activities for people with dementia (James 2006). Problems may arise when a caregiver takes on a parenting role that leads to, for example, physical abuse. The underlying themes, however, stem from the differing philosophies of reality orientation and validation therapy (Feil 1985; Feil 1993; Morton and Bleathman 1991).

Underlying Salari’s argument (2001) is the belief that the caregiver ought to treat the PWD by their “real” lived age, despite the PWD’s “experienced” age or preferences. James (2006), on the other hand, argues for a more person-centered approach, which validates a PWD’s perceptions and does not necessarily mean focusing on loss.

Taylor (2008) and Fuchs (2005) discuss the significance of developmental changes associated with retrogenesis as the “firsts” and the “stills”. The “firsts” -- as in the above developmental chart -- include e.g., “first word” and “first steps”. The “stills” are unique to the changes wrought by dementia: “The social worker will ask the still questions: Does she still feed herself? Good. Still chew? Good! Still toilet? Well, that is to be expected” (Fuchs 2005:4). Friends and family, however, may have different “stills”. “Still like to get her hair done… Still hang on to her French and German… still like
parties?”(Fuchs 2005:4). Taylor adds that, in spite of dementia, her mother was still a cheerful and affectionate person (though not everyone is so lucky). She also noted that she began to have new firsts once her mother’s dementia began to progress: “The ‘first’ time since my early childhood that my mom and I walked down the street holding hands. The first time I tucked her into bed at night with her stuffed animals all around her” (316). For Taylor, there was a renewal of the tender love between a mother and her child, even if the roles had shifted. Thus, the construction of AD and related dementias creates a dynamic re-negotiation of social roles. As abilities are lost, the caregiver assists with more and more essential needs, called “activities of daily living”.

**Activities of Daily Living (ADLs)**

The above scales (FAST and GDS) include a more basic evaluation of what activities the PWD is able to complete during each stage. These activities are known as the activities of daily living (ADLs). They are a way to evaluate a person’s independence (or dependence) (See Appendix V). There are seven activities of daily living usually affected by the disease: bathing, eating, using the toilet, moving from bed to chair, personal grooming, and indoor mobility (Katz et al.1970; Albert 2004). The Instrumental Activities of Daily Living Scale (IADL) evaluates a person’s ability to complete more complex household tasks independently (Lawton and Brody 1969). For example, the IADL scale evaluates how much help a person needs with shopping, by asking whether or not the PWD: 1) Takes care of all shopping needs independently; 2) Shops independently for small purchases; 3) Needs to be accompanied on any shopping trip; or is 4) Completely unable to shop (See Appendix V). Notably, these measurements are employed by the State of Florida to determine whether a person is eligible for funding support or access to social services.
The Department of Elder Affairs of the State of Florida requires a “Prioritization Assessment Form; DOEA Form” 701A (10/03) to be completed if a PWD requests funding for social services. Information requested on this form includes: A. Demographic Information  B. Consumer Conditions (physical health, ADLs, IADLs)  C. Consumer Resources (assistance when needed), D. Nutrition Status; E. Caregiver Assessment  
F. Patient Medications, G. Social Resources, and H. Environmental Assessment (See Appendix V). For the purpose of this research, it is worth noting that the demographic section collects information on whether the “client” is in “need outside assistance to evacuate [in the event of a hurricane or other disaster]”, and whether they are “registered with county special needs registry.” However, there is no definition of “need” for “outside assistance” or what might qualify a person with the special needs registry on the form. The “Prioritization Assessment” also does not include an evaluation of cognitive functioning. Cognitive functioning only appears to be a concern to the State of Florida if the PWD is unable to complete functional tasks for themselves. However, a person may be able to dress themselves but “fail to dress appropriately for the season”, for example, walking outside wearing sweatpants and sweater in the height of a Florida summer. A PWD may be fully ambulatory, but be at risk for becoming lost in their own home or in the community (Rowe 2003). My position on this issues is that the “Prioritization Assessment Form” does not fully consider (and therefore will not prioritize) the unique risks that face PWD. In short, the needs of PWD are not captured by the ADLs and

If there is a caregiver a caregiver assessment is recorded (which will be discussed further in the next section). The information recorded for the caregiver includes: 1) name, 2) relationship of the CG to the client, 3) telephone number and 4) a self-reported health rating (excellent, good, fair, poor) and 5) whether the CG will have the ability to continue to provide care (very likely, somewhat likely, unlikely). The assessor is asked to subjectively report whether the caregiver “in crisis” and whether this crisis is financial, emotional or physical. Basic demographic information is also collected on the caregiver.
IADLs alone. The real needs of people with dementia are not currently prioritized in the Health and Human Services areas, making access to state support more difficult.

**Dementia and Risk.**

Great stress is placed on the need for a caregiver to be vigilant in their supervision of the PWD because of the danger the PWD may pose to themselves or others (Mahoney et al. 2003; Leibing 2006). The NIH-published pamphlet entitled Home Safety for People with Alzheimer’s Disease, which lists several specific risks that caregivers should be aware of and prevent, including:

1) Wandering,
2) Rummaging/hiding things (potentially toxic materials or other dangerous objects);
3) Hallucinations, illusions, and delusion;
4) Impairment of the senses;
5) Driving;
6) Natural disaster safety.

The pamphlet provides a number of suggestions for caregivers to reduce risks for each of these categories. I will focus on the suggestions for natural disasters below, as they are most pertinent for this research. I will also discuss wandering behaviors, since PWD are more likely to become lost during a crisis situation (NIH 2010).

The pamphlet suggests alerting neighbors to the PWD’s condition in case they should see the PWD walking unaccompanied. The neighbors might also serve as point of contact should there be a crisis. Secondly, it suggests that families keep an extra week’s worth of supplies available. Essential supplies include an extra medications, personal hygiene items (i.e. adult diapers) and extra prescription glasses and hearing aids (if
needed). The pamphlet suggests having the PWD wear an identification bracelet (like the one provided by the Safe Return Program, described below). It is stressed that “under no circumstances” should a PWD be left unaccompanied during or after a disaster because of the possibility of becoming separated. If PWD are separated from their caregivers during a disaster, they might have trouble advocating for themselves during an emergency (Adams, Kaufman, Van Hattum, and Moody 2011).

Caregivers must consider safety concerns that other sub-sets of the population do not. They must be vigilant to maintain safety in their own homes, let alone against the risks that they might face before, during or after a hurricane. Though they might have the primary duty to assess risk and determine the safest plan of action, caregivers might become overwhelmed by their responsibilities during a crisis. Furthermore, the PWD to whom they provide care might be resistant to the caregiver’s decisions about what is safe or not.

**Wandering and Becoming Lost**

A well-documented risk is wandering, which is defined as:

> a syndrome of dementia-related locomotion behavior having a frequent, repetitive, temporally disordered and/or spatially-disoriented nature that is manifested in lapping, random, and/or pacing patterns, some of which are associated with eloping, eloping attempts or getting lost unless accompanied (Algase, Moore, Vanderweed, and Gavin-Dreschnack 2007: 696).

Approximately 60% of people with dementia will wander (Alzheimer’s Association 2011; Rowe 2003). Though the direct cause of these behaviors has not been determined, one trigger for exit-seeking is anxiety about one’s environment (Gerdner, Buckwalter, and Reed 2002; Lai and Arthur 2003; Moore, Algase, Powell-Cope, and Beattie 2009). Wandering behaviors can be observed in wheel-chair users as well as those who do not
need assistance (Schonfeld et al. 2007). If there has been a sudden change in the environment, such as during a disaster, or the PWD no longer recognizes where they are, they may wander and try to exit in an attempt to find surroundings that are more familiar. This is a significant concern for hurricane preparedness because PWD who evacuate with their caregivers to an unfamiliar environment may become agitated and disoriented. A successful exit, leading to elopement, is a risky event (Aud 2004; Moore et al. 2009). When a person leaves their home and caregiving situation unaccompanied, they are at risk of dying from exposure to the elements, drowning, or being hit by cars (Rowe and Glover 2001; Rowe 2003). Most deaths associated with wandering happen during months of extreme heat or extreme cold (Rowe and Glover 2001; Rowe 2003). Florida’s hurricane season is an especially risky time for a PWD to elope, which can increase a lost elder’s chance of becoming dehydrated in the heat of the summer or early fall.11 Caregivers may become distracted when responding to an environmental crisis and the PWD might become lost. During Hurricane Katrina, for example,

many older survivors in need of housing and physical or mental health care... were separated from loved ones for an extended time, and one of the most pressing issues aside from essential care needs was locating loved ones of evacuated citizens (Cherry, Allen and Galea 2010: 121).

The above statement illustrates the importance of families caring for a PWD participating in a centralized location and communication system. Gibson and Hayunga (2006) emphasized the voluntary use of “special needs” registries and taking advantage of the Alzheimer’s Association Safe Return Program (8).

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11 The ability for the human body to regulate temperature decreases over time. It is considered to be a ‘normal part of aging. However, when a person has a disease that causes dementia, the person may not be able to recognize the signs of heat stroke or dehydration.
Mechanisms for Reducing Risks

Alzheimer’s Association Safe Return®. The Safe Return® program is similar to the MedicAlert® program. It has two essential components: 1) 24-hour nationwide emergency response service for individuals with Alzheimer's or a related dementia who wander or have a medical emergency; 2) Individualized emblem (on a piece of jewelry) engraved with MedicAlert® and Safe Return's 24-hour emergency response number.

Should the PWD go missing, the jewelry will provide information to others about the PWD’s condition and contact information. The contact information can be used to help return the PWD to caregivers. Additionally, the Alzheimer’s Association offers resources for disaster preparedness, which are available on the internet (alz.org).

Alz.org Disaster Preparedness Information.

This Alzheimer’s Association (2007) provides disaster preparedness suggestions for people with dementia and their caregivers. They suggest planning before a disaster, such as enrollment in the Safe Return program and preparing an emergency kit. They make suggestions for tailoring the disaster kit for PWD, by having: 1) at least two sets of “easy on/off clothes” including Velcro shoes/sneakers, 2) supplies of medication (or, minimally, a list of medications with dosages) in a waterproof bag, 3) a spare pair of eyeglasses, 4) incontinence products, 5) extra identification items for the person, such as an ID bracelet and clothing tags, 6) copies of legal documents, such as a power of attorney, in a waterproof bag, 7) copies of medical documents that indicate the individual’s condition and current medications, physician’s name, address and phone numbers, and 8) copies of insurance and Social Security cards. The Administration on Aging also provides a toolkit for people with dementia living in the community during disasters (Administration on Aging 2011). In the discussion and conclusions (chapter 8), I
adopt some of these suggestions and include activities for reducing PWD stress during the environmental disruption that might occur during disasters.

**Driving: Silver Alert**

The Florida Silver Alert was based on the Amber Alert system for missing children. The pilot program started in Pinellas County, Florida and was designed to coordinate response efforts when a PWD goes missing in a vehicle. On October 8, 2008, Governor Charlie Crist signed an Executive Order enacting the Florida Silver Alert. In June, 2009, the Florida Silver Alert Support Committee was established by the Department of Elder Affairs (DOEA), and in June 2011 it was signed into law, thanks in part to advocacy from ACC (including the visit described at the start of this chapter). The alerts result in faxes with identifying information (of both the person and the vehicle) sent to all police stations, via media alerts and roadway messages.

**Summary and Key Points AD and Related Dementias**

Our understanding of illness is largely shaped by social influences, even when scientific and biomedical frameworks are the predominant means for understanding disease and illness. The attempts to define and measure AD are an example of the cultural construction of illness. The measurement of the progression of AD and related dementias, though constructed, is a useful tool for understanding and anticipating changes over time. This progression reflects an “unlearning” of basic tasks, which (both metaphorically and biologically) simulate a return to childhood or infancy.

Loss of abilities increases dependency on family, friends, and society for survival. In Western societies, this often means a loss of “adult” social status and at times, a loss of personhood or humanity. There are a number of “risky” behaviors associated with
dementia, particularly wandering, which can lead to a person becoming lost. During natural disasters, risky behaviors such as exit-seeking might be exacerbated by changes in the environment or location.

**Part II: Background and Literature Review: Caregiving for a Person with Dementia**

*It isn’t just the person with the diagnosis. Alzheimer’s is a family disease. It affects everyone* (CEO of Alzheimer’s Community Care).

Dementia does not occur in a vacuum; a network of friends, family, and coworkers surrounds an affected individual. When a person is diagnosed and/or begins to show signs of cognitive decline, the impact ripples throughout these networks.

In this second part of the chapter, I introduce the concepts of home and community-based care for PWD and its connection with neoliberal forms of governance. Core theoretical concerns include the **feminization of dementia care**, since caregiving has decidedly gendered skew with most informal caregivers being women. Furthermore, these caregivers rarely have training on dementia or in techniques for responding to associated behavioral disorders, which puts both the caregiver and the PWD at risk for injury and other stress.

I briefly explore the theoretical concept of **personhood** in relation to caregiving and the **shift in social roles** when someone takes on that identity. Another theoretical concern is the risk associated with becoming a caregiver. Caregiving, in general, is a risky endeavor, as is evidenced in increased morbidity and mortality rates (when compared to the non-caregiving population). I attempt to place these demographic changes within the push for home and community-based care, and compare concerns with the deinstitutionalization that took place for people with psychiatric needs in the
1980s. Finally, I present literature on family “older adult” decision-making during hurricanes.

Social Roles: Nature and Nurture

_The daughter has become the mother, the mother the daughter. Catastrophic disease often alters roles, but only Alzheimer’s disease can fully reverse them_ (Shenk 2001:130)

When human children are first born into the world, they are helpless and completely dependent on others for food and safety. While most mammals provide care for their young, Homo sapiens have a prolonged juvenile rearing period (Jurmain, Kilgore, Trevathan, and Trevathan 2011). Caregiving for people with disabilities has been a part of the human experience for thousands of years. The archaeological record suggests that early Homo sapiens (both Homo sapiens neanderthalensis and Homo sapiens sapiens) cared for their elderly and disabled (Roberts and Manchester 2007; Appleby 2010). A frequently cited example is that of the skeleton Shanidar I, located at an archaeological site in modern-day Iraq, who had sustained and survived multiple injuries, including a damaged shoulder and arm along with a blow to the head that likely blinded him (Roberts and Manchester 2007). Since he lived for many years after sustaining these injuries, archaeologists have hypothesized that he would not have been able to hunt or otherwise obtain food without the help of others. His formal burial in later life indicates that he was surrounded by people (or at least one person) who cared for him in his disability.

Who Provides Informal Care?

When treatment for a person is provided in their own home (rather than an institutional setting, such as a nursing home), it is considered to be home and community-
based care. Home and community-based care can be provided by paid professionals who come into the home to provide services, or by unpaid family caregivers. The acceptability of institutionalizing the person with a chronic illness varies among different societies (Sokolovsky 1997; Henderson 1997; Cohen 1998). However, while the relationship of the person expected to take on the caregiving role varies across place and time, across all societies, caregivers are usually women (United Nations Expert Group Meeting 2008). In the United States, this trend holds true as well: approximately 66% of family caregivers are female, and informal care is usually provided by a spouse or an adult child (Colello 2007). More specifically, wives are more likely to care for their husbands and older widows are more likely to be cared for by their daughters (Colello 2007: 9). There are many hypotheses on why women bear the greatest burden in caregiving; many suggest that it is linked to the fact that women live longer than men, and therefore tend to outnumber them (Sokolovsky 1997; Hutton 2008). Rather than simple gender ratios, however, it is more likely that this occurs in concert with normative gender roles as part of a historic trend of patriarchy (based on the presumption of the inferiority of women and their relegation to “domestic” tasks such as childrearing). This fuels gender inequality in the sharing of caregiving responsibilities (United Nations Expert Group Meeting 2008). Gender stereotypes promote assumptions about what kind of work women and men are “naturally” capable of doing:

In this context, the ideal location for men is perceived to be in the public sphere where they can be entrusted with power and authority while the private sphere is assigned to women. Both inside and outside the home, most activities have a notional label of ‘male’ or ‘female’ attached to them. Women are identified as ‘natural’ caregivers and caring is therefore seen as women’s work (United Nations Expert Group Meeting 2008).
Illustrating this point is Henderson’s (1997) research with Latin American families in Tampa, Florida. His work focused on culturally-specific support groups for Latino families caring for a PWD. He found ample evidence to support the preference for female caregivers. Women were expected to become caregivers, even if they were not a blood relative to the PWD (usually, this was a daughter-in-law) and even if a blood-related son were available. Once the PWD died, however, male family members “would take charge of the father because it then entered a business dimension, namely, the cost of the funeral and a matter of public display” (Henderson 1997: 433, cited in Sokolovsky 1997).

In spite of these observations, existing literature on caregiving in the United States rarely addresses broader structural issues such as the equitable distribution of care responsibilities by gender, race, and social class (Estes and Linkins 2001). While spouses provide a great deal of care, it is important to note that they are frequently elderly as well and may be contending with their own health issues. Adult children who take on the majority of caregiving responsibilities are likely to be in their 40s and 50s, may also suffer from health problems, be employed full-time, or even have children of their own living in their home. This group termed the “sandwich generation” because of the familial demands from both children and parents (Colello 2007:11).

As suggested in the opening quote, social roles can be entirely disrupted. In a great twist of irony, the person with the most life experience once again becomes totally dependent on others for survival. Children take on the parenting role; they take away car keys, vigilantly watch the front doors, and, eventually, change their parent’s diapers. Spouses become parents to their loved one; a man who never cooked prepares meals and
encourages his wife to use a spoon as she eats. A woman who had never paid a bill now manages the household finances.

As the disease progresses and the PWD experiences shifts in roles, responsibilities, identities and selfhood, caregivers also undergo parallel transitions. Loboprabu (2006) describes the caregiver’s transition from “their family role as spouse or adult child to caregiver, and ultimately from the caregiver stage to that of care manager” as a necessary response to the progressive cognitive deterioration of the PWD. She argues that these steps allow for separation from the impaired PWD as he or she is less able to reciprocate (2006: 95).

In addition to the greater life span and hegemonic gender stereotypes about appropriate “women’s work”, some research highlights the “positive aspects” of caregiving, from which other motivations for taking on the role can be derived.

**Motivations to Provide Care for PWD**

It is important to note that finding positive aspects in providing care for a spouse or parent is not the same as understanding the reasons why a person takes on the caregiving role. While there appears to be little research on motivations to provide care for family or friends, it is assumed that a sense of obligation or reciprocity plays a role. For instance, in the absence of widespread state provision in most parts of Southeast Asia, the elderly in Hong Kong have no choice but to follow the traditional strategy of reliance on personal ties (Fry 1980; Hashmi 2009). It is also possible that many caregivers in the US feel economically confined to home and community-based, informal care. Others might feel socially obligated to fill this position (such as in Henderson, 1997).
Moliari (2006) summarizes the findings of several studies that explored the positive aspects of caregiving, including feelings of accomplishment in meeting a challenge in spite of the odds, fulfilling moral obligations to someone who has cared for them, maintaining a helpful function, enjoying little moments of pleasure with the loved one, promoting a role model for children, and maintaining a sense of life’s purpose. In one study of 289 caregivers (68.5% of whom were women), a majority cited at least one positive aspect of caregiving (Cohen, Colantonio, and Vernich 2002). These included companionship (22.5%), fulfilling/rewarding activity (21.8%), enjoyment (12.8%), and duty/obligation (10%). Given the assumptions in the literature, it is interesting is that only 10% said that they found the caregiving role satisfying because they were fulfilling a duty or obligation. Perhaps this is because duty is not necessarily considered something positive, or the sense of duty is not explicit in caregiver’s mind.

Some instruments, such as the Caregiver Health Effects Study, attempt to measure positive aspects of caregiving, for example, “the extent to which caregiving has made the caregiver feel more useful, feel needed, feel good about him/herself, learn new skills, and give more meaning to life” (Switzer et al. 2000:214). In short, in spite of challenges, caregiving can also be a satisfying experience.

However, the caregiver role will change as the disease develops over time. The tasks that might begin with assistance with finances or shopping, however, over time, the caregivers must help with ADLs such as bathing, dressing and grooming (Ostwald 2006:32). As the involvement in care increase, so does caregiver burden. Research has shown that providing assistance with three to six ADLs and not being able to leave the care recipient alone was associated with the termination of informal caregiving at home.
(Kasper, Steinbach and Andrews 1994). Spouses were more likely to continue to provide care even in overwhelming situations (Ostwald 2006).

**Caregiving and Risk**

Though dementia is technically a chronic illness, it is distinguished from other type of caregiving for chronic illnesses. Compared to other caregivers, dementia caregivers tend to have more stress, worse health, and fewer friends and family members to support them (Ory et al. 1999). As mentioned by Janelle Taylor (2008), a diagnosis of dementia acts as a kind of “solvent” for friendships. Stigma can isolate caregivers as well (Goffman 1963). A person who takes on the responsibility of caregiving for a PWD also assumes several health risks, which can take a psychological, physical, social, vocational, and financial toll on the caregiver (Ostwald 2006).

Factors linked to negative health outcomes for dementia caregivers include lower socioeconomic status, being married to the PWD, low levels of social support, low levels of self-esteem and mastery, and poor prior relationship with the patient. The more “problem behaviors” exhibited by the PWD, such as violence or exit-seeking, also raise the level of negative health outcomes for the caregivers (Switzer et al. 2000).

Caregiver vigilance is a way of conceptualizing the constant surveillance required of caregivers to manage and, ideally, prevent risks. As described by Oswald, 2006, “when caregivers are vigilant, they are supervising, anticipating, managing disruptive behaviors and initiating protective measures…” (34). Caregiver vigilance has been cited as a cause of higher caregiver burden and stress (Mahoney et al. 2003).

According to the Alzheimer’s Association (2011), 61 percent of family caregivers of people with Alzheimer’s and other dementias rated the emotional stress of caregiving
as high or very high. Forty-three percent also rated the physical stress of caring for a person with AD or a related dementia as high or very high. In addition, about 33 percent of family caregivers of people with Alzheimer’s and other dementias report symptoms of depression. Many caregivers become ill because of the chronic stress, making them “secondary patients”. The physical and emotional impact on Alzheimer and other dementia caregivers is estimated to result in $7.9 billion in increased healthcare costs in the United States.

**Quality of Care**

Many researchers assume that family that provides care for a PWD is doing so because there are affectionate bonds between them or a sense of obligation. If this assumption holds, they often further assume that “the care delivered is generally is of high quality” (Switzer et al. 2000:214). Unfortunately, there is little evidence to support these assumptions. Much of the literature that problematizes informal care focuses on the lack of quality care and instead indicates neglect and exploitation (Switzer 2000).

Though family caregiving plays a crucial role in long-term care, it is essential that the shift from formal to informal (unpaid) support be problematized in a more meaningful way. Researchers contend that in requiring unskilled family members to provide high-tech, complex medical care in the home, several risks arise (Guberman et al. 2005). Many of the procedures that caregivers provide (oxygen, giving tube feedings, and administering injections) occur with minimal training and they may not recognize problems, or may have difficulty managing challenging behaviors such as violence or wandering (Ostwald 2006).
Home and Community-Based Care: Costs and Benefits.

Nursing home admission is associated with a constellation of negative impacts on both the PWD and caregivers (Gaugler, Duval, Anderson, and Kane 2007; Gaugler et al. 2010). Nursing Home admissions are associated with “questionable quality of care, early mortality for many residents, and psychological or emotional upheaval for caregiving families” (Gaugler et al. 2007: 2; Kane 2001; Schultz et al. 2003). Furthermore, the estimated cost for institutionalized care is astronomical: 150 billion in 2007, and 62% is taxpayer funded through Medicaid and Medicare (Gaugler et al. 2007). In 2011, aggregate payments for health care, long-term care and hospice were $183 billion. Seventy percent (70%) of this was covered by Medicare and Medicaid (Alzheimer’s Association 2011). Unpaid family caregivers in the community are estimated to have saved these government programs an estimated $202.6 billion worth of services (Alzheimer’s Association 2011). For these reasons, scholars and policy makers alike tend to prefer to provide home and community-based services (when possible) over nursing home admissions.

When caregivers provide care to a PWD in the community, they frequently reduce the cost to the Federal, State and county governments. While the benefits of having unpaid workers providing the bulk of the care for people with dementia are not lost on legislators, the negative aspects are less evident. First, most informal caregivers are not only unpaid, but they are also untrained. Caregiver burden, expressed in increased morbidity and mortality has been a well-documented area of concern for public health professionals and other scholars (Czaja, Eisdorfer, and Schulz 2001; Zarit 2006). However, recent research has established that caregiver burden does not end after a PWD
is admitted into a nursing home for care (Gaugler et al. 2010). Caregivers often remain active in the PWD life, assisting with “financial and legal affairs, making arrangements for medical care and providing emotional support. Some also continue to help with bathing, dressing and other ADLs even in institutionalized care” (Alzheimer’s Association Facts 2011: 27). Gaugler et al. 2010 explained that women are more likely to have a high rate of caregiver burden and men are more likely to suffer from depression after a PWD under their care is institutionalized.

However, the emphasis on as shift to home and community-based care must be critically assessed. This shift has many parallels with the deinstitutionalization of the mentally ill that took place in the United States during the 1980s. Like the deinstitutionalization movement, the shift in political discourse went from social policy to fiscal policy (Thomas 1998; Lamb 2001). The Reagan administration supported deinstitutionalization for several reasons, (including the development of new psychiatric drugs that could treat people with schizophrenia and the exposure of abuse in state hospitals), but primarily because it fit within the neoliberal ideological framework, which relies on privatization (Thomas 1998; Lamb 2001). Deinstitutionalization allowed the federal government to dismantle social policies that had supported the state hospitals. Though home and community-based care is more economical, the shift has placed the care of people with disabilities into the hands of the county mental health services. This meant that home and community-based care has been under constant fiscal strain (Lamb, 2001). Though deinstitutionalization appeased special interest groups, many of those who were relocated to the community were not properly transitioned (Shapiro 1994; Thomas...
Many services that could have supported a successful transition to home and community-based care, such as “adequate, comprehensive, and accessible psychiatric and rehabilitative services... when necessary, provided through outreach programs” (Lamb 2001: 7). Beyond medical provisions, “[r]ehabilitative services should include socialization experiences, training in the skills of everyday living, and social and vocational rehabilitation” (Lamb 2001: 7). These services were not provided during deinstitutionalization. Many people were moved from state mental hospitals to nursing homes rather than truly being transitioned back into community life (Shapiro 1994; Lamb 2001; Koyanagi 2007). Furthermore, there was an increased burden on families who were asked to step into caregiving roles without training.

The Kaiser Commission on Medicaid and the Uninsured uses lessons learned from the deinstitutionalization movement to map the path to community-based care for the elderly (Koyanagi 2007). Though federal and state governments favor community-based care in theory, there is little financial backing for alternatives to nursing homes in practice. Insurance reimbursement policies continue to generally encourage institutional care rather than support care in the community (Koyanagi 2007). For an effective transition to community-based care, legislators must recognize the importance of funding programs that support informal caregivers. Programs such as adult day care can enhance...

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12 The deinstitutionalization movement also fit within the neoliberal framework because it stresses “equal opportunity” over “equality of results”. Equal opportunity means that individuals should have the chance to succeed, while equality of results means that, all said and done, individuals will have equality. An example might be, everyone is given the opportunity to have a job and make money and therefore, are considered equal. Equality of results focuses not on the opportunity to make money, but whether needs are met in the end. Degener and Quinn (2002) speculate that, in welfare states (i.e. Germany), equality of results might be emphasized, while in a free market economy (i.e. US), equality of opportunity is valued. These concepts of equality are often an implicit part of policy making surrounding the care of individuals with developmental disabilities. See Christensen (2005).
the quality of life among adults with AD and their caregivers (Silverstein, Wong, and Brueck 2010).

The framework for a transition to community-based care began to be established by the Florida state legislature in 1985, with the Alzheimer’s Disease Initiative (ADI). The ADI pays for a limited number of community-based services, for both people with dementia and their caregivers. Families must provide a co-pay for services such as respite, adult day care services, and caregiver training. ADI funding is administered through the Department of Elder Affairs and is distributed locally through the Area Agencies on Aging. For several months, there was a Medicaid waiver program available for assisted living. A similar Medicaid waiver program (MAP) was explored for home and community-based care (Chiriboga et al. 2009). This program was designed to assist caregivers in providing care in the communities by offering several supports that were missing after deinstitutionalization. These included: 1) case management; 2) adult day care; 3) respite care; 4) wandering alarm systems; 5) wanderer identification and location programs; 6) caregiver training; 7) behavioral assessment and intervention; 8) incontinence supplies; 9) personal care assistance; 10) environmental modification; and 11) pharmacy review. These services were more comprehensive than those offered through ADI. However, while ADI provides for people with memory disorders 18 years and older, MAP requires that that a person be eligible for Medicaid at 60 years and over (Chiriboga and Brown et al. 2009). While a report put forth by the Office of Program Policy Analysis and Government Accountability (OPPAGA 2010) claimed that the waiver program did not significantly delay nursing home entry, Chiriboga and Brown et al. (2009) found that this program was more effective than other waivers. The difference
in results can be explained in the way the OPPAGA defined an “extended stay” in a nursing home (which was “receiving nursing home care for at least 30 days within two months) (OPPAGA Report 2010). Chiriboga et al. argued that this definition encompasses respite and rehabilitation; a true “extended stay” in a nursing home is one that is more than two months because it is more likely to lead to permanent placement. Unfortunately, the OPPAGA report sharply impacted community-based funding, and the Florida Legislature did not renew the Florida Medicaid Alzheimer’s Home and Community–based Waiver Program in April 2010. ACC was still reeling from this funding change when I arrived. In short, there are tentative shifts to better supporting caregivers in home and community based settings, however, skepticism and political skittishness can hinder its progress.

Caring and Disaster Planning

Research has consistently shown that older populations interpret disaster warnings differently than younger populations (Hutchings and Norris 1989; Roberto, Kamo and Henderson 2009; Cherry, Allen and Galea 2010). Anthropologists, Gladwin and Peacock (1997), found that households headed by or containing “aged persons” (70+) were less likely to evacuate during Hurricane Andrew in 1992. When they did evacuate, they tended to evacuate as a family unit. Additionally, ethnic minorities (Black and Hispanic individuals) were less likely to evacuate than whites (Gladwin and Peacock 1997: 65). The authors posit that it is “probably a result of economic conditions rather than race or ethnicity per se in that minorities have fewer evacuation options” (66).

This suggests that ample informal support for dementia caregivers may not translate to successful preparation or response to a disaster. Findings from Eisenmen,
Cordasco, Asch, Golden and Glik (2007) support the ambiguous nature of informal networks when a disaster threatens. They found that elderly may have refused to evacuate and therefore, younger family caregivers chose to stay behind with parents (Eisenmen et al. 2007). This may suggest that differential risk perceptions among social networks can influence decision-making. In other cases, there may not be enough resources for the entire extended family to prepare or evacuate. In spite of this, informal support during a disaster threat may be very helpful (Eisenmen et al. 2007). Saunders, Bowie and Bowie (2003) state that social support (including emotional and psychological support) result in a quicker recovery after a disaster. However, Kaniasty and Norris (1990) found that many elderly overestimated the amount of support they would receive from family and friends.

Regardless, older populations are less likely to evacuate, either because of previous successful storm experiences or because a disability complicates evacuation (Cherry et al. 2010). Previous hurricane experiences, such as surviving Hurricane Camille in 1965, might have given older populations a sense of security in following storms, such as Hurricane Katrina (Cherry et al. 2010). Cherry et al. also cite “possible physical and cognitive limitations that might interfere with successful evacuation,” however, they do not elaborate on how this limitation might impact evacuation (2010:121).

**Summary and Key Points of Caregiving**

Currently, women provide the vast majority of caregiving for people with disabilities and the frail elderly, both in the US and abroad. It is likely that patriarchal norms influence the gendered skew of caregiving. Both paid and informal, unpaid caregiving tends to be undervalued. There are, however, also many positive aspects of caregiving cited in the literature. References to the relationship between the caregiver and
PWD are central to finding positive aspects of caregiving. Providing care for a parent or spouse with dementia can cause a shift in social roles. Adult children are often forced to make parental-like decisions for their parent. Spouses might also experience a shift in their responsibility within the relationship, forcing them to take on more decision-making.

Caregiving for a PWD can be risky. Dementia caregivers face a higher risk of becoming physically or psychologically ill than other caregivers. The more problem behaviors a PWD displays, the higher the caregiver burden. Caregiver vigilance is often required to ensure that the PWD is safe, and this can lead to higher caregiver burden.

In response to hurricanes, families tend to evacuate as a unit. If elders refuse to evacuate, they may convince other individuals (such as their caregivers) to stay in place also. Stressed caregivers might have difficulty with decision-making immediately before, during, and after a disaster. The next chapter will further explore the history and background of disaster planning and decision-making, and discuss theoretical concepts that frame disaster management and disaster planning.
Chapter 4: Literature Review Hurricane Vulnerability and Constructions of Risk

In this chapter, I discuss the disaster cycle and theoretical issues surrounding risk and vulnerability, which captures the differential impact of disasters on populations (such as those with lower socio-economic status, the disabled, and the frail elderly). I tie hurricanes to the theoretical concept of “risk society” and examine trust in the experts, who predict the course and severity of hurricanes. I discuss the use of the pressure and release model for assessing risk and vulnerability.

Disasters and Vulnerability

Poverty attracts an unfortunate abundance of risks. By contrast, the wealthy (in income, power or education) can purchase safety and freedom from risk (Beck 1986:35)

The ways in which a hazard impacts a population is determined by several structural factors, including socioeconomic status, minority group membership, and age (Cutter, 2003). The existence of preparations and plans for mitigation can also impact the outcomes of a hazard event and ultimately determine whether it will be labeled a true “disaster” or not. The public health impacts of hurricanes are outlined by Shultz, Russel and Espinel (2005) as the following: storm-related mortality, injury, infectious disease, psychosocial effects, displacement and homelessness, damage to the health-care infrastructure, disruption of public health services, transformation of ecosystems, social dislocation, loss of jobs and livelihood, and economic crisis. An increase in
communicable diseases after hurricanes is important to note, especially in regards to vulnerable populations (such as the poor and the elderly) (Shultz et al. 2005).

The concept of “vulnerability” is central to the understanding of disproportionate disaster impacts. Particular populations, such as those with lower social-economic status, marginalized minority groups, and the elderly tend to be more vulnerable to the deleterious effects of the hazard (Phifer, Kanisty, Krzysztofand Norris 1988; Phifer 1990; Morrow 1999; Hutton 2008). Most of the casualties of Hurricane Katrina in 2005 fit into one or all of these categories (Jenkins et al. 2007; Rothman and Brown 2007). The concept of vulnerability in disaster research refers to certain subsets of the population that bear an undue burden of the impact due to their lower socioeconomic status or preexisting health conditions. Vulnerability is defined by Wisner et al. (2005) as:

*The characteristics of a person or group and their situation that influence their capacity to anticipate, cope with, resist and recover from the impact of a natural hazard (an extreme natural event or process). It involves a combination of factors that determine the degree to which someone’s life, livelihood, property and other assets are put at risk by a discrete and identifiable event (or series or ‘cascade’ of such events) in nature and in society.*

The authors also explain that a person (or group’s) resilience, defined as the capacity to recover their livelihood, is considered an integral part of the concept of vulnerability.

The elderly experience disproportionately high levels of poverty in many countries around the world, which in turn, makes it difficult for them to respond in the face of a disaster (Fernandez et al. 2002; Hutton 2008). Furthermore, as elderly populations have a higher incidence of debilitation and disability than the general population, they may have more physical barriers to appropriate preparations and response to a threat of a hurricane. As Wisner et al. (2005) elaborate, “debilitation and
disability mean that people have less time to invest in protecting themselves from other hazards” (Wisner et al. 2005: 29). This is important to note because individuals living in nursing homes may be expected to have greater support from the staff than vulnerable elderly living in the community.

Community-dwelling elderly, particularly those who have disabilities or are caring for someone who does, are particularly vulnerable in the event of a hazard. This is exacerbated when the individuals are also in the lower socio-economic bracket and come from a wide range of minority groups, as is the case for the communities in the current study. As explained by David Hutton (2008) in a report for the WHO, many of the vulnerabilities are social, including the potential for abuse and exploitation. This is important to note because individuals living in nursing homes may be expected to have greater support from the staff than vulnerable elderly living in the community.

At Alzheimer’s Community Care (ACC), the community partner and site of this study, individuals fit the demographic for vulnerability in several ways: they are frequently Medicaid recipients (indicating lower socio-economic status), caregivers are elderly themselves, and the family members with Alzheimer’s have cognitive and sometimes physical impairments that require special assistance and special needs shelters (SpNS). For many organizations, the goal is to aid and inform them of their resources and how to utilize them to minimize negative impacts of the disaster. Some research, such as Laditka et al.’s (2007) work on disaster preparedness for vulnerable populations receiving long-term care, has specifically addressed how organizations can better support their clients.
The Disaster Cycle

Disaster researchers and emergency management teams have broken hazard events into four distinct phases: 1) mitigation, 2) preparedness, 3) response and 4) recovery (Neal 1997). These phases are necessary to determine what kind of intervention would be most useful at which time. Though the phases are multi-dimensional and may overlap, the mitigation phase is generally considered to be the first. It is during the mitigation phase that building codes and public education are put in place to reduce vulnerabilities. The preparedness phase includes the specific response strategies in place when a disaster actually strikes: warning systems, emergency escape plans, and disaster drills.

The response and recovery phases happen during and after a disaster event respectively and, as they are not central to this research, will not be covered in depth here.

Mitigation

Mitigation includes disaster-related law and disaster management, such as development and building codes (Mason 2006). Mitigation can take place at the federal, state, county and city level. Covington and Simpson (2006) review the disaster preparation literature and outline fundamental features of preparation. They note that one of the weaknesses of disaster research in general is that there is no single set of definitions, theory or set of theories that can be referred to within (let alone across) disciplines. An attempt to classify different types of disaster models is offered by Asghar, Alahakoon, and Chirilov (2006), who postulate that most fit into one of four categories: 1) logistical models, 2) integrated models, 3) causal models and 4) other kinds of models. Causal models include the “pressure and release model” and the “crunch model,” among
others. Due to space limitations, I will provide only details on the pressure and release model (causal), which is used by FEMA, the State of Florida, and Palm Beach County.

**Disaster Preparedness**

Disaster preparedness can be in place at either the individual, organizational or governmental levels. At the individual level, citizens are expected to have a disaster plan, be familiar with emergency warning systems and have disaster supplies available Brown, Hyer, Polivka-West (2007). At the organizational level, especially in long-term care, entities are often mandated to have a comprehensive emergency plan, which may or may not include disaster drills. According to The Department of Homeland Security/Federal Emergency Management, Preparedness as "a continuous cycle of planning, organizing, training, equipping, exercising, evaluating, and taking corrective action in an effort to ensure effective coordination during incident response" (FEMA 2012).

Within disaster preparedness is risk communication systems- to warn people of impending risk. Currently, a great deal of emphasis is placed on “individual preparedness” such as having a disaster escape or evacuation plan and compiling a disaster kit (Citizen Corps 2009; FEMA 2012).

**Pressure and Release Model**

The “pressure and release” model (also known as PAR) considers the collision of structural factors (root causes, dynamic pressures, and unsafe conditions) with a hazard (earthquake, hurricane etc.) (Wisner et al. 2005). When the structural conditions create a vulnerable population, then this collision creates a disaster (Appendix V). The authors of this model suggests that risk is defined by a hazard (such as a hurricane) multiplied by vulnerability (or R=H x V). This tool is used to demonstrate how disasters have a differential impact on vulnerable populations.
Root causes, which include economic, demographic and political processes, are the most important factor in determining vulnerability (Wisner et al. 2004: 52).

Systematically marginalized individuals are often vulnerable not only to exploitation but to the greatest level of morbidity and mortality when a hazard strikes. Root causes exist on multiple levels, and include ideologies, such as political economic systems, in which some people have limited access to power, or resources. This was well-illustrated during Hurricane Katrina, where the differential impact became evident for marginalized African American populations living in cheaper (and more dangerous) areas, such as the Ninth Ward.

The next phase (or layer) of vulnerability is conceptualized as dynamic pressures. Dynamic pressures “are processes and activities that ‘translate’ the effects of root causes both temporally and spatially into unsafe conditions” (Wisner et al. 2004:53). Examples include skills, learning, and local institutions as well as other macro-level factors, such as rapid population growth and urbanization.

Tobin et al. (2006) adapted this model to explore the impacts, perceptions and behavior of displaced persons relocated to a FEMA park following 2004 Hurricane Charley (in Florida). This study examined the experience of evacuees by identifying who moved to relocation sites, examining their immediate needs, and assessing their long-term concerns. Their findings were in line with the pressure and release model, which illuminated the conditions that predisposed them to vulnerability. “Root causes” identified in this research included lower levels of access to knowledge, political power, social capital, networks and lifelines, mobility, and resources. The dynamic pressures
considered included age, mobility, and income, as well as geophysical location. The ‘root causes’ and the ‘dynamic pressures’ combined to create ‘unsafe conditions’.

Unsafe conditions that contributed to vulnerability included gender, race/ethnicity, and educational attainment as well as physical structural attributes, like housing type (renting vs. homeownership). Combined, these factors determined the levels of vulnerability. Vulnerability was defined in this article as a systematic circumstance measured by the degree of potential and actual loss of an attribute of individuals or groups characterized by a range of variables that influences exposure and coping abilities (Tobin et al. 2006). Many park residents were highly vulnerable because they were predominately poor families with little formal education. The park also contained many families with members who had special needs or were elderly. Most who evacuated did so only two hours before storm landfall and they most commonly evacuated to friends or relatives’ homes or motels. Most gained access to FEMA and other long-term help via Red Cross shelters. The most common reason given for evacuation was having had negative hurricane experiences in the past and anticipated force of the hurricane. Four vulnerability factors were found to be prominent: special needs, race, access to resources (including information), and social networks. As will be presented in the Discussion chapter, similar factors apply to the population that lives near Lake Okeechobee.

Local Emergency Management Plans.
The Florida State Emergency Management Plan was put into place in February 2004 after a hazard and risk assessment and is addressed in Chapter 252 of the Florida Statutes. While the plan “provides guidance to State and local officials on procedures, organization, and responsibilities, as well as provides for an integration and coordinated local, State and federal response,” it does not reference any specific disaster plan. The
PAR model may be useful in evaluating the risks described in the Palm Beach County emergency management plan. I will revisit the PAR model in the Discussion, specifically applying it to the Lake Okeechobee area.

**Measuring Destruction: The Saffir-Simpson Wind Scale**

The Saffir-Simpson Hurricane Scale classifies the intensity of hurricanes in the Western hemisphere. This scale was created in 1975 by Saffir and Simpson, employees at the US National Hurricane Center. The scale serves as a heuristic device to convey the amount of damage that each hurricane could bring. It originally divided hurricanes into five categories, based on the predicted wind values, storm surges, and flooding. In 2009, this scale was altered; the predicted storm surges and flooding were removed because of their inaccuracies (NOAA 2009). The scale has been renamed the Saffir-Simpson Hurricane Wind Scale, which went into effect May 15, 2010 (NOAA 2010). This scale is designed to help citizens evaluate risk by anticipating the potential damage of a storm by describing the amount and types of damage predicted to take place with each category. However, according theorists on modernity and risk, the outcome of this tool (warnings about hurricanes) might be ignored by many citizens. In the next section, I present reasons why people might not respond to risk evaluation and/or risk communication.

**Theoretical Frameworks: Risk Society**

*Risk determinations are based on mathematical possibilities and social interests... In dealing with civilization’s risks, the sciences have always abandoned their foundation of experimental logic and made a polygamous marriage with business, politics, and ethics* (Beck 1986:29).

Deborah Lupton, an anthropologist and public health professional, notes that, in its original usage, “‘risk’ is neutral, referring to probability, or the mathematical likelihood
of an event occurring (1993, 1999). The risk of an event occurring could therefore be relate to either a positive or negative outcome, as in the risk of winning the lottery” (Lupton 1993: 425). In public health, she notes, “risk” is used as a synonym for “danger”.

Public health campaigns are conducted to warn the public about risks to their health, assuming that armed with this knowledge, people will avoid these risks. Lupton (1993) distinguishes between two kinds of risks: 1) environmental (such as toxic waste, radiation, or a hurricane), over which the individual has little control; and 2) risk behaviors, resulting from lifestyle choices, such as smoking. The second category assumes that the risk is something over which the individual has control, while the former does not. For instance, during Hurricane Katrina, people were frequently blamed for not evacuating, even though they were warned to do so (Select Bipartisan Committee 2006). Though they did not have control over the hurricane, it was assumed that people had control over their location during the hurricane.

Public health professionals and anthropologists (such as Lupton (1993) and Nichter (2003)) argue that individuals must believe that a threat actually exists (risk identification) and believe that protection is needed (risk assessment) before they are willing to engage in risk-reducing behaviors, such as making a disaster plan (Nichter 2003). In order for individuals to work through these steps, they must thus believe that the information provided by the government and experts is valid and that the safeguards they depend upon will be in place. For example, citizens must believe that a hurricane warning is valid and poses a true risk to their wellbeing to heed warnings. Those that plan to evacuate to shelters must believe that the government will adequately provide a safe and reliable sanctuary. According to Giddens (1990), this trust may not exist, and when
individuals are skeptical of the “so-called experts” they may choose to ignore the risk entirely. If citizens do not trust the experts, who determine the direction of a hurricane and its severity, they may not identify it as a risk. Beck (1986) likewise contends that a condition of modernity is that science no longer has “a monopoly on rationality,” and, as a consequence, “there is no expert on risk” (29).

According to Beck, a condition of modernity is that citizens and publically elected officials are routinely bombarded by the risks in the world around us; the air we breathe, the water we drink and even the sun we walk under all have the potential to cause us harm. From a long list of hazards, people have to decide which to prioritize so that they can mitigate, prepare, and respond to them as necessary. This, coupled with often conflicting information, can be overwhelming. This distrust in experts has been cited as a reason for poor evacuation trends before Hurricane Katrina (Select Bipartisan Committee 2006). More specifically, there were multiple “false alarms” issued by scientists and political leaders (i.e. experts) during previous storms, which lessened their credibility. This phenomenon has been called “hurricane fatigue” and will be discussed further below.

While Beck argues there has been an actual increase in hazards with modernity, Giddens counters that it only appears this way because risk is more visible (Lupton 1999:81). What is important, however, is that both theorists agree that individuals in the modern era tends to be hyper-aware of the risks they face (sometimes referred to as “risk society”), including their risk of being affected by a disaster. This exacerbated by an increased distrust in government and expert opinion of scientists and public health officials (who, at times, provide conflicting or inaccurate information). The implication
of these social trends is that it is difficult for individuals to determine exactly when to act (or what to do) when threatened with a natural disaster, such as a hurricane.

Anthropologist, Mark Nichter (2004) uses these theories to explore “harm reduction” in the United States, noting that, while in epidemiology risk “refers to a calculated probability, the odds that something will occur (not occur) within a given population”, many individuals do not perceive themselves at risk, even if the statistics indicate that they are, in fact, at risk (2003:23). A large role of public health professionals (including emergency managers) is to inform the public of their level of risk and convince them to adopt risk-reducing strategies (Guion, Scammon, and Borders 2007). If public health officials cannot convince the population that hurricane preparedness is important, then it is unlikely that citizens will comply with efforts or pressure elected officials to legislate additional mitigation measures. One important challenge is to convince the public that disaster preparedness is a priority among all other risks of daily life, especially outside of hurricane season.

Caregivers, as explained in Chapter 2, must be constantly vigilant to prevent daily risks for both themselves and the PWD. Tasks that once contained only minimal risk, such as using a gas stove to cook or going for a long walk, can become serious threats to well-being once judgment becomes impaired. I argue that caregivers who are mitigating and preventing small daily risks might have more trouble prioritizing prospective, seemingly far off, risks such as hurricanes. Even if a hurricane is less than 100 miles off the coast, caregivers might remain apathetic to the risk (this will be discussed in depth further in the “hurricane fatigue” and “risk fatigue” sections below).
Certainty in the Cone of Uncertainty

One method of risk communication related to hurricanes is the image of the “cone of uncertainty”. Specialists consider the possible paths that a hurricane might take from its current location and generate “spaghetti models”. They are used to create a “cone of uncertainty”, which is an overlay of all of the different paths generated by the models. This cone of uncertainty has become the measure by which local governments (and many citizens) gauge their response to a hurricane (Broad, Leiserowitz, Weinkle, and Steketee 2007). Broad et al. (2007) argue that modified versions of the “cone of error” or “spaghetti models” have become embedded in popular culture. The image, they posit, represents the contrast between risk and safety. These images are very accessible; the cone of uncertainty can be viewed on television, in newspapers, the internet, and even texted to a person’s personal cell phone (one local news station now offers the “cone on your phone” as an alternative way to access forecast information when a storm threatens South Florida). The “cone on your phone” feature allows to people to view the spaghetti models and attempt analyzing them on their own. In turn, people can view the “cone of uncertainty” and decide their own level of risk. Additionally, the Palm Beach Post can send summative texts to cell phones, providing a ready-made interpretation by an unnamed newscaster. According to Broad et al. (2007), lay knowledge of the cone can lead to misinterpretation. These cones are used as a marker of risk for government officials as well as the lay population.

The irony, of course, is that the “cone of error” and spaghetti models are meant to capture the inherently unpredictable nature of a hurricane path. Since hurricanes can rapidly change course or intensity, people can be deceived by an image of safety showing their home outside of the hurricane’s path. If people gauge their hurricane plans and
response based on the scientifically generated models, it may indicate a trust in the science. However, if they are told that they are at risk by the experts, yet, choose to stay, they are displaying a distrust of experts. Anthropologists Dash and Gladwin (2009) state that, “knowledge about hazards alone is not enough to motivate action. Instead, information must be translated into a concrete conception of pending danger” (70). The “cone of error” and the Saffir-Simpson Wind scale are two ways in which information can be translated from risk communication (the sender) to risk perceptions (the receiver) and ultimately to action. A consideration of people’s past behaviors before, during, and after hurricanes can provide insight into how the lay population interacts with experts that are communicating hurricane risk information.

**Summary of Disaster Literature**

Florida has seen and will continue to see severe weather. Disaster researchers and emergency management teams have broken hazard events into four distinct phases: a) mitigation, b) preparedness, c) response and d) recovery. Vulnerability is a key concept in disaster research, as not all populations experience the same risk or damage when a hurricane strikes. The poor and the elderly fare far worse than other populations. Advanced planning, preparation, and mitigation and response can save lives but even the most vulnerable have difficulty prioritizing disaster planning.

The pressure and release (PAR) model posits that when structural conditions create a vulnerable population, this collision may create a disaster. Root causes, the most important factor in determining vulnerability, include limited access to power, structures and resources as well as ideologies, such as political and economic systems. Root causes influence the next phase, dynamic pressures, which include skills, learning and local
institutions as well as other “macro” factors such as rapid population growth and urbanization. A “risk society” is defined by its overexposure to potential risk and distrust in scientific experts and “evidence”. This predicts that people may be resistant to disaster planning.

The 1928 storm of Okeechobee demonstrated the unique vulnerability of this area. It remains a racially and economically segregated area in Florida. The dike that holds the lake water is in disrepair. Hurricane Andrew (1992) illustrated the devastation that can be brought on highly populated urban areas during a hurricane, and much was learned about evacuation for older adults during this experience.
Chapter 5: A Theoretical Synthesis of Anthropology of Dementia and the Anthropology of Disasters

Anthropology, as a holistic discipline, necessarily draws and builds upon research in other disciplines such as gerontology, and public health (as seen in the previous literature review). This chapter will serve to present current anthropological theory as it relates to: 1) health policy and disasters (Castro and Singer 2004; Whiteford and Tobin 2004), 2) disability and disasters (Fjord 2007; Fjord and Manderson 2009), 3) aging and disasters (Adams, Kaufman, van Hattum and Moody 2011), 4) the anthropology of dementia, which includes the loss of personhood, citizenship and social roles (Cohen 1995; Cohen 1998; Kaufman 2006; Taylor 2008; Hashmi 2009). While these topics inform my research none of them explicitly explore disaster preparedness for people with dementia or their caregivers. They do, however, give insight into the implication of my research. I present these theories so that they can be synthesized into my findings in the discussion chapter. Of note, is Fjord’s critique of the vulnerability concept used in disaster studies. She argues that the concept of “vulnerability” can create a self-fulfilling prophecy of disproportionate loss among populations that are “expected” to suffer. I assess her critique and argue that, while her argument has traction, vulnerability is still an important concept when considering disasters.

Finally, I build upon literature on population based reactions to multiple hurricanes, such as “hurricane fatigue” and “hurricane amnesia” and offer the term “risk fatigue” to explain why some populations might not respond to disasters warnings.
Anthropology of Policy

In the following sections, I will review the recent historical developments of the Anthropology of Policy. In the U.S., the Anthropology of Policy historically has existed within and between other sub-disciplines. Wedel et al. (2005) argue that the anthropological study of policy was an implicit part of many anthropological studies even if it was not directly acknowledged; areas in which policy has been indirectly studied include: 1) institutions and power, 2) interpretation and meaning, 3) ideology and discourse, 4) politics and identity, and 5) the global and local (Wedel et al 2005:31).

Cochrane (1980) directly compared “policy studies” and “anthropology” and claimed that policy tends to be “less contested” than laws are because policy includes mundane processes such as “the granting of passports and visas, the awarding of pensions” (445). He argues that Anthropology has framed policy studies as “the manipulation of power” rather than what the author views as the “true” definition of policy studies, which is the decision making behind the distribution of scarce resources. I argue that the distribution of resources IS a form of power. Cochrane argued that the “economic consequences of policy” are “insufficiently highlighted” in anthropological literature (1980: 445). I do not find this to be an accurate assessment because Wolf (1983) and many other Marxist anthropologists considered political economic impacts of policy and interaction (Roseberry 1988). Certainly, more recent works have thoroughly explored the connections between policy, power and the flow of resources.
Health Policy and Critical Medical Anthropology.

The framework for the health policy research based on the critical medical anthropology paradigm presented in Unhealthy Health Policy: A Critical Anthropological Examination (Singer and Castro 2004). Locating the study of health policy within critical medical anthropology (CMA) is a helpful framework for my research because it “emphasizes the importance of political and economic forces, including the exercise of power, in shaping health, disease, illness experience, and health care” (Singer, Baer 1995:5). Castro and Singer clearly outline the distinctive aspects of CMA:

The CMA perspective 1) recognizes that health itself is profoundly political issue one that often is contentious if not explosive; 2) is cognizant and critical of the colonial heritage of anthropology and the tendency of conventional medical anthropology to serve as a ‘handmaiden of biomedicine’; 3) balances concern for unbiased social science with an awareness of the sociohistoric origin and political nature of all scientific knowledge; 4) acknowledges the fundamental importance of class, racial and sexual inequity in determining the distribution of health, disease, living and working conditions, and health care; 5) defines power as a fundamental variable in health-related research, policy, and programming; 6) avoids the artificial separation of local settings and micropopulations from their wider political-economic contexts; 7) asserts that its mission is emancipatory: it aims not simply to understand but also to change culturally inappropriate, oppressive, and exploitative patterns in the health arena and beyond; and 8) sees commitment to change as fundamental to the discipline.” (xiv)

As illustrated in the literature review, the relationship between senility, dementia and age has been (and in some fields continues to be) contested. The fact that “old age” remains the greatest predictor of Alzheimer’s disease continues to beg questions about whether dementia is indeed part of “normal aging”. The job of the anthropologist adhering to critical medical anthropology is to deconstruct the sociohistoric origins of the scientific knowledge about Alzheimer’s disease. They also must consider who and how decisions
were made about how to define and measure diseases (as I have done in Chapter 3). The definitions and designations are linked with policy and power; those who define and relegate Alzheimer’s disease into different funding streams determine who and what aspects of the disease are funded. Whether the person with the disease or the person who provides care for them is of interest can determine how disease research is funded (or not funded). In this way, the framing of disease is largely in the hands of health policy makers. As discussed in Chapter 3, some policy makers emphasize the need to “find a cure” while others consider the caregiver “the true victim” of Alzheimer’s disease.

In Unhealthy Health Policy, there is an example of anthropological research that connects health policy, health and disasters within the CMA framework: Whiteford and Tobin (2004) provide research on the policies in place to protect citizens from disasters in Ecuador at the foot of the Tungurahua volcano. In “Saving Lives, Destroying Livelihoods,” they cite Chan’s (1995) four most common strategies for protecting citizens as: 1) protection by preventing or modifying the disaster; 2) accommodation through changing human use to avoid the disaster; 3) redirection through population resettlement; or 4) no action. According to this same source, the most common course of action in the face of disaster is resettlement. The authors point out that this is highly problematic because the disruptive nature of resettlement is well documented in disaster literature. This research questions why this trend remains even when the “significant political, economic, social and physical consequences to resettlement policies” have been well established (Whiteford and Tobin 2004: 190). They use the Tungurahua volcano evacuation of 1999 to explore resettlement policy, its shortcomings (the separation of families, damage to health and livelihoods), and why these policies persist.
While evacuation policies may appear to be similar, whether they are written for the United States, Canada, or Ecuador, in practice they become very different. Differences in socioeconomic class, access to resources, ethnic identity and levels of support all shape the local context in which evacuation and resettlement occur (191).

In short, the socio-political environment shapes the ways in which policies are interpreted and carried out on the ground. Our analyses must go beyond the written policy in order to fully understand its impact on people’s daily lives.

In Ecuador, disaster preparedness and management are planned primarily by the country’s civil defense system, which at the national level is staffed by paid professionals, while local and regional levels are composed of volunteers who are often retired military personnel (192).

They pay particular attention to the history, policies or processes of evacuations, which have not been fully explored in the literature. One of the major problems with mass evacuations is that they often require military force. The military model often requires that people leave by force; but those who were “least able, as well as those who were least willing, to leave felt the greatest effect of the military force” (193). Those who had strong social support (families and friends) in neighboring cities, access to telephones and transportation were able to relocate their families. Day workers and others without such support networks or material resources frequently had no place to go and were therefore more likely to be relocated into shelters. These vulnerable groups, particularly children, were more susceptible to illness in these settlements.

Emergency evacuations will continue; resettlement policies will continue to be enforced. But by making public the experiences and stories of those resettled and by demonstrating the unequal and untoward effects of those polices, the basis for their failure is made clear and not obfuscated (199).
The theoretical contributions of Whiteford and Tobin include using the anthropology of policy to document the very real public health consequences of resettlement policies through questionnaires and in-depth interviews. The paper focuses on post-disaster “recovery” phases and, as the authors point out, there are not reliable baseline health measures. They compensated for this by comparing the health of resettled residents and the people in the hosting communities, thus showing how policies impact health.

**Anthropology of Disasters**

*When hazards threaten and disasters occur, they both reveal and become an expression of the complex interactions of physical, biological, and sociocultural systems. Hazards and disasters not only manifest the interconnections of these three factors but also expose their operation in the material and cultural worlds.* Oliver-Smith and Hoffman (2001:5-6)

The concept of vulnerability in disaster research refers to certain subsets of the population that bear an undue burden of the disaster impact due to their lower socioeconomic status or preexisting health conditions. Anthropologist Anthony Oliver-Smith (1998) succinctly summarized the importance of the vulnerability concept: “In very graphic ways, disasters signal the failure of a society to adapt successfully to certain features of its natural and socially constructed environment in a sustainable fashion” (303). An excellent example of anthropological work that considers the historical and political-economic foundations of differential vulnerability is Button 2006, who conducted ethnographic interviews with the marginalized black populations in New Orleans after Hurricane Katrina. He finds that those who suffered the most from the impact of Katrina, the poor and racial minorities, perceived the hurricane very differently than the official reports on the news and official documents. Many of the individuals in the Ninth Ward, one of the poorest areas in New Orleans, did not believe that the levees
had been overwhelmed by Hurricane Katrina as the experts claimed; rather they believed that the levees had been intentionally compromised. Some participants claimed to have ‘seen flash and hear a boom’ and indicated they believed that the levees had been blown up (8).

Button calls these stories counter-narratives because they contradict the official narratives put forth by the popular media. Rather than dismissing these counter-narratives as fabrications or delusions, he explores the origins of these stories to highlight the political-economic and racial tensions that existed in New Orleans. Button references history to contextualize the experience of New Orleans black residents. For example, poor areas of town were intentionally flooded in the 1920s; the Great Mississippi Flood of 1927 was a purposeful flooding of the poor (and mostly black) parts of the city. In fact, “the white fathers of New Orleans” obtained permission from the federal government to blow up a levee downriver from the city (9). The explosion flooded both St. Bernard and Plaquemine Parish and destroyed the homes and livelihoods of thousands of marginalized people who never received the compensation they were promised. This story has not been lost on at least some of the evacuees (9). The historical experience of this marginalized population retains the memory of intentional victimization. Anthropologists have much to offer to the extrapolation of complicated social issues through their ability to privilege groups who have been marginalized (Henry 2005).

Other contribution that anthropologists have to offer is their experience studying disasters in many locations around the world, therefore, allowing for a comparative perspective (Henry 2005). According to Doug Henry (2005:1), what differentiates Anthropology from other disciplines is the “comparative, relativistic approach” which
often results in a “critical stance, privileging local knowledge and local ways of management, while problematizing the dominant models of relief”. Anthropologists recognize that socially created patterns of vulnerability exist and how the history of colonialism and current global trade can influence these patterns (Roseberry 1988; Button 2005; Henry 2005). Anthropologists emphasize local models of risk construction, stress the importance of understanding socio-cultural context of judgments, and indigenous linguistic categories and behaviors about what is dangerous and what is not dangerous (Henry 2005: 5). They also note the shared context of public perceptions regarding risk and acceptability, and that people choose between risks based on culturally informed values within their social context of poverty or power.

Oliver-Smith argues that the holistic approach of anthropology allows this discipline to capture the multidimensionality disasters and therefore, can contribute to “disaster mitigation and reconstruction” (2001:46-47).

**Anthropology Disaster and the Aged**

Anthropologists Vincanne Adams, Sharon Kaufman, Taslim van Hattum, and Sandra Moody (2011) present the plight of nearly 23,000 people who evacuated to the Astrodome in Texas after Hurricane Katrina.

> Here and elsewhere, medical personnel and shelter volunteers found that dozens of elderly were demented, had severe physical and mental impairments, and/or were gravely ill and needed immediate transfer to more medically sustainable surroundings. That was not always possible (254).

Without mechanisms in place to address the needs of individuals with physical and cognitive impairments, many of these individuals did not survive. The most vulnerable were those without (or separated from) family or social networks. “Others – without
family, resources, or the wherewithal to obtain help – languished in shelters across the United States, falling into poorer health and sometimes dying before their families could find them…” (254). The authors also point to policy deficits, which “lacked effective communication systems for locating displaced (or dead) persons” (254). Programs, such as greater enrollment in the Safe Return Program, might help mitigate the separation of PWD from their social networks during disasters. When a PWD is surrounded by their social network, there is an increased chance that someone will help advocate for necessary care. Social networks can help individuals navigate the complicated process of recovery. For example, one participant reported that:

_Older people without family, who were incapable of managing the heavy demands of bureaucratic paperwork in order to receive insurance payments, Road Home monies, or Small Business Administration funds to rebuild, were overwhelmed, and many simply ‘gave up’: ‘they died because of depression and they are not getting their money for the property, the right deal, or no deal…’_ (255).

The primary findings and concerns of these researchers is that there is a “lack of government infrastructure for caring for evacuees, particularly the elderly” (Adams et al. 254). The failure to include mechanisms for securing the safety of the most vulnerable populations, anthropologists argue, is rooted in a “one size fits all” or “greatest good” paradigm. Fjord (2007) argues that the “one size fits all” disaster paradigm prioritizes able bodied individuals with the means to prepare and evacuate if needed. This excludes any person “who is temporarily or permanently cannot see, hear, move, cognize, and cope during and after disasters, who has dependent kin, no cash or bank account, nowhere to go and no way to get there if they did” (Fjord 2007: 53). This exclusion is
frequently justified in the name of “the common good”. Fjord critiques these disaster paradigms from the perspective of critical disaster theory.

**Anthropology of Disability and Disaster**

Anthropologist Lakshmi Fjord uses critical disability theory to consider the response and documentation of disability during the aftermath of Hurricane Katrina (2007). In particular, she analyzes the US House of Representatives Katrina Report on the media coverage “that lead to the militarized responses in New Orleans”. Within this document she considers the images produced from Katrina that created a skewed public perception of race, danger and disability. She argues that these iconic images are presented without consideration of how exclusionary disaster planning practices contribute to the disproportionate deaths borne by Blacks, the frail elderly and people with disabilities (2007:49). These exclusionary practices, she posits, are the factor that creates the true disablement of these populations. However, the images do not present this critique. Instead, they normalize the suffering experienced by these marginalized populations.

They are the ‘expected’ dead, whose infirmities and age are imagined as the cause of their deaths. Through a critical disability lens, these images narrate instead the epistemology of a disaster bioethics based on ‘one size fits all’ disaster paradigms (2007:60).

In other words, the public sees the age, the need for a wheelchair, as the cause of death. In reality, it is the fact that policy has not incorporated the needs of these populations into their disaster planning priorities. A person is not disabled by a physical impairment alone.
In such cases, it is the social environments that are disabling, not the impaired body of the individual. This is known as the social model of disability. The social model distinguishes between an impairment and a disability. An impairment “is the functional limitation within the individual caused by physical, mental or sensory impairment” (Oliver 1996; Oliver and Barnes 1998). A disability is the “is the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers’ (DPI 1982). As explained by Stewart (2005):

_the social model therefore emphasizes societal reactions to an impairment, with the term disability calling attention to the oppression people with impairments experience as a result of prejudicial attitudes and discriminatory action._

These are important divisions because it elaborates on the social dimensions of disability. Many individuals with a disability can function within society as long as there are alterations made to restrictive environments. Wheelchair users, for example, can function in the workplace as long as there are curb-cuts and elevators that allow them access. Some individuals require assistance with daily activities only once or twice a day. Likewise, policies that exclude the needs of vulnerable populations during disasters can be disabling. Fjord (2007) implicitly references the social model of disability when she argues that disaster planning policies are disabling large segments of the population because they are not “normal” and are “special needs”.

While no one disputes the wisdom of preparing for the needs of disabled people of all sorts the social Darwinist assumptions that underlie the frameworks of disaster preparedness, responses and recover must be disputed vigorously. Bracketing out “special needs persons as having characteristics that are different from those found throughout their societies endangers those deemed to “have” special needs and also fails to prevent harm to everyone else... (60).
Fjord (2007) calls for more inclusive disability policy. Additionally she critiques the concept of vulnerability as normalizing the death of marginalized populations.

Critique of Vulnerability

Though Fjord accepts that the vulnerability concept in disasters was meant to highlight the social causes of differential burden during disasters, it may now serve as a justification of loss from vulnerable populations:

*The concept of vulnerability, as it is used in disaster rhetoric may inadvertently reconstitute categories of persons for whom ‘expected losses’ will occur. Intended to foreground the relationship between existing sociopolitical and economic inequalities and disproportionate losses after disasters, the vulnerability concept now fuels a hermeneutics of expectancy... (Fjord 2007:60).*

She argues that the vulnerability concept is at risk for being warped; rather than being used as a tool to examine the underlying, root causes of unequal access to safe housing, transportation and health care, the vulnerability might instead be used to justify disproportionate losses among differing populations. My position on this is that, while researcher need to be aware that some lay persons (i.e. politicians, journalists) might use the concept as a ‘short-cut’ for explaining disproportionate loss, it is still an essential concept. It is the role of the research to critically examine root causes, structural violence and help the lay populations to ‘connect the dots’ between these concepts and disproportionate loss during disasters.

Fjord and Manderson (2009) build on the critique of disasters and vulnerability in “Anthropological Perspectives on Disasters and Disability: An Introduction”. They reference the ‘social model of disability’ by locating the source of disablement in social practices and policy, not in physical impairment. Fjord and Manderson argue that
“vulnerable persons” ought to be conceptualized as “vulnerable situations”. Citing Wisner’s (2007) concept of “shifting vulnerabilities”, they posit that vulnerability is a situation “which people move in and out of over time” (Fjord and Manderson 2009: 67). The benefit of conceptualizing vulnerabilities as shifting, according to Fjord and Manderson, is allows theorist to “split apart the embodied or social characteristics of an individual or group from the social situation that cause differential burdens of harm because of barriers that deny them access to social and material resources” (2009: 67). I find the concept of shifting vulnerabilities particularly helpful because a disease, such as Alzheimer’s, also shifts over time, thereby changing a person’s relationship to the social and policy environment. Shifting vulnerability fits nicely with the fact that AD is progressive and changes over time. Therefore, a family’s vulnerability can change. Disaster plans and services need to reflect those changes. This will be discussed in the following section, “Anthropology of Dementia” which documents loss of social status and personhood as one loses cognitive abilities. This is also connected to the measurements of loss that are provided in the literature review.

Fjord and Manderson also argue that the population at large can benefit from an expansion of disaster response services, not just “special needs populations” (2009: 64). FEMA is now requiring that all shelters, not just special needs shelters, are equipped to accommodate people with functional disabilities (FEMA 2010).

*Children and adults with disabilities have the same right to services in general population shelters as other residents. Emergency managers and shelter planners have the responsibility of planning to ensure that sheltering services and facilities are accessible. The decisions made in the planning process determine whether integration or segregation occurs during response* (FEMA 2010: 8).
Some counties have balked at the cost and manpower that is necessary to make this transition, should it require a generator in each shelter and trained staff (personal observation 2011). I accept the social model of disability and the policy implications. It seems however, that PWD need specialized attention and training. All Red Cross Volunteers should be trained in the unique needs of PWD during disasters, however, segregated special needs shelters that accept people with dementia might provide a slightly less chaotic environment. Furthermore, it may be difficult to find enough volunteer nurses to staff all of the shelters since many nurses are required to report to duty for their primary employer. This will be explored further in the results and discussion of special needs shelters.

Anthropology of Dementia

The first few slips get chalked up to anxiety or a lousy night’s sleep or a bad cold... What begin as isolated incidents start to mount and soon become impossible to ignore. In fact, they are not incidents; collectively, they are signs of a degenerative condition. Your brain is under attack. Months and years go by. Now you are losing your balance. Now you can no longer make sense of an analog clock. Now your handsome young husband has disappeared and a strange elderly man has taken his place. Why is someone taking your clothes off and pouring warm water over you? How long have you been lying in this strange bed? (Shenk 2001: 20).

Anthropologists such as Lawrence Cohen (1998, 2006), Elizabeth Hertzkovits (1995), Sara Poveda (2003), Annette Leibing (2006), Sharon Kaufman (2006), Janelle Taylor (2008), and Mahnaz Hashmi (2009), have contributed to a nuanced understanding of the social construction of the PWD in Western societies. Building on theories drawn from the anthropology of chronic illness (see Estroff 1993), these anthropologists deconstruct how the loss of mental capacities frequently equate a loss in social status,
adult status and sometimes, even the distinction of being alive. Ultimately, PWD are in what anthropologists consider a “liminal” space that defies categorization.

The rhetoric of “the loss of self” and other themes of death and evidence of personhood have been salient in both professional and popular literature on AD since in the 1990s (Leibing 2006:242). The loss of the self can also be conceived of as death of the self; I note that death appears in the literature on personhood and dementia in several distinct ways:

1) Biological death of the body: the heart and respiratory system stop as part of the advanced stage of the disease, and there is no longer any function of the brain;

2) A living death: the person becomes a shell with nothing inside, and yet the body lives on (Cohen 1993; Kaufman 2006; Hashmi 2009);

3) Relational death: friendships dissolve as the PWD can no longer reciprocate or “recognize others” (Taylor 2008; Dosa 2010).

4) Biosocial death: death of the role of an adult with “full citizenship,” also represented as a decline into infancy (Hertzkovits 1995; Poveda 2003; Leibing 2006; Fry 2007; Hashmi 2009);

The last three categories are juxtaposed against biological death, since there is “still a person in there” (Castleman 1999).

Anthropologist Mary Douglas’ Purity and Danger (1967) discussed the profound discomfort people have with something that does not conform to preordained categories. Turner (1969) built on this concept in Liminality and Communitas, defining liminal individuals as those who are “neither here nor there; they are betwixt and between the
positions assigned and arrayed by law, custom, convention, and ceremony” (95). People with dementia are in a liminal position because people have trouble categorizing them as either fully “alive” – though they breath and observe – or fully “adult” though their age defines them as such. Their liminal space has multiple policy implications which are illuminated during disasters, especially in the use of Special Needs Shelters in Florida. I will argue that because they are perceived as between life and death they are dangerous (exhibiting unpredictable behavior) there is Bio-social death. They do not fit in the preexisting categories and are therefore, excluded.

**Biological Death.**

The question of when biological death begins plays a predominant role in the field of bioethics. What remains relatively undisputed is the definition of biological death; it occurs when 1) the heart stops (and cannot or will not be revived) and/ or 2) all brain activity ceases (i.e., a person is absent of brainstem reflexes) (Wijdicks 2002; Bagheri 2007). AD attacks several parts of the brain, eventually destroying the brain stem, which is responsible for basic functions such as breathing and the beating of the heart. When this happens, biological death occurs. Usually, however, opportunistic illnesses, such as infections from pressure sores or pneumonia, cause death in persons with AD before the brain stem is destroyed (Burns 1990; Förstl 1999).

**Living Death.**

People with dementia are frequently described as being a “shell” of who they once were. Alzheimer's has been described as “‘a marathon', an 'exhausting vigil' given bodies 'who need to be constantly watched or restrained', an 'ordeal', 'round-the-clock', and most tellingly, an 'endless funeral'” (Cohen 1998:54). The phrase, “endless funeral” implies that the PWD is almost, but not quite, dead.
Kaufman (2005) entitled a chapter in an edited volume, “death-in-life and of life-in-death” to highlight the constructed liminality of a PWD. She describes an exchange between a doctor and the family members of a person with advanced dementia (26-27). The doctor tells the family that, “[Your mother] doesn’t demonstrate anything. She cannot respond in any meaningful way.” The daughter counters that sometimes her mother hears her talking and opens her eyes. “I believe she recognizes my voice,” she says. Nonetheless, in cases like this, medical professionals are tasked with convincing the family that medical care is no longer necessary. Kaufman explains that memory, consciousness, and the modern task of self-making are considered essential to being “fully alive” (2005: 27).

The question is not simply what constitutes life, but what is it to be human. In a related piece, Taylor highlights the narratives of horror that surround AD, complete with zombie imagery of the “walking dead”:

*a person dies but their body lives on: this is the basic zombie story....the zombie variants of the Alzheimer’s narrative depart from the same basic premise: the body may continue to live, but the person with Alzheimer’s is dead, gone, no longer there, no longer a person. He or she does not know your name, does not “recognize” you, therefore cannot “care” about you, but you must “care” for him or her—and such “care” is conceived as an unending toil of unrelieved grimness* (Taylor 2008: 322).

These narratives, Taylor argues, can do real harm; if a caregiver conceives of a PWD as inhuman, as a member of the walking dead, it could lead them to ignore the needs of the PWD or treat them in dehumanizing ways. So, for instance, she provides the example of a man who not only described living with his wife with advanced AD as like being with the “living dead,” but also how he ignores her. Later in the narrative, he describes how he ties her to the toilet when he leaves the house.
**Relational Death and the Politics of Recognition.**

Alzheimer’s disease is relational, because it involves more than just the person with the disease. Hashmi (2009) argues that, despite which disease is causing dementia, it usually takes more than one person to diagnose and define the illness; at least two people are required: “a senile body in which the disease process is located and another who has noticed change in the first” (210). Dementia is further experienced not just by the person with the diagnosis, but by the people who provide care. Often, caregiver experience is utilized to gauge the significance of the disease. It is through the

> Caregivers that the disease is publicly experienced and made to matter. This is the irony of Alzheimer’s, that other than in the very early stages of the disease process, the suffering of the stricken brain is experienced primarily by those with brains intact (Hashmi 2009:210).

In the later stages of the disease, the PWD’s changed sense of reality alters their ability to reflect on (or at least articulately communicate) their own suffering. It is then that the caregiver, who can reflect and communicate, speaks to the damage caused by the dementias (Poveda 2003).

One of the most painful aspects of AD and related dementias, from the perspective of caregivers, is when the PWD no longer recognizes friends and family members. Taylor (2008), in response to pervasive questions about whether her mother with AD could still recognize her, reflects on the meaning of “recognition”. She applies Ricoeur’s (2005) philosophy of “recognition” to the realm of dementia; this framework examines the concept of recognition in three different ways: 1) the identification and recognition of things; 2) self-recognition; 3) being recognized by others in a social dynamic. These definitions move from the active to the passive. It is precisely this shift, she argues, that has ethical and political considerations when applied to people with
dementia. When a person asks her about her mother’s ability to “recognize” her, she says, “the question concerns my mother’s ability, as a sovereign self, to actively draw intellectual distinctions among the object and people around her” (2008: 314). However, there are also political and ethical implications to the question: Does a person who cannot recognize the people who care for them still exist? Are they granted social and political recognition by others?

Taylor notes that with an AD diagnosis, previously large social networks disintegrate.

_Dementia seems to act as a very powerful solvent on many kinds of social ties… Friendships in this social world are also built up and sustained through ongoing exchanges of invitations, confidences, favors, gifts, cards, and the like…When friendship is grounded in reciprocity, then a person who no longer can engage in the usual social exchanges is difficult to ‘recognize’ any longer as a friend._ (Taylor 2008: 319-320)

The inability to reciprocate is a fundamental act of sociality. In the US, as in other societies that value independence, “chronic dependency violates this reciprocity and becomes more problematic” (Taylor 2008:320).

Hashmi (2009) also discusses relational death, suggesting that the emphasis on individualism in American society, and associated values of freedom and independence, do not leave much room for those who cannot care for themselves. She also ties the relational death to dependency without reciprocity.

_If one is not self-reliant, one’s humanity is reduced and one’s morality questioned. To be independent indicates the ability to give and take in reciprocal relationships, therefore a non-reciprocal taking indicates dependence. Whilst limited periods of dependency are acceptable at certain times, for instance during acute illness or childhood, chronic dependency violates this reciprocity and becomes more problematic._ (Hashmi 2009:208)
The relational death of self is tied to people’s ability to recognize the other within their social relationship. People are expected to participate in this interaction; chronic illness can strip a person of their ability to play their role.

**Biosocial death.**

Relational death is tightly linked to a biosocial death. A biosocial death refers to the related inability to participate in society. When one is unable to fulfill social interactions, there is also a loss of social status as a “citizen” or the role of a functional “adult”. In Western societies, for example,

*Adults with incurable chronic illnesses such as schizophrenia frequently fail to retain the expected roles of student, employee, spouse, and parent... [the] progressive role constriction accompanying chronic illnesses contributes to simultaneous loss of valued, competent role experiences and increase in devalued, incompetent roles and experiences* (Estroff 1993: 259).

One result of chronic illness is that it leaves people unable to provide for themselves and, therefore, often dependent on family and on society for subsistence. One of the values promoted as an American cultural ideal (and in capitalist systems in general) is that “adults should have and produce more resources than needs, have or earn more money than is spent” (Estroff 1993:259). Another perspective is that with adulthood comes responsibilities and “full citizenship” (Fry 2007:14). When one can no longer fulfill their responsibilities, citizenship is lost. When they lose this role, they may experience stigma and social isolation (Goffman 1963; Hashmi 2009).

In biosocial death, agency is stripped of a PWD. Echoing the observations of Estroff (1993), Hazan (1994) and Hashmi (2009) note that, not only the loss of social roles and social status, but a loss of humanizing elements:

*In societies where the self is defined by its individuality, agency and autonomy, it is hardly surprising that those suffering with a disease*
process which undermines those very features can become viewed as ‘culturally ambiguous entities lacking some of the properties of human beings’ (Hazan, 1994). The madness that sometimes occurs in more advanced dementia – the violence, the delusions, the failure to recognise what is dearest and most familiar, confirms the death of selfhood (Hashmi 2009: 210).

People with dementia not only lose their status as a productive adult, but they may also lose their personhood and place within a social network. Their citizenship is revoked, and they are relegated to a category closer to that of a child, rather than a productive and responsible adult. In short, especially in the Western societies defined by independence, the status of the PWD will change with diagnoses. They may no longer be considered an adult capable of making reasonable decisions. As the disease progresses, the role of adult, family, friend, human or alive is constantly reconstructed and contested between actors.

The regulation of a PWD to that of a child without full citizenship has political consequences. AD has also proven difficult to categorize for lawmakers. Funding for AD related programs is often relegated through the Department of Elder Affairs, which means that the disease is defined by its connection with aging. It has also been pigeonholed into categories such as mental illness, and developmental disabilities. These issues become important in the results (final administrative interviews) and in the discussion. As will be discussed in Chapter 7 and Chapter 8, PWD are frequently excluded from special needs services before and during hurricane because they are not “physically” sick and/do not require electricity for medical treatment. While bureaucratic definitions are frequently used to justify the exclusion of PWD from SpNS, the implication is that PWD, I argue that there are underlying assumptions about who is worthy of these services. While the Florida Statutes technically includes PWD as part of the special needs population, local county level variation and interpretation reveals the
liminal space in which PWD are so frequently placed: neither sick, nor well; neither
adult, nor a child; neither alive, nor dead. Certainly, it is unclear whether they are a “full
citizen”, worthy of tax payer funded social services.

Exploring and Developing an Explanatory Model of “Risk Fatigue”

There are a number of terms that relate to both individual and population level
responses to disasters: hurricane “fatigue” (Hanlon 2009; Grey 2008), hurricane
“burnout” (Moore and Moore 1997), “hurricane amnesia” (Olmstead 2008) and “chronic
disaster syndrome” (Adams, Van Hattum and English 2009). Building on Lupton 1993
and Nichter’s 2003 adaptations of risk and modernity I attempt to develop explanatory
models for the public’s lack of action before a hurricane. I specifically argue that people
with disabilities and their caregivers are more likely to be overwhelmed by the prospect
of a disaster and therefore, are less willing to prepare.

While some Florida families may have learned how to streamline their disaster
response during multiple hurricanes, other became exhausted and tattered. “Hurricane
fatigue” is a term used to explain why people are less likely to respond to a potential risk
– in this case, a hurricane that threatens – after being exposed to it multiple times. It has
not been widely used and the etymology of the term is somewhat unclear, though I
attempt to trace it in the following sections. “Hurricane burnout” is a related term that has
also been infrequently in hurricane research and typically has referenced the ongoing
mental health concerns in individuals after a disaster (Moore and Moore 1997)\(^\text{13}\).

\(^\text{13}\) A related term is “disaster fatigue”, which is related to “combat exhaustion” or “battle fatigue”; however,
“disaster fatigue” has, in the literature, primarily referred to the response of people related to nuclear attack
(Glass 1957; Davis 2007; Pastel and Richey 2011). The diagnosis was given to individuals and appeared to
be similar to post traumatic stress syndrome. The term “disaster fatigue” does not currently seem to be in
Similarly, anthropologists Vincanne Adams, Taslim Van Hattum and Diana English (2009) present the concept of “chronic disaster syndrome” to explain the effects of long-term stress following a disaster. They argue that this syndrome (or cluster of symptoms) expressed by hurricane Katrina survivors, is the result the chronic trauma of a disaster and the following displacement. The individual suffering, they argue can be exacerbated by disaster capitalism (2009: 616). This concept is distinguishing it from the “disaster fatigue”, which is built upon Beck and Giddens theories of risk and modernity (discussed further below). The concepts of risk and modernity was refined and applied to public health and anthropology by Lupton (1993) and Nichter (2004) (as described in chapter 4). I refine it further to explain why at risk populations might fail to respond to a disaster when it is threatening. “Chronic Disaster Syndrome” considers the long-term impact of post-disaster trauma and exploitation. Still it is a useful because it overlaps with and compliments the PAR model.

Another term, “hurricane amnesia,” refers to the fact that people begin to forget the risks associated with a hurricane after a long hiatus from the risk (i.e., several years without a hurricane). It is assumed that, during hurricane amnesia, people do not respond to a current threat because they have simply forgotten how serious the risk can be.

Green (2005:203) explained her own journey through the storms by comparing the experience to watching a loved one decline in health:

> As our elders gradually lost ground in their courageous battles with a multiplicity of age-related conditions, I waited. I hoped for more time to love and be loved by them. I felt powerless in the face of the inevitability of their loss. I was frustrated by the uncertainty of when and how the loss would occur. I spent many sleepless nights dreading the phone call that would signal the end of my waiting. I wished for the

| 110 |
waiting to be over and felt profoundly shamed by that wishing. By the end of last year’s storm season, I felt similarly ‘battered by the waiting.’ I had the perverse feeling that if was going to lose my home and everything in it, I just might prefer to lose it sooner rather than later. I was not alone in this peculiar feeling. It was a common topic of conversation after several weeks of on again–off again storm preparation. We began to feel the burden of our once-treasured possessions. We were tired of anticipating their loss. We wanted it over with (Green 2005: 206).

The emotional strain of multiple storms also has public health consequences, including mental health impacts. Mental health issues, including posttraumatic stress disorder and depression, have been well-documented after hurricanes (Norris et al. 2002; Moore and Moore 1997; Galea et al. 2008). Mental health concerns can also become physical safety concerns, as people who may have evacuated to safety for earlier storms might fail to evacuate after experiencing multiple storms. As noted above, a term that has been occasionally been used to describe this phenomena is “hurricane fatigue,” though I believe the more appropriate term is “risk fatigue” (which will be explained further below).

The term “hurricane fatigue” appeared in the popular media after Hurricane Katrina as an attempt to explain why people did not respond to mandatory evacuation. Reeves wrote an article, “Some Faced Katrina with ‘Hurricane Fatigue’” for the Associated Press on August 31st, 2005. He drew the term from a statement made by Mississippi Governor Haley Barbour,14 who said:

*I worry that we had a little hurricane fatigue. People boarded up for Ivan, evacuated and nothing happened. Then they boarded up for Dennis, evacuated and nothing happened. I think until very, very late, a lot of people thought, ‘Ah, I’m not going to do that again.’*

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The term was used to imply that the government had “cried wolf” with previous hurricanes and, therefore, people failed to appropriately respond to the hurricane. This article also presented two other cases of people who did not evacuate: 1) a man who used a wheelchair, did not own a car, and could not afford to leave; and 2) An older woman in her 80s, who refused her son’s pleas to evacuate. The term appeared in the popular media again in a 2008 Time Magazine article authored by Steven Gray. He also used the term “hurricane fatigue” as Ike was posed to strike in 2008:

*Even though Louisiana (in addition to Texas) has already declared a state of emergency, government officials must puncture the popular perception that Gustav was a false alarm. That perception is partly driving what’s been dubbed “hurricane fatigue,” but also complacency: many residents say they won’t evacuate for Ike, or future hurricanes.*

The term “hurricane fatigue” has also been found in the occasional academic journal. For instance, Hanlon (2009) connects the term to Beck’s concept of “risk society” (1986). As mentioned above, Beck’s view of modernity posits that people are skeptical of experts, increasingly individualistic, and tend to be hyperaware of risks. Hanlon argues that, when it comes to hurricanes, people do not react to expert advice in objective or neutral ways; rather, lay populations construct “expert” knowledge as “different to, but not necessarily better than, their own (Hanlon 2009:216).

*...people with ‘hurricane fatigue’, prior experience of hurricanes, concerns over money, security, etc., placed expert advice within a set of previous warnings, trust of state officials, etc., and decided to remain where they were (Hanlon 2009:206).*

In other words, hurricane warnings must be contextualized within other social phenomenon that might impact a person’s decision to evacuate or not. While “hurricane fatigue” refers most specifically to an increase in public skepticism of the experts issuing
a hurricane evacuation order (after multiple false alarms), I use the term “risk fatigue” to refer to the multiple factors, such as poverty or disability, which might influence people’s decision to defy a mandatory evacuation order. Hurricane fatigue might be one or the many factors that ultimately causes “risk fatigue”.

Thus, I use the term “risk fatigue” to describe an increasing apathy demonstrated by citizens after multiple hurricanes. According to Barnes, “[e]vacuations for the storm [Jeanne] were far less complete than those for Frances. During Frances, communities like Stuart were said to be like ‘ghost towns’, whereas during Jeanne, many residents stayed home” (2007: 338). Some people decided to stay because they felt they needed to protect what remained of their property, but “others were apparently disgusted with the evacuations and emotionally drained; they were tired of moving in and out of their homes” (Barnes 2007:338). Though their previous evacuations had been necessary and potentially saved lives, they had become exhausted after so many (legitimate) threats. It is possible that some of them, like Green, suffered “risk fatigue”. Barnes paints a picture of the psychological toll that the previous hurricane season had taken on Florida residents, stating that, “thousands of Florida residents were emotionally drained by the continuous string of hurricane disasters that had swept over them” (2007: 348). The Florida Department of Children and Families started Project Hope (Helping Our People in Emergencies), a counseling program that aids people through the residual stress and mental health issues associated with surviving a disaster. In the words of a FEMA article,

[a] major disaster such as a hurricane – and the process of coping with its aftermath – can bring about all sorts of emotions: depression, anger, frustration, withdrawal…. Seeking help at the outset can reduce the risk of troubles down the road. And officials emphasize that there is a strong connection between mental health and physical well-being (FEMA Crises Counseling 2005).
An estimated 153,000 Floridians utilized the Project Hope hotline after the 2004 season (Barnes 2007:349). These services continued into the 2005 hurricane season, however, they were discontinued in 2006.

**Hurricane “Amnesia” and Public Health Implications**

The term “hurricane amnesia” refers to the general complacency of a population when they have not been affected by a natural disaster for a long period of time. Dave Olmstead, a senior public affairs and code compliance specialist, reflected on the 27-year period of little to no hurricane activity in South Florida that affected reactions to Hurricane Andrew in 1992, noting that the same had happened during the quite hiatus between Hurricane Andrew and the 2004-2005 hurricane seasons:

*Another 12 years pass without a major event and by then everyone has gotten Hurricane Amnesia (again), or consider this: on average, Florida gains approximately 484,600 new citizens annually—most of whom have never experienced a hurricane* (Olmstead 2008).

These new citizens may not focus on hurricane preparedness, and therefore, are unlikely to pressure elected government officials to pass stronger mitigation legislation. However, even when government officials issue preparation reminders, citizens might fail to heed the warning. In 2005, when Hurricane Wilma hit Florida, it “proved to be the ultimate demonstration of the public’s general refusal to prepare for hurricanes” (Olmstead 2008). Though Wilma was on clear path to hit South Florida and citizens had a week to prepare, “[t]he morning after the storm, people were lined up for blocks waiting for water, ice and other supplies. People in South Florida were not prepared for the storms that wreaked havoc in the area” (Olmstead 2008). This was in spite of numerous preparation reminders issued by the Governor’s office; Olmstead attributes this lack of preparation to “hurricane amnesia”, or a collective forgetting of the dangers that hurricanes can pose to the
population. However, I argue, it is unlikely that Florida citizens “forgot” the impact of the 2004 hurricane season in the year before Wilma. It is more likely they were still “fatigued” from the multiple hurricanes that had slammed the state, culminating with Jeanne. Rather than conceptualizing this phenomenon as a collective forgetting, it may be more useful to think about it as a collective aversion to thinking about the risk.

Though hurricane amnesia is an excellent tool for understanding what can happen if several years pass between storms, it is confounded by the fact that the population may shift to include people who have never experienced a hurricane before. Alternatively, people who have not experienced a hurricane in several years may become complacent when another hurricane draws near. This lack of vigilance can translate to delays in purchasing supplies, hardening the home (i.e. installing shutters), or evacuating. In some cases, this lack of preparation can result in injury or death. However, hurricane amnesia is not the only factor that can contribute to lack of preparations. When a population has been repeatedly bombarded by an event, they may become simply overwhelmed, exhausted, and fatigued. Though the end result can appear the same (people may not fully prepare or respond, such as the lack of evacuations after Jeanne and Wilma), the reasons for lack of action are different.

Prior research indicates that several factors can contribute to low levels of disaster planning: 1) People do not have the information about risk or how to prepare for it (access); 2) They do not understand the information or how to use it (comprehension); 3) They do not have the means to properly prepare (socio-economic factors); 4) They do not trust the people or entities that are providing them information about risk (risk perception) (Sorensen and Vogt Sorensen 2006). Anthropologists Dash and Gladwin
(2007) also consider factors that influence evacuation decision-making and behavioral responses at the individual and household level. They argue that the literature focuses on three primary (and overlapping) areas: warning, risk perception, and evacuation.

Research on evacuation decision-making in Florida indicates that having children in the household is a predictor of a family evacuating before a storm (Solis, Thomas and Letson 2009). This same research also found that people who lived in “risky environments”, specifically in mobile homes or flood zones, were more likely to evacuate. Conversely, people who owned their homes and/or had pets were less likely to evacuate than others (Solis et al. 2009). It is notable that caregiving for a frail elder or a person with a disability (cognitive or otherwise) is not considered as a decision-making factor in these studies. Furthermore, the category of the storm (as measured by e.g., the Saffir-Simpson Wind Scale) is not considered.

Summary of Anthropological Theory

This chapter was a review of anthropology’s theoretical contributions to the understanding of disasters and dementia. I attempted to synthesize the existing theories of “vulnerability”, “personhood”, “bio-social death”, to frame my research on anthropology of disasters and dementia.


Chapter 6: Methodology

The primary research question of this study concerned how caregivers who participated in the Alzheimer’s Community Care (ACC) programs planned for hurricanes. The goals of the methodology in this study were twofold: 1) To examine the status of caregiver and persons with dementia (PWD) disaster planning at ACC; and 2) To illuminate disaster planning needs unique to the caregiver and PWD populations. This information was used to improve disaster planning for caregivers at ACC. A mixed-methods approach illuminated which disaster planning needs were necessary to provide continuity of care before, during, and after a hurricane. The organization of the data collection was designed to provide context for how staff recorded disaster plans and how caregivers planned to implement them, with the caregivers then furnishing a means for understanding the impact and effectiveness of disaster planning under the organization’s guidance.

This chapter will begin with a description of the partnering organization, ACC, and the programs it offers to caregivers and people with dementia in Florida’s Palm Beach, Martin, and St. Lucie Counties. Disaster planning is only one of the many services it provides to support community-dwelling caregivers.

In the second part of this chapter, I will present an overview of the mixed-methods design employed in my research. This includes a general discussion of mixed methodology and how it frames my research, specifically. The third section is a detailed description of the individual methods used. These methods included:
1) participant observation;
2) staff interviews (n=8);
3) preliminary caregiver interviews (n=5);
4) baseline chart/disaster plan review (n=290);
5) intervention (presentation to staff and administration) and form revision;
6) follow-up chart/ disaster plan review (n=259);
7) caregiver survey(n=253);
8) final caregiver interviews (N=15- total number of caregiver interviews 20);
9) disaster literacy testing (n=20);
10) final group interview with ACC administration.

For each method, I present the purpose, procedure (implementation), and analysis and limitations.

**Partnering Organization.**

Alzheimer’s Community Care (ACC) is located in Palm Beach County, Florida, and includes programs in metropolitan areas such as Boca Raton and Fort Lauderdale. Its purpose is to assist the family (caregivers) of individuals (beneficiaries) diagnosed with Alzheimer’s disease (AD) in order to keep beneficiaries in their communities and to prevent premature admission into a long-term care facility. The program is significant in that it allows beneficiaries to continue to be cared for in their homes, surrounded by loved ones, thus contributing to a higher quality of life. Additionally, the costs to supporting family members caring for beneficiaries are less than if these beneficiaries were to be admitted into nursing homes.
ACC provides the following services to approximately 2,500 families: 1) Alzheimer's day-care programs, which include health monitoring and specially designed activities for cognitive and social stimulation; 2) a family nurse consultant program, which provides caregivers with the guidance, support, education, and links to services that are critical in coping with and caring for a person with AD; 3) an Alzheimer's 24-hour crisis line, staffed by registered nurses and available to caregivers, police, and the community; 4) caregiver support groups; 5) case management; 6) a prescription assistance program; 7) professional and community education; and 8) specialized disaster preparedness. The last of these is the focus of this research.

ACC case managers, family nurse consultants, and adult day-care staff work together to form a safety net for families recovering from a disaster. A disaster event, such as a hurricane, might increase the stress placed on family caregivers. Caregivers may be uninformed on how to keep a person safe during the environmental changes caused by the disaster (for example, power outages, increased darkness due to hurricane shutters, the sounds of the hurricane). It is important for caregivers to have support when planning for a disaster. Many caregivers work full time, in addition to caring for their family members, and they may experience other barriers, such as a lack of vehicle ownership. In light of the problems facing this population, ACC provides support to overcome them, including disaster planning, and provides extensive publications on disaster preparedness, which are both sent out to clients and made available on the internet (see Alzheimer's Community Care in references for a link to these publications). ACC provides an annual, personalized disaster plan review co-created between clients and nurses who work in their adult day-care centers (family nurse consultants contact the
clients who do not utilize the adult day-care centers.) ACC staff members also collect emergency contact information from families and discuss what the families plan to do during different categories of hurricanes. Those who live in an evacuation zone and who do not have an alternative evacuation location can opt to stay at the Palm Beach County Special Needs Shelter (SpNS), which is operated by the Palm Beach County Emergency Operations Center (EOC). The Palm Beach County EOC has developed a unique relationship with ACC -- the county has added a dementia-specific component to the Special Needs Shelter services (SpNS). The Family Nurse Consultants employed by ACC are placed in the SpNS to provide specialized care and activities for people with dementia and for their families. This service helps to reduce agitation experienced by people with dementia (whose confusion might be exacerbated in an unfamiliar environment). The SpNS in surrounding counties do not offer dementia-specific services.

Support groups are also offered through ACC. The organization works to have the adult day-care centers up and running as quickly as possible after a hurricane so that caregivers can repair damaged property while knowing the PWD is being safely cared for. The extent to which individual clients of ACC consider disaster planning to be both important and viable was unknown at the start of this study. It was also unknown if ACC is the primary source for disaster preparedness information, or whether it is preferable to other sources (e.g., the government, television, radio, or newspaper). A better understanding of their disaster literacy will help respond to the needs of caregivers providing for family members with Alzheimer’s disease in South Florida.

ACC has partnered with local governments to provide multiple services for vulnerable populations. Though ACC is an available service in St. Lucie and Martin
counties, those have not yet incorporated ACC services into their emergency response plans. To best explore how services contribute to caregiver disaster preparedness, I used a mixed-methods research design.

**Mixed Methods**

The term “mixed methods” refers to a strategic combination of both qualitative and quantitative approaches. Mixed methods may be employed in multiple ways; for example, interviews can be used to help develop more effective survey instruments or to triangulate findings (Teddlie and Tashakkori 2009). Researchers using mixed methodology have begun to codify mixed methods into typologies in order to establish a common language when speaking about them. Each phase of my research encompassed the conceptualization stage, experimental state, and inferential stage (Teddlie and Tashakkori 2009).

My initial methodology can be conceptualized in the following shorthand:

\[(\text{QUAL} + \text{QUAL} + \text{QUAL} + \text{QUAN}) \rightarrow \text{quant} + \text{QUANT} \rightarrow \text{qual}\]

This notation means there were three different qualitative methods (QUAL), i.e., 1) participant observation, 2) staff interviews and, 3) pilot testing caregivers’ interviews, and one quantitative method (QUAN), the baseline disaster plan review). All four of these methods were employed simultaneously, indicated by the brackets and “+” signs. The results of these methods informed the creation of a fifth method, the quantitative caregiver survey (indicated by the arrow). I used the data collected to this point to identify the status of disaster planning at ACC and to outline potential improvements. I presented the preliminary findings to ACC staff and administration, which I will call an “intervention” because it resulted in modifications to their disaster plan process. This
presentation addressed missing data in the disaster plans, missing demographic data (such as caregiver ages), and gaps in other safety measures (such as low PWD enrollment in the Safe Return program, which will be discussed in the “Results” chapter to follow). I also used findings to advise the ACC administration on possible improvements to be made to the disaster plan checklist sheet before the start of the start of the 2011 hurricane season (see the Appendix II and III for a comparison). Further, I used basic demographic information from the disaster plan review to select a purposeful sample for caregiver interviews. I selected interview participants to reflect the larger distribution of caregiver sex, relationship to PWD (child, spouse, other family member), ethnicity, and race in the ACC population.

The second phase of my research included: 1) the newly created caregiver survey; 2) the follow-up disaster plan review; and 3) the final 17 caregiver interviews and disaster literacy tests (bringing the total number of caregiver interviews to 20). This second phase can be notated as:

quant + QUANT + QUAL

ACC staff administered the caregiver survey when they contacted them to update disaster plans (using the new forms). I collected the follow-up disaster plan review data in June 2011, just as hurricane season was beginning, to determine if the intervention was effective. I completed final caregiver interviews and disaster literacy tests in August 2011. I qualitatively analyzed the caregiver interviews, then converted these results into quantitative data for analysis (see below for details) (Teddlie and Tashakkori 2009: 149).
Ethical Considerations

While considering research design, it is important to bear in mind the potential ethical challenges. Primary ethical values in research are respect, beneficence, and justice for the participants (Beauchamp and Childress 1994). When doing research at the intersection of anthropology and medical provision, several additional ethical codes must be considered (Aagaard-Hansen and Johansen 2008). Whiteford and Trotter (2008) recommend using the following steps to work through an ethical dilemma: 1) Determine facts of the research case, 2) Identify values at risk, 3) Describe the primary ethical dilemma, 4) Determine possible solutions, 5) Chose one, 6) Defend the choice. I used this process to consider potential problems while undergoing the USF internal review. All interview participants signed informed consent forms. Survey data was collected with the use of a verbal consent form (since most data was collected over the phone).

Anthropologists have much to add to the discussion of both disaster research and the place of elders in American society. Ideally, my research will find a balance between recognizing the voices of nursing home caregivers and their experiences during hurricanes without compromising their integrity or causing harm.

Changes from the Dissertation Proposal.

This research has been slightly altered from the proposed plan presented in March 2011. The focus of the research shifted from a focus on social networks and disaster literacy to a more organic understanding of how the progressive nature of Alzheimer’s disease influences disaster planning for caregivers living in the community. Many of the methods from the original research design remain the same, though a disaster plan review has been added. After the first disaster plan review, I provided an educational
presentation to staff based on my findings. I did a follow-up disaster plan review two months afterwards to measure any changes. Finally, the staff –caregiver disaster plan development was reduced in size and was incorporated into the participant observation.

Table 6.1 Dissertation Timeline

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<thead>
<tr>
<th>Phase</th>
<th>Methods</th>
<th>Time</th>
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<tbody>
<tr>
<td>1. Preliminary</td>
<td>Internet Research; Complete IRB application</td>
<td>August- December 2010 (4 months)</td>
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<tr>
<td></td>
<td>Relocate to Palm Beach</td>
<td>December 2010</td>
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<tr>
<td>2. Data Collection</td>
<td>Volunteer Training, Staff Interviews (N=10)</td>
<td>January 2011-February (2 months on site)</td>
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<tr>
<td></td>
<td>Participant Observation</td>
<td>January- March 2011 (3 months on site)</td>
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<tr>
<td></td>
<td>First Tallahassee Advocacy Trip</td>
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<td></td>
<td>Begin Volunteer Work 3 days a week</td>
<td>December 2011</td>
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<td>Staff Interviews</td>
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<td>Pilot Test Caregiver Interviews</td>
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<td>Caregiver Interviews and Disaster literacy testing</td>
<td>February-August 2011</td>
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<td>Baseline Disaster Plan Review</td>
<td>March 2011</td>
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<td>Presentation to staff on Findings</td>
<td>April 2011</td>
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<td>Follow-up Disaster Plan Review</td>
<td>June 2011</td>
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<td>Increase volunteer time to four days a week</td>
<td>June 2011-September 2011</td>
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<td></td>
<td>Disaster Literacy Testing and Caregiver Interviews</td>
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<tr>
<td>3. Data Analysis and Write up</td>
<td>A. Data Analysis-Second Tallahassee Advocacy Trip</td>
<td>Sept-Nov (3 months) 2011</td>
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<td>B. Final group Interview with ACC Administration</td>
<td>December 2010</td>
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In the following pages, I will discuss these methods in depth, providing the purpose, procedure, analysis and limitations of each method.
Participant Observation

Purpose
Participant observation involves immersing one’s self in a way of life different from one’s own, actually participating in the activities under study, and attempting to “intellectualize about what you have seen and heard” (Bernard 2006: 344). Anthropology has long been characterized by such long-term fieldwork, with researchers immersing themselves in the place and population under study. The benefits of this approach, frequently augmented with participant observation, have been argued to be: 1) reduced reactivity of participants over time; 2) the ability to ask relevant questions; and 3) a deeper sense of the meaning in the data. The benefit of long-term participant observation is that the participants “let down their guard” over time and reduce the problem of reactivity. In Bernard’s words, “Presence builds trust. Trust lowers reactivity. Lower reactivity means higher validity of data” (Bernard 2006: 354).

Procedure
I volunteered at the adult day-care centers over the course of an eight-month period (January - October 2011), conducting participant observation. I participated in the provision of basic care and in a variety of activities to better understand what was required. While volunteering, I observed different manifestations of Alzheimer’s disease across different types and stages. I took field notes upon returning from my volunteer sessions.

The participant observation at the adult day-care center provided me with more opportunities to meet the family caregivers of the ACC beneficiaries, as well as contributing to a deeper insight into how ACC operates at an organizational level. This
long-term participant observation helped me develop a deeper understanding of both caregivers and organization alike. It also allowed me to build rapport with families and to recruit participants for the disaster literacy testing phase of my study. I completed over 250 hours of volunteer time in adult day care centers over the course of 10 months.

I completed a total of 20 home visits while conducting caregiver interviews in another phase of the project. This gave me an opportunity to observe the physical structure of the participants’ homes in addition to asking them questions informally. It also provided me with a sense of the environment in which the PWD was living, and if and how that environment had been adapted for ease of patient care.

As a final component of participant observation, I accompanied ACC administration, staff, caregivers, and community partners on an advocacy trip to the state capitol of Tallahassee, Florida, to promote home and community-based care (May 2011 and November 2011). During the lengthy bus ride, I had an opportunity to listen to the caregivers and staff as they interacted, participated in the interactions, and also was a participant in meetings between caregivers, staff, and legislators.

Additional activities included:

1) Assistance with Caregiver Burden Form design

2) Special needs shelter training and application review (Palm Beach County EOC)

3) Attended the Palm Beach County Disaster Recovery Coalition Conference

4) Red Cross training

5) FEMA Professional Development certification


   b. “IS-00235.a Emergency Planning”,
c. “IS-00240.a” entitled "Leadership and Influence",
d. "IS-00241.a" entitled "Decision Making and Problem Solving"
e. "IS-00244.a" entitled "Developing and Managing Volunteers",
f. “IS-00242.a” entitled "Effective Communication",
g. "Emergency Support Function (ESF) #8 Public Health and Medical Services".

Analysis
After each observation I took notes in a field journal to document my impressions and findings, as well as document any informal conversations, and then documented them using Microsoft Word word-processing software. I then coded my notes for themes and major findings. Reoccurring issues and concerns were noted and entered into a code book.

Limitations
I had originally planned to observe staff (specifically, the family nurse consultants) as they assisted caregivers in developing disaster plans. However, while I was able to observe the development of three plans, logistical barriers prevented me from obtaining the desired number. The family nurse consultant (FNC) that I had been assigned was based out of Boca Raton, approximately an hour south of where I was located. I volunteered at adult day centers two to three days a week, which made coordination with the FNC more difficult at such a distance. I believe my research would have been strengthened had I been able to systematically observe how the ACC staff prompted caregivers to think about disaster planning. However, I was only able to conduct three observations with two different staff members, which were not enough to reduce reaction bias.
Semi-Structured Interviews with Staff (N=8)

Purpose
The purpose of the staff interviews was to: 1) gain insight into their perceptions of caregiver preparedness and needs; 2) tap into their knowledge of community resources for caregiver disaster planning; and 3) examine their understanding of which laws and regulations might influence a caregiver’s preparedness. I designed these interviews to provide context and to give insight into the disaster planning methods valued by the staff and of staff perceptions of caregivers’ disaster planning needs.

Procedure
I asked program managers and family nurse consultants to participate in a semi-structured interview. Semi-structured interviews require the use of a standardized interview guide (Bernard 2006: 211). I conducted seven of the eight interviews in the participants’ place of work (the remaining interview took place over the phone). The interviews lasted between 15-25 minutes. I recorded the responses by hand and immediately transcribed my notes.

Analysis
I coded the resulting transcripts for themes, using an inductive approach to develop codes within and among the quotes (Creswell 1998; LeCompte and Schensule 1999). During the open-coding phase of the analysis, I analyzed the texts for reoccurring themes, patterns, and structures (LeCompte and Schensule 1999). During the axial stage of analysis, I developed sub-codes to elucidate patterns within the over-arching themes.

Limitations
The eight interviews were a convenience sample, which means there may be sampling bias. However, there were only about 25 staff members who were qualified to do the
disaster plan intake forms (all nurses). The eight staff I interviewed represent 32% of the relevant staff. Concerns when doing interviews in person may induce response effects or expectancy effects, such as social desirability affect (Bernard 2006: 250). In other words, participants may feel that they ought to give researchers the answers that they want to hear. However, since this is a qualitative method, sampling bias is not detrimental to results, as with quantitative methods. Nonetheless, it remains a limitation. A second limitation is that I was unable to obtain ten interviews, as originally planned, and conducted only eight.

**Initial Baseline Disaster Plan Review (N=290)**

**Purpose**  
By reviewing caregiver disaster plans, I obtained baseline disaster preparedness data on both the caregiver and PWD populations. My review of disaster plans revealed how many caregivers planned on sheltering in their homes, how many planned on evacuating, and how many planned to utilize special-needs shelters. My review additionally allowed me to identify where staff might help caregivers improve their disaster plans.

**Procedure**  
I spent the month of March 2011 driving to each of the ten ACC adult day-care centers to meet staff, view the centers, and review the disaster plans each enrolled family had on file with the organization. I reviewed each chart for basic demographic data on both the caregivers and the PWD, and recorded their answers to the disaster plan intake sheets. I found inconsistencies in charts because some families who had been enrolled the longest sometimes had older, less detailed forms.
In total, I collected data from 290 charts at the ten ACC adult day-care centers located in Palm Beach, St. Lucie, and Martin Counties, Florida. The data included both basic demographics and the disaster plan on file for each dyad (the caregiver and the PWD for whom they provided care). I recorded basic demographic data, such as age, sex, and the relationship between the caregiver and the PWD.

I recorded whether dyads (PWD and caregiver) planned to evacuate or not (Yes/No) and where they intended to go if they did plan to evacuate. I also recorded whether they stated that they needed a shelter and if they needed transportation to safety. Caregivers reported whether or not the PWD was registered and up-to-date with the SafeReturns program (an identification bracelet provided in case the PWD becomes separated from the caregiver). The intake form also recorded whether either the caregiver or the PWD was dependent on equipment requiring electricity. Finally, the intake form documented where the dyad planned to go if their home was damaged by a hurricane (an open, fill-in-the-blank response).

I then reported the findings that follow to ACC staff at a meeting in April, 2011. I intentionally timed this analysis to allow for revisions of disaster plan intake procedures before the staff contacted caregivers for their annual hurricane season update in May, 2011. I scheduled an opportunity to revisit the in June, 2011, to assess any changes in disaster plans (more on this below).

Analysis

Using the SPSS statistical program, I ran basic frequencies to determine the demographic make-up of the caregiver and beneficiary populations. This allowed me to describe the gender and age breakdown of both caregivers and beneficiaries. Secondly, I ran a cross-tabulation of caregiver-to-beneficiary relationships, by caregiver sex. This
allowed me to determine if one relationship had a different gender breakdown than another (for example, whether or not spouse caregivers were more likely to be male than adult caregiver children). Third, I ran non-parametric t-tests to determine whether the age or sex of the caregiver associated with the decision to evacuate to an address out of town or to stay in the same area. “Age of the Caregiver” and “Age of PWD” were the only two continuous variables.

Limitations

Some charts were not complete, limiting the available data to be collected. Several disaster plans were missing information, such as whether the PWD was enrolled in SafeReturns or the location to which the dyad planned to evacuate. Some charts remained in the files even though the PWD had been discharged. I included these charts initially because I wanted to have the broadest impression of the disaster plans. I did not repeat this for the follow-up disaster plan review.

Follow-up Disaster Plan Review (N=259)

Purpose

My purpose in conducting this review was to determine if caregiver disaster planning had improved after the disaster plan intake sheet had been changed to distinguish between plans for Category 1-3 and Category 4-5 hurricanes (See Appendix to view the format and content changes between the two documents). As mentioned in the background chapter, hurricane categories are defined by their strength and the potential damage they can cause. Since higher categories are defined by more damage, I suspected that some caregivers might evacuate for more severe storms but not lower categories.
In addition to the change in the disaster plan intake form, I provided the staff with the baseline findings. My presentation emphasized the importance of disaster planning and discussed methods for improving caregiver disaster plans. I did this, in part, by providing statistics from the aftermath of Hurricane Katrina, which illustrated the disproportionate burden borne by elderly populations (see Literature Review).

**Procedure**

I viewed the disaster plan intake forms in patient charts at all ten adult daycare centers. I entered all data into an Excel spreadsheet, and compared simple frequencies with the 2010 disaster plan intake to see if more caregivers provided an evacuation plan (rather than leaving blanks). I reviewed fewer charts (N= 259) during this (2011) round of data collection, because not all were completed by June 1st. Furthermore, I had previously reviewed the charts of clients who were likely to be discharged from the program, which I did not do this time.

**Analysis**

I repeated the same analytical procedures as with the baseline disaster plan review. I ran basic frequencies to determine the demographic make-up of both caregiver and beneficiary populations. This allowed me to describe the gender and age breakdown of the caregivers and people with dementia.

**Limitations**

Not all staff members who administered disaster plan intake were at my presentation and were, therefore, not advised on the specific importance of disasters planning for people with dementia or how to probe when collecting data. Second, if the disaster plans seem to have improved, it might be because the instrument is more sensitive and captures more data, not because caregivers are inherently better prepared.
Finally, I could not observe the disaster plan intake in practice, so I do not know how well the staff probed for answers during the disaster plan collection.

**Caregiver Survey (N=253)**

**Purpose**

The caregiver survey allowed me to collect in-depth information on disaster preparedness and responses that were not available in the ACC charts. I used this information to triangulate data from the disaster plan reviews and caregiver interviews.

**Procedure**

I developed the survey in a collaborative effort with ACC administrative personnel. ACC staff administered the survey at the same time they conducted the 2011 disaster plan review with caregivers. Inclusion criteria required that the caregiver be currently providing care for a person with Alzheimer’s disease (or a related dementia) and currently receiving services from ACC.

From March until May, 2011, ACC staff in the adult day-care centers, along with a specially trained volunteer (a medical student who had passed an ACC background check) administered the caregiver survey at the same time that the disaster plan update was completed. I went to five centers to assist with disaster plan intakes and survey administration.

The first section of the survey collected demographic data about the PWD, including age, gender, year of dementia diagnosis, and mobility level (as a proxy for the progression of the disease). The second part of the survey asked demographic questions about the caregiver, including age, gender, and relationship to the PWD. This section also asked specific questions about the amount of social (formal and informal) support that caregivers received while caring for the PWD. I made an additional attempt in this
section to quantify caregiver burden by adapting one question from the widely-used Zarit Caregiver Burden Assessment: “Overall, how often do you feel burdened in caring for the PWD?” The survey also asked about caregiver employment status and two questions about caregiver hurricane experience and whether the PWD dementia was: 1) living with the caregiver during the hurricane, and 2) whether the PWD had a dementia diagnosis during the hurricane.

The third section of the survey included questions about disaster preparedness. For example, these included whether or not the dyad had a disaster kit, hurricane shutters, or impact-resistant glass; whether there was access to a generator; the type of housing, the year in which housing was constructed, including the number of stories of the housing, and the structure of the housing frame (wood or cinder block); and proximity of their home to water.

The fourth section asked questions that could help predict ease of disaster recovery. These included whether or not the dyad had homeowner’s or renter’s insurance and, if so, whether the policy included wind-protection or flood insurance. Caregivers were asked if they felt they had sufficient money to repair any damage caused by a hurricane. Finally, caregivers were asked to estimate their household income. (Refer to Appendix I for the complete list of questions).

**Analysis**
I used the survey to calculate simple frequencies, discussed in the Results chapter to follow. These frequencies give insight into the general level of preparedness in a large sub-section of the caregiving population at ACC.
Limitations
In order to obtain a statistically significant representative sample of the 1,100 families (at a 95% confidence interval), I calculated that 320 people must be surveyed. Unfortunately, I was able to procure only 253 surveys, meaning that my results cannot be generalized across the entire ACC population. However, the sample does provide a cross-section of the primary services provided by ACC: family nurse consultants, case management, and the adult day-care centers.

I noted that people were uncomfortable when asked to give their household income, and thus some staff members administering the survey did not ask for this information at all. As a result, much data is missing for this topic. Participants are only required to give income information if they are requesting government assistance. If they did not want financial assistance (or did not qualify), these data were not available for analysis.

Semi-Structured Interviews with Caregivers (N=20)

Purpose
I used caregiver interviews for two reasons. First, to explore their experiences in providing care during a hurricane to someone with dementia. These caregiver experiences illuminated issues of concern that could be further understood through the subsequent caregiver survey. Second, these interviews allowed me to triangulate my findings from the disaster plan reviews and caregiver surveys.

Procedure
I used the demographic information from the baseline disaster plan review to determine how many males and females/ Hispanics and non-Hispanics I needed to
interview to match the larger population trends. While I was volunteering at the adult day centers, I invited caregivers that fit the needed demographics. If some refused, I asked others. I had only one direct refusal, and two that did not meet me at designated times or did not return phone calls. I piloted a sample interview about disaster preparedness with three caregivers to identify and discuss unclear questions. After the initial disaster plan review in March, I collected interview data from a purposeful sample of 20 caregivers. I sampled caregivers who would reflect the general distribution of these groups in the larger population, choosing participants by their sex (20% male and 80% female), relationship to the PWD (20% spouses, 75% adult children, and 5% other family member), race (30% Black and 70% White), and ethnicity (30% Hispanic/Caribbean Islander and 70% non-Hispanic).

Of the twenty caregivers, the breakdown by sex amounted to four males and 16 females. In family relationships, there were four spouses (two wives, two husbands) and one other family member (a sister). The remaining familial relationships between caregivers and PWD were adult children (two sons and thirteen daughters). In terms of race, six caregivers were black and 14 were white. With ethnicity, two of the caregivers who identified as black were “Afro-Caribbean” rather than “African American.” I identified 6 caregivers as Hispanic or Caribbean Islander and 14 who were “non-Hispanic.”

Most of the caregivers (18 of 20) had family members in one of the three adult day-care centers at which I volunteered (Greenacres, Palm Beach Gardens, or Pahokee). A family nurse consultant recruited one additional participant, and the final caregiver was one I met on the road trip to Tallahassee. Of these last two, one lived north of Palm
Beach County, in Martin County. With the caregivers’ permission, I contacted each of them to set up a home visit. I conducted interviews in their homes, each of which took about an hour. I provided monetary compensation of $20 to each caregiver in exchange for his or her time, though four of the caregivers waived payment.

Analysis

I transcribed the resulting interviews and created Microsoft Word documents, which were divided to reflect categories of past hurricane experience and future hurricane plans. I coded for sub-themes, and in the discussion below, I elucidate salient themes.

For “past hurricane experience,” I coded for those who had hurricane experience at the same time their family member had been diagnosed with dementia. For those who had hurricane experience while living with someone with dementia, I divided their experiences into the following categories: 1) the hurricane as a neutral experience for PWD; 2) the hurricane caused problems for the PWD; and 3) shelter experiences.

Under the “hurricane as a neutral experience PWD” I noted three sub-categories: a) the PWD helped prepare for the hurricane; b) activities and distractions during hurricane; or c) the PWD did not notice the hurricane.

Under the “hurricane caused problems for the PWD” I also noted three sub-themes: a) the PWD could not help the caregiver prepare for the hurricane; b) the PWD resisted Evacuation; and c) difficulty with recovery. Under “shelter experiences,” I noted whether the shelter was: a) a “special needs shelter”; or b) a “regular shelter.”

Limitations

A limitation for this method is recall bias. The last hurricane to strike Florida was in 2005, meaning that caregivers attempted, during their interviews, to remember experiences from six years ago.
Disaster Literacy Measurement (n=20)

Purpose
Public health professionals and emergency managers are charged with 1) informing the public of risks and 2) convincing them to adopt risk-reducing strategies (Guion et al. 2007). In some cases, this is done through distribution of disaster preparedness materials. I designed this aspect of the research to evaluate how well caregivers understand such disaster preparedness materials. If someone does not understand a risk, or believes they are not at risk, he or she is less likely to try to reduce the risk.

Procedure
In the Newest Vital Sign (NVS) procedure, individuals are asked to read health-related materials (e.g., a medicine bottle) and then demonstrate the ability to use that material by answering questions (Weiss et al. 2005). The procedure developed by Brown (2010) is similar to the NVS, but with the following changes: 1) we incorporated a Wide Range Assessment Test (WRAT), which is a brief and basic assessment of literacy, and 2) we supplemented the “health related information” with disaster preparedness materials. As with the NVS, we asked participants to demonstrate their ability to comprehend and use the information we provided by answering questions about specific materials. The disaster literacy aspect of the interview consisted of two parts: 1) a short reading test (WRAT) (see below) and 2) a disaster literacy evaluation. I incorporated this literacy test into the qualitative interviews, with the goal not of generalizing literacy levels across the ACC population, but rather to yield rich, detailed data about each participant’s understanding and perceptions of the disaster preparedness materials.
The reading subtest if the WRAT includes the recognition and naming of letters and the pronunciation of out-of-context words. I used the WRAT to ensure that each participant had basic English literacy skills. This prevented illiteracy from being a confounder for disaster literacy. The WRAT is not a measure for health literacy or disaster literacy on its own.

I asked participants to read one side of a two-sided pamphlet on SpNS, produced by the Palm Beach Board of County Commissioners, entitled “Palm Beach County Special Needs Program” (2009). The pamphlet is disseminated in public places and is also accessible online. When each participant finished reading, I recovered the pamphlet and then proceeded to ask six questions about the article. During each caregiver interview, I handed the caregiver the document as a flat piece of paper, with the primary text side facing up. I then immediately asked six questions about the information the caregiver had read in the pamphlet. I recorded their answers and transcribed the results into a Microsoft Excel spreadsheet file.

Most of these questions were qualitative in nature, for example: “What is this article about/what is this article’s topic?”; “What services are provided at a special needs shelter during a hurricane?” and, “How does a person get to the special needs shelter?” (See Appendix I for a full list of questions).

Analysis

I analyzed disaster literacy in two stages. First, I analyzed the WRAT reading test and, following that, I analyzed the disaster literacy interview. First, I determined the Flesh-Kincaid reading level of the disaster preparedness document (Flesch 1948; Kincaid and Fishburne et al. 1975). Second, I administered the WRAT to ensure participants had a basic literacy in the English language (which has a possible score of 1-70). After the
caregivers had read the disaster preparedness literature, I asked them a series of questions about the information contained in the document. I created a rubric of questions and assessed them by the accuracy of the answers, scoring them on a level of 0-3 (0 being no answer, 1= attempted an answer but was incorrect, 2= partially correct answer, 3= fully correct answer). I added up these scores to create a “disaster literacy score” of each caregiver. I then ran a chi-square to determine if there was any correlation between the WRAT scores and the disaster literacy scores.

After each caregiver had read the pamphlet about SpNS (SpNS) in Palm Beach County, I then scored the correctness of each caregiver’s answer to each question. I numerically scored the qualitative questions by determining how accurately they understood the material. As mentioned above, scored the answers to the first five questions on a scale of 0-3, and scored the final question as either 0 or 1. The total score possible was 16 points, which would indicate a higher level of disaster literacy.

For the first question, “what is this article about?,” I gave caregivers a score of “3” if they stated that the article was about “special needs shelter services.” I gave caregivers a score of “2” if they did not state that the article was about SpNS specifically, but said that the article was about “shelters,” “emergencies,” or “hurricanes”. I gave caregivers a score of “1” if they attempted an answer but that answer was incorrect, for example, “it is about animals.” I gave caregivers a score of “0” if they did not answer the question at all. I repeated this scoring process for all of the questions about the article. Upon completion, I calculated the mean and mode of the scores and reported these for each question.
Limitations
Disaster literacy is a new term that has not yet been validated, and it may not be an effective tool for generalization about the larger population. Finally, because of the way in which I printed the pamphlet from the website, I handed each caregiver a flat piece of paper to read. I might have had different results had I handed them a folded pamphlet, which is the way it is intended to be distributed.

Final Group Interview with Administration: 12-22-2011

Purpose
The purpose of this group interview was to ask a small, key informant group of ACC administrators (n=3) about themes that I had found over the course of this study, in order to contextualize, triangulate and better understand my findings.

Procedure
I met with three ACC administrators in mid-December 2011 at the ACC headquarters. The participants included the President and CEO, the Vice President of Community Care Services, and the Chief Operating Officer. The format was informal and unscripted. I presented several questions based on my research findings. Questions and themes I specifically asked them to reflect upon included: 1) the history of the disease (senility, dementia and AD); 2) the narrative of a person with AD as being “a shell” of who they once were; 3) how, in an ideal world, they would like to see AD and related dementias addressed in the public and policy spheres; 4) initial findings on the increased difficulty with caregiver disaster response when the PWD was in the early stages of the disease; 5) the concept of “retrogenesis” and the parallels between the progression of AD
and childhood development; 6) how SpNS should be utilized and if it is possible to improve the system.

Analysis

The discussion was digitally recorded and transcribed. I grouped the responses by topic to explain the themes that I had seen emerging from the previous research findings.

Limitations. One member of the group clearly outranked the other two (being the organization’s CEO), which means some members might not have been as forthcoming.

Summary and Key Points

The primary research question was, “how do people caring for someone with dementia in the community plan for hurricanes?” and the methods described in this chapter were designed with this in mind. This research is a mixed-methods design, with data collection via participant observation, staff interviews (n=8), preliminary caregiver interviews (n=5), baseline chart/disaster plan review (n=290), intervention (presentation to staff and administration) and form revision, follow-up chart/ disaster plan review (n=259), caregiver survey (n=253), final caregiver interviews (N=15- total number of caregiver interviews 20), disaster literacy testing (n=20), and, finally, a group interview with ACC administration to contextualize the findings. The partnering organization is Alzheimer’s Community Care, which provides services in the Treasure Coast of Florida (Palm Beach, Martin and St. Lucie Counties).
Chapter 7: Results

In this chapter, I present the results of data collected through the methods described in the previous chapter. I begin by presenting the results from the staff interviews, which give an overview of staff perceptions of caregivers and PWD and caregiver disaster preparedness. Secondly, I present my findings from the baseline disaster plan review. I briefly discuss the presentation I provided for ACC staff, which included the results from the baseline review. I then present the results from the follow-up disaster plan review. The fourth part of this chapter includes the results from the caregiver survey, and fifth, the results from the caregiver interviews. Finally, I present the findings from a final group interview with ACC staff.

Throughout the chapter, I provide basic demographic information on the participants, including their credentials, such as Licensed Vocational Nurse (LVN), Registered Nurse (RN), and Program Managers who run the adult day centers (also required to be RNs).

Staff Interviews

The data for the eight interviews with ACC staff nurses were collected between February and April, 2011, and were intended to provide staff impressions of caregiver preparedness levels. Seven of the participants were female and one was male. The range in age was from 27 years to 63 years old, with an average of 45.6 years. Participants were asked about the length of time they had been employed at ACC, which has only been an
autonomous organization for 12 years. The average length of service that these nurses have worked for ACC is 4.5 years. Only 50% of the staff interviewed (four out of the eight) had been working at ACC for more than a year.

**Populations Served.**
Each staff member serves a different sub-set of the ACC population, either at an adult day care center or when providing family nurse consulting over in a particular geographic area. Their description of population served provided insight into how they gauged vulnerability and economic stability within their own sub-set of the ACC population, as they often described them in terms of those who were vulnerable and those who were not. The greatest number of clients served by a participant was 120, and the lowest was 30. The average number of clients served was 54.4 clients.

These staff members collectively represent approximately 455 clients out of the 1200 (38%) served at ACC. Four of the eight described the population they served as “lower income” and the other four described their population as “average to higher income”. Interviews revealed several factors that might complicate disaster planning attempts, including client income level, age, dementia diagnosis, living alone with dementia (“live-alones”), and being low in English language proficiency. The level of socio-economic status was based on the number of people who qualified for financial assistance for ACC services, versus those who were “private pay”. For example, one program manager described the majority of the population she served as “average income”. She qualified the statement: “They tend to have more monetary means than some of the people at the other sites…We have a lot of private pay clients” (LPN). Another staff member described the population she served as an “average” socio-economic background, but also indicated that the caregivers tended to be older.
Most of the caregivers are in the 70s [years of age]. They are mostly middle to middle-upper class. The only people who are really at risk are the “live-alones”. I would say that about of the 77 people I serve, there are about six people who have early onset dementia and live alone (FNC/RN).

Thus, even though this staff member identified her population as “average” on the financial spectrum, she quickly identified a second factor that might make disaster preparedness more difficult, with age as a primary factor. The second factor identified was the “live-alone” population, that is, people who have early onset dementia but do not have family members living with or near them.

Another staff member also described her population in terms of financial needs, stressing that even if a family did not qualify for financial assistance, that they might still have unmet needs:

Most of the patients and caregivers are Caucasian and middle class. Not a lot of financial assistance [requested]. A lot of the time, though, they have nice homes but not enough money to meet their daily needs. They often have too much to qualify for financial assistance but not enough to meet their needs for medications and supplies to care for someone with AD. I try to give them information on other community resources (Program Manager).

This description begins to show that there are no clear-cut distinctions within and between conceptions of socio-economic status. Caring for a PWD can mean an increase in costs for supplies, such as incontinence control (adult diapers, wipes), medications, and special dietary needs (Ensure and supplements).

Staff that described lower socio-economic population indicated that caregivers struggled to provide care for their family members:

Most are low income and have trouble getting proper resources to care for their loved ones. Day care is very important for them. I have about 100 cases... and only one or two of those cases have
the means to get everything they need to care for their family member. I deal with a lot of Spanish speaking clients (FNC).

This same staff member went on to describe how the socio-economic status of her clients impacted their disaster planning:

This [low income] influences disaster preparedness... most are not prepared when I go to their homes. Most don’t want to sign up for the special needs shelters. I go over proper preparation. They say they will stay home... but sometimes caregivers are not physically fit enough to put panels up [to protect their windows]. I tell them the dangers of caring for someone during a hurricane. They [the people with dementia] can become agitated (FNC).

The above statement begins to contextualize caregiver socio-economics as a challenge to disaster planning. The fact that caregivers might have health issues of their own might make disaster preparedness more difficult.

Another program manager, who works a more rural adult day care center, described his population in detail. He begins with a historical contextualization of his designated area:

Most of the people who originated here came in the 1920s and 1930s. They came from Georgia and Alabama mostly, to do farm work in sugar cane. This was before the civil rights movement and most of them were black. Many of them still have families here. A lot of their families now work in the sugar cane industry. Recently, things got worse. The hurricanes in 2004 and 2005 destroyed a lot of the crops. This last year, we lost some more in the freeze. They are talking about laying off more people. It is a very impoverished area and it is getting worse. So, most of the people in this area are largely uneducated. There is a lot of poverty. Then on the other side of the spectrum, some have A LOT of money; the people own the land and the sugar processing plants. The people who have money own the land...have been here four generations but they are usually white... they have been farmers for three or four generations here. Very nice people, you would never know that they were rich. But, all of the business folk in the area are white. The area is 90% black... but, at least since I have been here, there has not been a black mayor (Program Manager/LPN).
This program manager illustrates the link between historical, political, economic and racial tensions that have brought the populations he serves to their current situations. He goes on to discuss the economic consequences:

\[ I \text{ would say that most of the people who come to our program make only about } \$650-800 \text{ a month in government benefits. I am not sure about the caregivers, but with the lay-offs, it can only get worse. The unemployment rate right now is 20\%... that is what they show, but it is probably closer to 40\% (Program Manager). } \]

This was the only staff member interviewed who attempted to quantify the income levels that of his population, perhaps because the more rural location he served was more homogenous and generalizations somewhat easier to make. I confirmed that, according to the US Census, 21.5\% of all families were below the poverty level in 2009 in the city in which this program manager worked.

**Staff Hurricane Experiences**

Only three of the eight staff had been working at ACC during the 2004 and 2005 hurricane seasons. The experiences in the following quote are that of a program manager:

\[ [\text{Hurricane}] \text{ Jeanne [in 2004] hit us badly and it took part of the roof off of the facility here at the church [where the adult day care center is housed]. Part of the protocol is for the manager to come back after the hurricane and assess the damage to the building. We salvaged what supplies and activities we could and put them in our cars. We were only out of commission two days after the hurricane. We went to the county Senior Center and asked if we could temporarily have our adult day care there. They said yes. It would be hard for them to turn us away because we are serving seniors too and they are seniors in need (Program Manager/LPN).} \]

The first part of this program manager’s experience illustrates several aspects of ACC’s disaster response protocol. For example, depending on the adult day care center construction, staff brings client charts to the main office building for safe-keeping before a hurricane strikes. The main office is located in a sturdy building in West Palm Beach.
(built in 1997). Secondly, she stated that it was her responsibility to return to the center immediately after a storm to assess any possible damage. In this case, a damage-and-recovery plan had to be developed immediately since the program’s building had been damaged. If adult day care centers are not available and alternative structures are not available, then people with dementia have to stay at home with their families. This might prevent caregivers from returning to work, or hinder the caregiver’s own recovery plans. Fortunately, in this instance, the county Department of Senior Services (DOSS) was receptive to ACC’s needs and agreed to give them the space to continue running the dementia specific adult day care services. This staff participant continued to describe her experience working with DOSS:

We were there [at the Senior Center] for nine months while repairs were being done here. At first, I think the manager there was a little put out that we were using so much of their space, but it ended up being very beneficial for them too. They learned a lot about dementia care. They sometimes get someone with memory problems at their adult day care, but they are not really staffed or trained to deal with it. Once a person started wandering, they simply could not provide for them. We worked together and now they are my number one referral service (Program Manager).

For this participant, the 2004 hurricane season resulted in damage to the church in which the adult day care center was housed. She worked with her activities coordinator and the county DOSS to continue to provide care for the families enrolled in her adult day care center. While in the end the relationship between ACC and the county was strengthened as a result of the hurricane damage, there were some families who did not fare as well:

I, myself, was without power for a week at my house. [The activities coordinator] and I were pretty much working out of our cars at the Senior Center... At the time, most of the families were very well prepared for a hurricane and there was not too much damage. Their biggest fear was the closure of the adult day care center after it was damaged. There was one family though,
that had to evacuate because they lived in a mobile home park. They went to a hotel. The person with dementia became so stressed that she passed away. She simply could not understand why they could not stay in their home, where she was familiar and comfortable with it (Program Manager).

The above statement highlights the difficulty of evacuating a PWD: depending on the level of cognitive deficit it can cause increased agitation and, therefore, more behavior problems. In some cases, leaving one’s home might increase stress and as a result, morbidity and mortality. Evacuation can be particularly disorienting and stressful for a PWD (Dosa 2009).

A different program manager, who worked in a rural area located on the banks of Lake Okeechobee, described the aftermath of Hurricane Wilma in 2005.

*There was total devastation. Most of the buildings here are old and they are not up to code. There are a lot of poor people. I wasn’t here for [Hurricane] Francis, I was out of town on vacation when it hit. I could not get back. Wilma was a direct hit. It was bad. There was a lot of destruction. Not a lot of deaths, but a lot of property damage. The National Guard was here. The building across the street from us was used as a food and water distribution point*(Program Manager).

The program manager went on to describe the structural, socio-economic factors that created a unique vulnerability in the area that he served. The primary danger, the program manager noted, was the proximity to Lake Okeechobee, which flooded with devastating effects after a direct hit in 1926 and 1928. Though communication and infrastructure has improved, this rural area, which is also defined by racial and economic disparities, remains a largely underserved area in Palm Beach County.

*If we get hit by a Category 4, the dyke will break. There are already breaches that you can walk through. If we get hit by a Category 4, it will flood to Loxahatchee... not deep, not like a tsunami, but still. It is not maintained. We are kind of a forgotten area. When they do the traffic reports, they hardly ever talk about*
the bad accidents about here. The library here has a display on the 1928 hurricane. That was really bad. I don’t think it would be that bad again because we have better warning systems and better shelters. Also, people have cars and family in West Palm Beach that they can go to. The younger generation is relocating, so the other folks [people still in the Okeechobee area] have a place to go (Program Manager).

The above statement illustrates a continued neglect of poorer areas, which contribute to the very real risk of a breach of the dykes that hold Lake Okeechobee back from the homes built on its edge. These factors are the same that were cited as the root causes for the disaster wrought by Hurricane Katrina in New Orleans (Cutter 2008). A report from the Army Corps of Engineers confirms that Pahokee is in an area that is most vulnerable if the Herbert Hoover Dike fails (Army Corps of Engineers 2007), and a plan has been laid out to begin restoration of the dike in 2011. As of spring 2011, over 20 miles of cutoff wall in the 22-mile southeast section are under construction or have been completed”. Most of the culverts (devices which channel water) had been put in place in the 1930’s are in disrepair. The Army Corps of Engineers (2011) reports that they have been systematically replacing these culverts.

The final example of a staff experience during a hurricane is that of a Family Nurse Consultant (FNC). This nurse describes the shared duties with the other senior nurse consultant and the CEO of ACC:

My role varies. As a RN, I am responsible for going to the [special needs] shelter. We [the senior FNCs and the CEO] take shifts. During one season I was the relay contact person. There was a land line at my home. If calls came in, I would call to another state. We kept a list of people who were signed up to go the special needs shelters (FNC/RN).

This illustrates the different roles that ACC can take during a hurricane. Some of the more senior members are trained to assist in the SpNS.
Staff Perceptions of Hurricane Likelihood

The staff was asked, “How likely do you think it is that a hurricane will hit this area (scale of 1-10, with 10 indicating 100%)?” The answer to this question provided some (albeit limited) insight into staff risk perceptions. This question is also present in the caregivers’ survey, which allowed me to see any differences between staff and caregiver risk perception (there was not a difference, which will be addressed in the Discussion). The lowest risk perceived was that of the program manager, who rated the risk of a “direct hit to Palm Beach County” as a “2”. The program manager explained that though Florida would be impacted, the likelihood of a direct hit to Palm Beach County was low. This program manager went on to say that, “the periphery of nearby storms can be enough” and “we are likely to get tropical storms”.

Three staff members rated the likelihood of a direct hit to Palm Beach County as a “4”, or less than a 50% chance. Two other staff members felt that there was over a 50% chance or a storm directly hitting: a “6”. Those that gave a “6” rating both gave similar explanations: “we are probably due one” or, “it has been quiet the past few years…it is about time”.

The remaining two staff members felt that Palm Beach County was at a very high risk of being hit in the 2011 hurricane season. One gave the risk rating as “8”, shook her head slowly and said, “I have a bad feeling about this year… It has been so hot this winter. Very hot. Where I come from, we worry when it is a hot winter like this.” Indeed, the scientific evidence corroborates her opinion: a warm winter can mean that the oceans heat up earlier in the season, and are more likely to cause hurricanes (Trenberth, 2007).

Another staff member stated flatly, “I think it is a 10,” and quickly went on to explain:
It isn’t based on science... it is women’s intuition. We haven't had a good smack in the face in several years. You see all of the other problems going on Australia, New Zealand, Japan... Catastrophic disasters. It is about our turn. I feel uneasy (FNC/RN).

In summary, four of the eight staff members felt that there was a less than 50% chance of being hit by a storm in the summer of 2011. The four staff members felt there was over a 50% chance of the Treasure Coast being hit by a storm during the season. It is interesting to note that, though the midpoint of the 10 point risk scale was “5”, none of the staff actually gave an answer of “5”. In other words, none of the staff interviewed felt that there was a 50/50 chance of being hit by a storm; they felt that there was either a strong chance or a very low chance.

Staff Perceptions of Caregiver Hurricane Preparedness

Staff was also asked, “In your opinion, are most of the families participating in ACC well prepared for a hurricane when you meet with them? On a scale of 1-10, 1 being unprepared 10 being totally prepared, how prepared are most families for a hurricane strike in this area?” The following table displays the risk ratings given by the staff members contrasted with previous hurricane experience (if applicable).

<table>
<thead>
<tr>
<th>Hurricane Experience?</th>
<th>Current Caregiver Preparedness Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes, 2004-2005</td>
<td>5</td>
</tr>
<tr>
<td>No</td>
<td>6</td>
</tr>
<tr>
<td>Yes, 2004-2005</td>
<td>8</td>
</tr>
<tr>
<td>Yes, 2004-2005</td>
<td>7, but the live-alones are a 0</td>
</tr>
<tr>
<td>No</td>
<td>3</td>
</tr>
<tr>
<td>No</td>
<td>5</td>
</tr>
<tr>
<td>No</td>
<td>5</td>
</tr>
<tr>
<td>No</td>
<td>3</td>
</tr>
</tbody>
</table>

The statement from a program manager explains her rating as “5” for overall caregiver hurricane preparedness: “It has been a few years since we have had a hurricane and people are becoming more lax. They tell you that they have a plan but once you start to
question them, they really don’t have one, or it is not a realistic one”. This participant goes on to describe the weaknesses in some of the disaster plans that she has worked out with caregivers.

“They say they have shutters, but that is not always enough. I tell them about our experience here and the damage to the roof. I also tell them about how I was without power for a week and how the stores were closed for a while afterwards. I don’t know if they really think about that and how that can affect the person they are caring for.

She also provided suggestions for ACC staff to consider when helping caregivers develop their disaster plan: “I think we need to pay more attention to the disaster plan intake and ask them more questions. Are they prepared to be in a house that does not have electricity or water?” Asking these questions can help prompt the caregiver to think about their needs realistically, she explained. The LPN at the same facility rated the same population as a “6” on a scale of one to ten, and offered the following explanation: “They have a vague plan. They have taken some consideration of the person they are taking care of, but it is not always realistic”.

Another program manager rated his population’s preparedness as an “8”. This program manager stated that, “I don’t think there will be a loss of life. Most of it is property damage. Most can get out.” In response to the question of how well prepared clients are when they first met them, they stated, “Well, they say that they are [prepared]. Though, there are some things that you can’t know. Like one woman, during [Hurricane] Wilma, lost her whole house. It was made of cinderblock but it still just disintegrated.” This program manager, though outlining the vulnerabilities that face the area this program manager serves, also stated that most of the population this program manager serves feels they are prepared. This statement suggests that the risk perception of this
population might be low. The example of a cinderblock home that did not withstand the storm illustrates how even seemingly storm resistant homes might be damaged in a storm.

The fourth staff member, an FNC, rated her population’s preparedness as a “7” but qualified the answer with the statement, “but the live-alones are a ‘0’. Also vulnerable are the frail, elderly caregivers who have family out of state”. When asked if the caregivers were prepared when she first met them, she said:

Yes, there is a lot of working knowledge. Do they have a disaster plan? No. Do they know where their shelter is? No. But, they know about the publications, how to store water and stock up and food. Publix [grocery store] and Home Depot [home improvement store] are a great community resource. They give out the publications that list what people need. Most families have a support system that help them put up plywood on the windows if they do not have shutters (FNC/RN).

This is an interesting statement because it calls out basic assumptions about community preparedness: that people may be fairly well prepared even if they do not have a disaster kit or a plan to go to a shelter. She states that most people are prepared enough to weather a storm in their own home, pointing out that social networks can help them to storm-proof their home. However, she later went on to say, “a lot look at me like I am crazy when I ask them about a disaster kit. They don't see it as a necessity to keep it together. They think they have enough time to prepare”. This suggests that the population she serves does not consider themselves to be at risk. Whether this belief is realistic or not is impossible to discern, but on the face of it appears potentially unrealistic: storms can swiftly change direction and speed.

Another staff member explained how she tries to elicit more detailed responses and help caregivers to consider their disaster plans:
I ask them about their past experiences with hurricanes and what they did then, and that helps prompt them a bit. I ask them about what supplies they have. We contact the ‘live-alones’ when a hurricane is coming (FNC/LPN).

The “live-alone” population was a concern for several of the staff members. This participant voices her concern for this vulnerable population.

I worry about the ‘live-alones’. They are somewhat self-sufficient and only have the beginning stages of dementia. I wonder, will they become more disoriented and confused in the shelter? They are supposed to have a caregiver with them in the special needs shelters but they have no one (FNC/LPN).

In addition to “live-alones” being at risk for injury if they should try to shelter in their homes alone during and after a storm, they are also at risk if they are relocated to a shelter. She goes on to demonstrate the difficulty of addressing vulnerabilities and the desire of families to shelter in place in their home.

A lot of people don’t want to register for SpNS. I guess they want to be in the comfort of their own home. Maybe they are worried that their loved one will not react well to the change.

Another program manager rated her (overwhelmingly Hispanic) population’s preparedness at a “5”. She said that most were unprepared when she first met them, citing “cultural” factors:

If we are talking about it, most [caregivers] say they will worry about a hurricane when it comes. It is part of the [Hispanic] culture. We kind of take things at the last minute. I am a nurse, so I have to prepare, but a lot take it at the last second.

This staff member’s perception is noteworthy because she herself is Hispanic, and appears to identify with her clients (as seen in the use of the term “we”). Despite variation within and among Hispanic cultures, she identifies “waiting to the last minute” as a cultural trait.
Staff Perception of Caregiver Preparedness after ACC Participation

Staff was asked, “Do you think that level of preparedness changes with participation with ACC? How or why not?” All three staff who had worked at ACC during a hurricane, as well as two who had not, said that they felt clients’ disaster preparedness improves with participation with ACC. Two other staff members who have not worked at ACC during a hurricane felt that caregiver preparedness was unlikely to improve.

Staff who that felt their clients’ disaster planning improved with enrollment had various reasons for claiming so. One said that her clients became more prepared because, “we give them a lot of information” (Program Manager/LPN). She also described that one of the methods she used to improve disaster planning was to fill out the disaster planning intake forms every year, since telephone numbers for both the caregivers and emergency contacts often change. At many of the centers, staff contacts the families to ask if there are have been any changes to their plans and simply sign off if the caregiver says, “No change”. Unfortunately, this method can mean that the newer, more updated and detailed forms do not always get filled out, and changes to telephone numbers are not documented.

Another highlighted the information that ACC provides, including regarding shelters. However, she also stated that, “the majority of them don’t sign up for special needs shelters... the people who don’t sign up for the special needs shelters seem to have a strong social network or a lot of family support.” In this case, informal support was cited as a reason for declining to sign up for SpNS. However, when later asked what support systems caregivers might have (see section below), the same participant did not mention family or friends.
Another person elaborated on the importance of information reminders: “We create an additional awareness. On the initial assessment, we address [preparedness]. Then we review it every year. We are constantly pressing the issue” (FNC). She explains why this process is important: “It can be overwhelming when a hurricane hits and there is so much to think about. You not only have yourself to worry about, but your pets, your home...” She lists the safety issues that caregivers need to consider when preparing: “Have bleach, water in the bathtub. Put candles on the sink so things don’t catch fire. Have battery-powered fans. Get refills on medications. We call and remind them.”(FNC) Another staff member also felt that the annual disaster review and update helps caregivers because, “is a reminder that supplements and informs. We remind them that it is hurricane season.” Even with information, however, “most say they will just figure it out when it happens”.

Two staff members stated that they did not see a change in caregiver disaster planning from one year to the next; however, both had worked with ACC for a shorter time than the others. Thus, they seemed to be hazarding a guess, and a third simply stated that she had not worked with ACC long enough to know. One said, “I am thinking that the same people who didn’t have a clue before probably still won’t have a clue what they will do this year either,” but stated that she would not know for sure until the disaster plans were updated in a month (Program Manager). Another, a FNC who had been with ACC for just over a year, said, “I can’t tell you from experience, but from when I first did the intakes to the annual review of their disaster plans, they are pretty much the same. So, no.” She explained that when she asked caregivers to tell her about their disaster plans, “A lot of them tell me that ‘I would get in my car and drive to Alabama or something’,”
shaking her head. “During the last hurricanes, no one could get out. The freeway was a parking lot.” She shrugged, “others say that ‘my son will fly me to New York’, but that would take a lot of planning and I don’t think it is realistic. A lot of people figure that the building they are living in ‘has been here for decades so it should be fine’.” She sums up her assessment with the following statement, “They just don’t think anything will happen.”

Several of the staff seemed to indicate that there was a low level of risk perception among the caregivers they served, which in turn impacted their disaster plans. However, the staff, overall, did feel that the information that ACC provided to caregivers was beneficial in that it served to remind and inform them.

Staff Perceptions of Caregiver Support Networks

The staff was asked to identify caregiver support systems (other than ACC) for preparation, response and recovery. Most of the staff found this to be a challenging question. Five of the eight participants identified the American Red Cross as a potential support for caregivers. Interestingly, most of the staff mentioned only formal support networks. Only one staff member mentioned the church membership and none mentioned family or social networks.

Staff Perceptions of Caregivers’ Unmet Disaster Planning Needs

The staff was asked to identify unmet needs for caregivers during disaster preparation. This question elicited several categories of responses; finances, transportation, caregiver health and strength were identified as barriers. All of these impact the caregivers’ abilities to acquire supplies (i.e., have a disaster kit), secure their property, and/or evacuate to safety.
Finances were identified by five of the staff as a major barrier for proper disaster preparedness, even among those who identified their population as being of “average income”. One simply answered, “Finances. Having the proper means to get ready on top of the medical care they already have” as the biggest barrier to caregiver preparedness (FNC/LPN). Another explained that, “to stock up on food and water takes time and money,” which can both be rare commodities for a caregiver (Program Manager).

Another barrier to having a disaster kit was transportation, as pointed out by three of the staff members; one noted that, “they have trouble getting food because many do not have transportation. So, transportation in general.” (Program Manager). Additionally, transportation concerns can arise, even when one has a vehicle, since heavy traffic can block evacuation attempts:

*I’m not sure they take into consideration the difficulty of leaving town with all of the traffic and everything. I don’t think they realize how hard it is sitting on I-95 in a car for two hours is when you have a person with dementia with you. It takes more planning than the average person* (Staff Nurse)

Traffic concerns were mentioned by other staff members in responses to other questions. This response also suggests a lack of “realistic pre-planning” for people caring for someone with dementia. After a storm, transportation remains a concern, especially if a person does not have the proper supplies: “The [electrical] wires are down and they can't really drive (Program Manager).”

Furthermore, “many caregivers have health issues also” (Program Manager). This idea is corroborated by another staff member, who explained how elderly caregivers might have trouble carrying heavy canned goods and other supplies when a hurricane is eminent: “I tell them to buy an extra can of food for their disaster supplies every time
they go to the store, that way they do not have to buy all of the heavy goods all at once” (FNC/LPN). She also considered that these caregivers might have difficulty securing their homes before a hurricane: “Most are elderly and don’t have a lot of strength. They need handyman to help them”. Another staff member also suggested handymen as unmet need for elderly caregivers:

*I think what people need are handyman services. In an ideal world, there would be a community organization that helps the elderly to secure property, get their equipment inside, get the plywood up on the windows and remind them what they need to do to keep safe, like put water in the bath-tub* (FNC/RN).

The above statement outlines several steps with which elderly caregivers need assistance before a storm. Even if they are aware of what they need to do in preparation for a severe storm, they may be physically unable to do it.

**Staff Awareness of Laws and Policies**

To better determine the legal environment in which staff members and caregivers operate, staff was asked, “Which laws and/or policies have the most impact on caregiver disaster preparation?” Like the question about caregiver support networks, staff had a difficult time thinking of relevant laws or policies that might influence a caregiver’s disaster planning. Three participants stated they simply were not aware of any laws or policies; two others attempted an answer, but were unsure. Two identified building codes and permits for building repairs. Transportation was mentioned by two staff members, in that it is difficult to travel after a storm, since many roads are closed and curfews are in place. Of note, ACC staff has permission to travel after curfew:
Last year was my first experience with the disaster plan checklist. We do have a letter that gives us permission to come out to people’s homes, even when there is curfew. We show it to the National Guard.

Program managers and FNC staff have these letters so they can reach clients in need after a hurricane. They are classified as part of the “essential personnel” in Palm Beach County.

Summary of Staff Interview Findings

The staff interviews highlighted several issues that might complicate caregiver disaster planning: income level; age; dementia diagnosis; living alone with dementia (“live-alones”); and being non-English speakers. Socio-economic disparities remain a problem in many areas that ACC serves, most specifically, the Lake Okeechobee area. Staff revealed that past hurricane experiences illuminated historical, political, economic and racial tensions in the Lake Okeechobee area. Some members did not think that having a disaster kit is essential for caregiver preparedness.

Staff had difficulty identifying social support networks for caregivers, at least when they were asked directly about them. Most of the staff mentioned only formal support networks. Only one staff member mentioned the church membership and none mentioned family or social networks. However, staff did talk about informal support networks indirectly, in answer to other questions. Overall, most staff felt that participation in ACC improved caregiver disaster plans.

There is a great deal of confusion and ambivalence evident in staff responses about who should sign up for the SpNS and under what circumstances. A “last-resort” philosophy prevails; however, there is little explanation of what qualifies as a “last
resort” situation. Some factors can include lack of a social network, living in a mobile home, and living in a flood zone.

Factors that could prevent a family from adequate disaster preparation include finances, transportation, caregiver health and strength. All of these barriers impact the caregivers’ abilities to acquire supplies (i.e., have a disaster kit), secure their property, and/or evacuate to safety.

Staff indicated a low level of legal consciousness. They were only able to identify one relevant law or policy that might impact caregivers planning for a disaster; staff was considered essential personnel during a storm and had permission to travel to client homes to check on their status.

**Baseline Disaster Plan Review**

I conducted a baseline disaster plan review to obtain basic demographics on caregivers, PWD, and their disaster plans. The plan information was gathered on the basis of staff interviews with caregivers. Though ACC records some basic demographic information about the population, they did not have digitalized data on disaster plans. Thus, I went to each of the 10 adult day centers in St. Lucie, Martin and Palm Beach Counties and entered data on each disaster plan into an Excel file for analysis.

**Demographics of Persons with Dementia**

Of the 290 charts surveyed, 204 (70.3%) of the people with dementia were female and 86 (29.7%) were male. The average (mean) age of the PWDs was 82 years old. The two oldest PWD being served at the adult day care centers were over 100. The youngest was 47 years old. Even after removing the outliers, the average age remained about the same. Figure 5.2 below provides an overview of the age distribution.
Of the 290 caregivers, 71.4% (N=207) were female and 28.6% (N=83) were male, which is nearly a 3:1 female male ratio. Over half of the caregivers were the adult children of the people with dementia (52.1%). At 32.8%, the second most common relationship to the PWD was that of a spouse. Table 7.3 below provides an overview of these relationships.

**Table 7.3 Caregiver Relationship to PWD**

<table>
<thead>
<tr>
<th>Relationship of Caregiver</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spouse</td>
<td>95</td>
<td>32.8%</td>
</tr>
<tr>
<td>Child</td>
<td>151</td>
<td>52.1%</td>
</tr>
<tr>
<td>Other Family</td>
<td>34</td>
<td>11.7%</td>
</tr>
<tr>
<td>Other arrangement</td>
<td>10</td>
<td>3.4%</td>
</tr>
<tr>
<td>Total</td>
<td>290</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

I used the crosstabulation function in SPSS 19 to see if caregiver sex was differentiated by relationship to the beneficiary. This revealed a predominance of female caregivers, regardless of relationship category.
Table 7.4 Caregiver Sex and Relationship to PWD

<table>
<thead>
<tr>
<th>Relationship</th>
<th>Spouse</th>
<th>Child</th>
<th>Other Family</th>
<th>Other arrangement</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Femal e % within CG sex</td>
<td>29.0%</td>
<td>53.6%</td>
<td>14.5%</td>
<td>2.9%</td>
<td>100.0%</td>
</tr>
<tr>
<td>% within Relationship</td>
<td>63.2%</td>
<td>73.5%</td>
<td>88.2%</td>
<td>60.0%</td>
<td>71.4%</td>
</tr>
<tr>
<td>% of Total</td>
<td>20.7%</td>
<td>38.3%</td>
<td>10.3%</td>
<td>2.1%</td>
<td>71.4%</td>
</tr>
<tr>
<td>Male % within CG sex</td>
<td>42.2%</td>
<td>48.2%</td>
<td>4.8%</td>
<td>4.8%</td>
<td>100.0%</td>
</tr>
<tr>
<td>% within Relationship</td>
<td>36.8%</td>
<td>26.5%</td>
<td>11.8%</td>
<td>40.0%</td>
<td>28.6%</td>
</tr>
<tr>
<td>% of Total</td>
<td>12.1%</td>
<td>13.8%</td>
<td>1.4%</td>
<td>1.4%</td>
<td>28.6%</td>
</tr>
<tr>
<td>Total % across relationships</td>
<td>32.8%</td>
<td>52.1%</td>
<td>11.7%</td>
<td>3.4%</td>
<td>100.0%</td>
</tr>
<tr>
<td>% within Relationship</td>
<td>100.0%</td>
<td>100.0%</td>
<td>100.0%</td>
<td>100.0%</td>
<td>100.0%</td>
</tr>
<tr>
<td>% of Total</td>
<td>32.8%</td>
<td>52.1%</td>
<td>11.7%</td>
<td>3.4%</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

The most common caregiver relationship to the PWD was the adult child at 52.1% (N=151). The second most common caregiver relationship to a PWD is of a spouse, at 32.8% (N=95). Other family accounts for 11.7% (N=34). Of the spouses providing care for someone with dementia, 62.3% were female and 36.8% were male. Of the child caregivers, 73.5% are female and 26.5% are male, which is nearly a 3:1 female to male ratio. Caregivers who were in the “other family member” caregiver population were also primarily female. Female caregivers, who were usually either granddaughters or nieces, made up 88.2% of the “other family member” caregiver population. This leaves only 11.8 percent of the “other family” male caregivers (grandsons or nephews) who provide care for their family member with dementia. It was extremely rare for a legal guardian or friend to be the primary caregiver. In these cases, 60% were female (N=6) and 40% were male (N=4).
Caregiver Age
There was a good deal of missing data for the caregiver age in the charts (78 out of the 290 charts were missing these data). The total number of caregivers who had a recorded age in the ACC charts was 212 (73.1%). One of the reasons for age data being missing was that many of the older forms in the ACC charts did not include a question about caregiver age; therefore, people who have been with the program for over five years were unlikely to have this data recorded. In other cases, the caregiver may have refused to provide this data. In addition, some staff may have felt uncomfortable asking for caregiver ages.

Of the caregivers with data on age, the youngest was 26 years old and the oldest was over 90 years old. The average caregiver age was 62.8.

Caregiver Ethnicity and Race
ACC does record caregiver ethnicity on the face sheet of the chart. The caregivers are asked to self-report ethnicity and the staff member records it by circling one of the categories on the sheet. They differentiate ethnicities within the “Hispanic” category, such as “Puerto Rican” and “Cuban”. They also listed “Caribbean Islander” and “Jamaican” as other possible ethnicities. Since race and ethnicity are not a central factor in this research, and because the proportion of these individuals was fairly low, I simplified the data by combining the Hispanic categories. I also combined the “Jamaican” ethnicity with “Caribbean Islander”.

165
Table 7.5 Caregiver Ethnicity

<table>
<thead>
<tr>
<th>Caregiver Ethnicity</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Non-Hispanic</td>
<td>228</td>
<td>78.6%</td>
</tr>
<tr>
<td>Hispanic</td>
<td>51</td>
<td>17.6%</td>
</tr>
<tr>
<td>Caribbean</td>
<td>11</td>
<td>3.8%</td>
</tr>
<tr>
<td>Total</td>
<td>290</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

As the table illustrates, the majority (n=228, 78.6%) of the ACC adult day center clients were white, non-Hispanic. There was a sizeable Hispanic population when combined, making up 17.6% of the population (primarily from Cuba and Puerto Rico). Non-Spanish speaking Caribbean Islanders (such as those from Jamaica or the Bahamas) made up only 3.8% (n=11) of the total population.

Caregiver race was recorded on a form issued by the Department of Elder Affairs (“Prioritization Assessment Form”). This form is specific to the state of Florida and is used to determine funding eligibility to families; it includes basic demographics on both the “consumer” and the caregiver. It is unclear whether the racial category on the form, which does not differentiate between Hispanic and non-Hispanic White, was self-reported by the caregiver or was simply entered by the staff members.

Table 7.6 Caregiver Race

<table>
<thead>
<tr>
<th>Caregiver Race</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
<td>216</td>
<td>74.5%</td>
</tr>
<tr>
<td>Black</td>
<td>74</td>
<td>25.5%</td>
</tr>
<tr>
<td>Total</td>
<td>290</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

There were 216 (74.5%) caregivers who were recorded as “white” and 75 (25.5%) who were recorded as “black”. Again, no other categories were listed.

Baseline Disaster Plan Review

Caregivers are asked if they plan to evacuate their home when advised to do so by the government. Slightly over half, 51.7%, circled “No” and 47.9 circled “Yes” (one
answer was missing). Whether those who plan to stay in their homes want to stay because they believe it to actually be a safe option remained unclear, since caregivers were not asked about the safety of their home. Furthermore, it was unclear if they would have the same plan for a Category 2 hurricane as for a Category 5.

In the space given to write their evacuation plans, only 54% (n=157) provided an answer. This leaves 46% (n=134) who did not write anything. Table 5.7 provides an overview of the responses. Of the 157 people who did provide an evacuation plan, the most common response (55, 35%) was that they would drive out of the area. As noted earlier, ACC staff has expressed concern about the viability of this plan, since traffic can bring evacuation to a standstill. Also unanswered is where they will go once they have driven out of town, since hotel rooms become scarce when a hurricane threatens.

Table 7.7 Hurricane Plan

<table>
<thead>
<tr>
<th>Plan</th>
<th>Number</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Drive Out of Area</td>
<td>55</td>
<td>35%</td>
</tr>
<tr>
<td>Family’s House</td>
<td>41</td>
<td>26%</td>
</tr>
<tr>
<td>Go to a Shelter</td>
<td>40</td>
<td>25%</td>
</tr>
<tr>
<td>Other</td>
<td>10</td>
<td>6%</td>
</tr>
<tr>
<td>Depends on Category of Hurricane</td>
<td>7</td>
<td>4%</td>
</tr>
</tbody>
</table>

The second most common plan was to go to a family member’s home. Again, the data does not reveal the location of the home or if the family member’s home is safer or not.

Perhaps the most interesting and relevant finding for the current study is that 40 caregivers reported that they planned on going to “a shelter”. When one compares this number to those who are signed up for a special needs shelter (SpNS), there is a disparity: only 10 of these 40 individuals are signed up for a special needs shelter. In other words, there are 30 people who may need to go to a special needs shelter, but are not signed up for one.
Through participant observation and caregiver interviews (discussed in more detail below), I discovered several reasons for these low numbers of SpNS registrations. First, some caregivers have a negative impression about how SpNS operate (they are often chaotic, do not take pets, and do not provide bedding). A second reason is that staff was unclear or ambivalent about suggesting the use of a SpNS, because there is no formal mechanism for determining who “needs” to use this service. County professionals and ACC staff frequently discourage using these shelters (which will be addressed in the discussion) because it is seen as “an option of last resort”. Some staff seemed unclear on how to determine when a client has no other option than to go to a SpNS. Third, there are simple service-related reasons in some counties for avoiding the use of SpNS: Martin and St. Lucie Counties do not have a dementia-specific component in their SpNS, rendering them less appropriate than the SpNS in Palm Beach County.

**Safe Return Enrollment**

Safe Return is a program that provides a registry of PWD and their caregivers. Like MedicAlert for people with health conditions, SafeReturns provides a bracelet (or another piece of jewelry, such as a necklace) with contact information that can reunite a caregiver with the PWD should they become separated. ACC staff encourages families to enroll in this program as a preventative measure during a disaster event, such as a hurricane. I found that 58.3% of the people with dementia were registered with SafeReturns during the baseline disaster plan review. This number ought to be higher, as the goal, according to ACC staff, is that all families be enrolled in SafeReturns. I did note that nearly all of the caregivers had been given information on SafeReturns and had received several follow-up phone calls to remind and encourage participation.
Table 7.8 Safe Return Enrollment
(During Baseline Review:)

<table>
<thead>
<tr>
<th>Registered with Safe Return?</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>121</td>
<td>41.7</td>
</tr>
<tr>
<td>Yes</td>
<td>169</td>
<td>58.3</td>
</tr>
<tr>
<td>Total</td>
<td>290</td>
<td>100.0</td>
</tr>
</tbody>
</table>

Transportation to Safety
Most of the caregivers did not feel that they needed assistance with transportation in the event of an evacuation. Of those who stated they were evacuating (n=71), only 7 (10%) reported that they needed help with transportation. The vast majority, 91% (n=263) reported that they had medications and information ready to take with them, should they need to evacuate. Dependence on electrical equipment was not a large concern for this population as only 3.4% (n=10) gave an affirmative answer.

The question, “Where will you go if your home is damaged?” seeks to gain information on caregiver’s disaster recovery plan. The most common answer (38%) was to give an address in the same city as the caregiver’s own home. The second most common response, 27%, was to leave the area blank or write “don’t know”. Another area in Florida was cited as the destination of 10% of the caregivers and 5% planned on going to an out of state address.

Table 7.9 Location if home is damaged

<table>
<thead>
<tr>
<th>Location if home damaged</th>
<th>#</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Address in the same city</td>
<td>111</td>
<td>38%</td>
</tr>
<tr>
<td>No plan/blank</td>
<td>106</td>
<td>27%</td>
</tr>
<tr>
<td>Another area in Florida</td>
<td>28</td>
<td>10%</td>
</tr>
<tr>
<td>Out of state address</td>
<td>15</td>
<td>5%</td>
</tr>
<tr>
<td>Another explanation</td>
<td>2</td>
<td>1%</td>
</tr>
</tbody>
</table>

It should be noted that many of these options have drawbacks. For example, if a person plans to go to a neighbor’s home if their own is damaged, they assume the other homes in
the area have not been affected. It probably not a safe assumption to make, considering hurricane damage can cover an entire area. We also do not know if this proposed arrangement had been discussed with the other party. The fact that 37% (n=106) do not have a plan if their home were damaged and became unlivable is a concern that can be a barrier to recovery after a hurricane. Another concern is that 5% (n=15) plan on living at a hotel until the damage is repaired. It is unclear if they can afford the cost of a hotel for up to several months, or if there will be long-term hotel rooms available.

To determine whether caregivers’ age impacted their decision to sign up for a special needs shelter, I ran a non-parametric test. I had hypothesized that age would be correlated with a higher rate of shelter needs. More specifically, I suspected that older caregivers would be more likely to need a shelter because they might have medical or frailty-related needs of their own. This hypothesis was not supported, however, since the distribution of caregiver age was found to be the same across those that needed shelter.

Table 7.10 Caregiver Age and Shelter Needed

<table>
<thead>
<tr>
<th>Hypothesis Test Summary</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Null Hypothesis</strong></td>
</tr>
<tr>
<td>The distribution of CG AGE is the same across categories of Evac Shelter Needed?</td>
</tr>
</tbody>
</table>

Asymptotic significances are displayed. The significance level is .05.

Caregiver age does not affect whether or not an evacuation shelter is needed. This might be because the number of people who actually reported that they needed a shelter was very small (n=40).
Summary of Baseline Disaster Plan Review Findings

Of the 290 caregivers, most were female at a 3:1 female to male ratio. Over half of the caregivers were the adult children of the people with dementia. The second most common relationship to the PWD was that of a spouse. In the space given to write their evacuation plans, only 54% (n=157) provided an answer. This leaves 46% (n=134) who did not write anything. Of the 157 people who did provide an evacuation plan, the most common response was that they would drive out of the area. As noted earlier, staff has expressed concern about the viability of this plan, since traffic can bring evacuation to a standstill. Also unanswered is where they will go once they have driven out of town, since hotel rooms become scarce when a hurricane threatens. Caregivers are asked if they plan to evacuate their home if they are advised to do so by the government. Over half, 51.7%, circled “No” and 47.9 circled “Yes.

Forty (40) caregivers reported that they planned on going to “a shelter”. When one compares this number to those who are signed up for a special needs shelter (SpNS), there is a disparity: only 10 of these 40 individuals are signed up for a special needs shelter. In other words, there are 30 people who need to go to an evacuation shelter, but are not signed up for a special needs shelter.

I found that 58.3% of the people with dementia were registered with SafeReturns during the baseline Disaster Plan Review. This number ought to be higher, as the goal, according to ACC staff, is that all families be enrolled in SafeReturns.

Most of the caregivers did not feel that they needed assistance with transportation in the event of an evacuation. The vast majority, 91% (n=263) reported that they had medications and information ready to take with them, should they need to evacuate.
Dependence on electrical equipment was not a large concern for this population as only 3.4% (n=10) gave an affirmative answer.

The question, “Where will you go if your home is damaged?” seeks to gain information on caregiver’s disaster recovery plan. The most common answer (38%) was to give an address in the same city as the caregiver’s own home. The second most common response, 27%, was to leave the area blank or write “don’t know”.

**Intervention with Staff/Presentation of Baseline Findings and Form Modification**

Following completion of the first five caregiver interviews (which will be presented later this chapter) and the baseline disaster plan review, I suggested changes to the ACC disaster plan checklist. One of the administrators worked with me to reformat the disaster plan checklist so that it now asked for different plans depending on the Saffir-Simpson Wind scale category (See Appendix II and Appendix III to see the differences between older and the updated forms). I also presented the aforementioned (baseline) findings to ACC staff at a quarterly meeting in April. I highlighted concerns such as low Safe Return enrollment and the low number of responses to the disaster plan. It appeared that there had been a lack of probing for complete answers when filling out the disaster plan checklist with families. The previous technique for updating the disaster plan checklist was for a staff member to contact families and ask if there had been any changes to their plan in the past year. Many caregivers would respond in the negative (“no change”). Unfortunately, this method can mean that the newer, more updated and detailed forms do not always get filled out, and changes to telephone numbers are not documented without prompting.
The updated form was implemented in May, right before the annual disaster checklist review. Staff collected disaster plans and updated charts from April-June 1\textsuperscript{st}. In the month of June, I completed a follow-up disaster plan review to see if there had been any improvements.

During the baseline disaster plan review, I included charts that remained in the file but the PWD was scheduled to be discharged. I included these charts initially because I wanted have the broadest impression of the disaster plans as possible. I did not repeat this for the follow-up disaster plan review because I wanted to see what existing disaster plans were on file. Furthermore, there was a decrease in the N because not all of the caregivers had been reached for the disaster plan interview by June 1\textsuperscript{st}. The N was reduced from 290 in the baseline, to 259 in the follow-up (a loss of 39 cases).

**Follow-up Disaster Plan Review**

**Age of PWD**

It was not expected that the demographics of this population would change to a large degree between March and June; however, basic comparisons were made to establish the overall continuity. In March, the mean age of people with dementia was 82. There was a slight drop in the mean age in the June review, to 81.3, however, the drop was not statistically significant.

In March, there were 29.6% (n=86) males and 70.3% (n=204) females out of the 290 PWD. There was a slight increase in the male population during the June review to 35% (90) and a corresponding a decrease in the female population, 64% (n=166) of the total 259 (there were three missing data). Regardless, the ratio of females to males remained relatively close to 3:1.
Table 7.11 Males Caregivers compared to Female Caregivers

<table>
<thead>
<tr>
<th></th>
<th>March Frequency</th>
<th>March Percent</th>
<th>June Frequency</th>
<th>June Percent</th>
<th>Change</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>86</td>
<td>29.6%</td>
<td>90</td>
<td>35.2%</td>
<td>+5.6%</td>
</tr>
<tr>
<td>Female</td>
<td>204</td>
<td>70.3%</td>
<td>166</td>
<td>64.8%</td>
<td>-5.6%</td>
</tr>
<tr>
<td>Total</td>
<td>290</td>
<td>100%</td>
<td>256</td>
<td>100%</td>
<td></td>
</tr>
<tr>
<td>Missing</td>
<td>0</td>
<td></td>
<td>3</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Caregivers

The records for caregiver age greatly improved in June review, with only 13 missing data compared with 78 in March. In March, the average caregiver age was 62.8, while in June it was slightly lower at 60.8.

Table 7.12 Caregiver Age Bar Graph

In March, females made up 71.4% (n=207) of the caregivers and males 28.6% (n=83). In June, the number of female caregivers increased slightly to 74.1% (n=192) and males decreased to 24.7% (n=63). There were four data missing in this category.

The adult children of the PWD continued to be the primary caregivers at 54.3% (n=138); in March they were at 52.1%, indicating a slight increase in adult children as caregivers. Spouses were the second most common caregivers at 30.3% (n=77) (March 32.8%). “Other family”, such as nieces, nephews, grandchildren, or parents, made up 11.8%
(n=30) of the caregivers and “other arrangement” was 3.5% (n=9) (in March other family was 11.7 and other arrangements were 3.4%).

Since the changes in demographics changes remained minimal, it is unlikely that performing a caregiver sex by relationship to caregiver crosstabulation (chi-square) would reveal anything new. For this reason, it was not performed as it was on the baseline data.

**Safe Return Enrollment**

The Safe Return enrollment showed a significant improvement. In my April presentation to ACC staff, I expressed concern with the low Safe Return enrollment. At the time, only 58.3% (n=169) of the participants were enrolled in the program. By June, the enrollment had increased to 75% (n=192 out of the total 259). This is an increase of 16.7 percent.

<table>
<thead>
<tr>
<th></th>
<th>March Frequency</th>
<th>March Percent</th>
<th>June Frequency</th>
<th>June Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>121</td>
<td>41.7%</td>
<td>64</td>
<td>25%</td>
</tr>
<tr>
<td>Yes</td>
<td>169</td>
<td>58.3%</td>
<td>192</td>
<td>75%</td>
</tr>
<tr>
<td>Total</td>
<td>290</td>
<td>100%</td>
<td>256</td>
<td>100%</td>
</tr>
<tr>
<td>Missing</td>
<td></td>
<td></td>
<td>3</td>
<td></td>
</tr>
</tbody>
</table>

The number of individuals who live in evacuation zones was not expected to change much. However, with the new form, I hoped that there would be more emphasis on describing the plan if the family decided to evacuate. In March, 47.9% (n=139 out of 290) planned to evacuate their homes. In June, we asked whether the caregivers would evacuate for a Category 1-3 hurricane on the Saffir-Simpson scale (which was provided to staff). In response, 32.4% (n=83) said that they would evacuate, and the other 67.6% (n= 173) would remain in their homes (three cases were missing data). However, when asked if they would evacuate for a Category 4-5 storm, the number of people who
planned to evacuate sharply increased to 67.2% (n=174). A remaining 32% said they would remain in their home regardless of the category.

Table 7.14 Evacuating for a category 1-3 Storm? Evacuating for 4-5?

<table>
<thead>
<tr>
<th></th>
<th>Frequency</th>
<th>Percent</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>173</td>
<td>67.6%</td>
<td>82</td>
<td>32.0%</td>
</tr>
<tr>
<td>Yes</td>
<td>83</td>
<td>32.4%</td>
<td>174</td>
<td>68.0%</td>
</tr>
<tr>
<td>Total</td>
<td>256</td>
<td>100%</td>
<td>256</td>
<td>100%</td>
</tr>
<tr>
<td>Missing data</td>
<td>3</td>
<td></td>
<td>3</td>
<td></td>
</tr>
</tbody>
</table>

Forty-nine caregivers out of the 256 (19.1%) reported that they needed shelter in the event of a hurricane. Of these, only 3.5% said that they needed transportation to the shelter. These numbers remained low, as they did in the baseline disaster plan review.

Most of the caregivers reported that they would not evacuate. 12.1% of caregivers reported that they would evacuate to a city other than the one in which their home was located. 5.5% said they would go to another state. The third most common response was to go to a regular shelter (5.1%). SpNS accounted for only 2%. This is similar to the findings during baseline review. Staff continued to find it difficult to decide when and if it was appropriate to have a family sign up for a SpNS or not. Reasons for this ambivalence will be addressed below.

Recovery

Caregivers were asked where they would go if their home were damaged during a hurricane. Out of the 255 responses, the most common (38.8%, n=99) was to name a city in Florida other than where their home was located. This is likely to be the most logical choice, since hurricane damage is often localized. If one’s own home is damaged, other homes in the neighborhood and city are likely to be damaged as well. However, in the baseline data, this was not a common response at all: only 10% (n=28) planned to stay at
an address located in another area of Florida. This shift in recovery planning is an improvement of 28.8%. (I would like to believe this is due the presentation of facts at the “intervention presentation”. I suggested that staff probe more and ask caregivers to think about friends and family who lived in other cities).

However, the second most common response (25.9%, n=66) in the June survey was to name a location in the same city. In the baseline data, caregivers most commonly expected to recover in the same city as their damaged homes. It is an improvement that this answer decreased from 38% (n=111) to 25.9%, since, as stated above, locations in the same zip code are more likely to have sustained the same impact of the storm as the damaged home. The third most common response, (16.1%, n=41) was to go to a location in another state. Previously, 8% (n=23) gave an out of state address.

15.3% (n=39) either did not respond or said that they had “no idea” what where they would stay if their home were damaged in a hurricane. This is a large decrease from the original 37% (n=106), who stated that they did not have a plan if their home were damaged and became unlivable. The remaining 3.9% (n=10), reported that they would stay in a hotel. In the baseline data, 5% (n= 15) planed on living at a hotel until the damage was repaired.

Table 7.1 Destination if Home is Damaged

<table>
<thead>
<tr>
<th>Destination if Home is Damaged (Recovery)</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>“No idea”</td>
<td>39</td>
<td>15.3%</td>
</tr>
<tr>
<td>Same city</td>
<td>66</td>
<td>25.9%</td>
</tr>
<tr>
<td>Different city in Florida</td>
<td>99</td>
<td>38.8%</td>
</tr>
<tr>
<td>Out of state location</td>
<td>41</td>
<td>16.1%</td>
</tr>
<tr>
<td>Hotel</td>
<td>10</td>
<td>3.9%</td>
</tr>
<tr>
<td>Total</td>
<td>255</td>
<td>100%</td>
</tr>
<tr>
<td>Missing</td>
<td>4</td>
<td></td>
</tr>
</tbody>
</table>
Summary of Follow-Up Disaster Plan Review Findings

The follow-up disaster plan review, completed in June 2011, revealed that females remained the primary caregivers. The adult children of the PWD continued to be the primary caregivers at 54.3% (n=138); (in March they were at 52.1%, indicating a slight increase in adult children as caregivers). Spouses were the second most common caregivers at 30.3% (n=77) (March 32.8%). Records for caregiver age greatly improved in June review, with only 13 missing data compared with 78 in March. In March, the average caregiver age was 62.8, while in June it was slightly lower at 60.8.

In the presentation to ACC staff, I expressed concern with the low Safe Return enrollment. Only 58.3% (n=169) of the participants were enrolled in the program. By June, the enrollment had increased to 75% (n=192 out of the total 259). This is a significant increase of 16.7 percent.

In March, 47.9% (n=139 out of 290) planned to evacuate their homes. In June, we asked whether the caregivers would evacuate for a Category 1-3 hurricane on the Saffir-Simpson Wind Scale. In response, 32.4% (n=83) said that they would evacuate, and the other 67.6% (n= 173) would remain in their homes (three cases were missing data). However, when asked if they would evacuate for a Category 4-5 storm, the number of people who planned to evacuate sharply increased to 67.2% (n=174). A remaining 32% said they would remain in their home regardless of the category of the storm. This new form better captured the nuances of caregiver disaster planning.

Caregiver Survey

The survey collection, unlike the disaster plan review, was not restricted to families receiving services from adult day centers. The survey was designed to augment
information found in the disaster plan review and to obtain other information that was not available in the charts.

A total number of 253 surveys were collected. The majority of the surveys, 26.1% (n=66), were collected by the family nurse consultants (FNCs) from ACC beneficiaries who did not attend adult day care. Case managers provided nine surveys for individuals who were joining ACC between April and June, 2011 (3.6%). Adult day care center staff collected the remaining surveys. PWD who lived alone were not surveyed. The survey, though it includes information from the adult day centers, draws from a different population, which changes the demographic layout of the results.

**Mobility of PWD**

Most (52.6%) of the PWD who were participating with ACC could walk without help (n=133). Another 36.4% (n=92) could walk with some assistance, for example, a cane or a walker. There were some (6.7%, n=17), who needed the use of a wheelchair for mobility, however, they could still bear weight and pivot for transferring between the wheelchair to toilet or another chair. The remaining (4.3%, n=11) required total assistance with transferring and mobility. Once a client reaches this stage, they are no longer qualified for adult day center services and, therefore, are less likely to show up in the surveyed population.

**Table 7.16 PWD Mobility**

<table>
<thead>
<tr>
<th>PWD Mobility</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Can walk without help</td>
<td>133</td>
<td>52.6%</td>
</tr>
<tr>
<td>Walks with assistance (cane or walker)</td>
<td>92</td>
<td>36.4%</td>
</tr>
<tr>
<td>Requires wheelchair but can bear weight</td>
<td>17</td>
<td>6.7%</td>
</tr>
<tr>
<td>Requires total assistance</td>
<td>11</td>
<td>4.3%</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>253</strong></td>
<td><strong>100%</strong></td>
</tr>
</tbody>
</table>
Caregiver Demographics

The caregiver gender ratio from this population differed from the disaster plan review population (all of whom received adult day center services). The caregivers in this population are 62% (n=157) female and 38% (n=157) male. The most common relationship between the caregiver and the PWD in this population was that of spouse (48.6% (n=123)). The second most common relationship was that of adult child (38.7% (n=98)). Caregivers who reported that they were “family” but not a spouse or child (i.e. “other family”) accounted for 8.5% (n=22). Friends or legal guardian made up the remaining 4% (n=10).

Employment Status of Caregivers

The majority of caregivers, 47.8% (n=121), stated that they were retired and therefore not employed. The second most common response was full time employed,

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15 See Chapter 8 for a discussion of the differences between the population and comparisons with the US population in general.
consisting of 29.8% (n=75). Another 14.7% (n=37) stated that they were not employed, but also not retired; this means they might have been out of work, on disability, or chosen to quit their job, among other possible explanations. The remaining 7.5% (n=19) stated that they worked part-time. One survey was missing this information.

Table 7.18 Employment Status of CG

<table>
<thead>
<tr>
<th>Employment Status of Caregiver</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employed full time</td>
<td>75</td>
<td>29.8%</td>
</tr>
<tr>
<td>Employed part time</td>
<td>19</td>
<td>7.5%</td>
</tr>
<tr>
<td>Not employed because I am retired</td>
<td>121</td>
<td>48.0%</td>
</tr>
<tr>
<td>Not employed because of another reason</td>
<td>37</td>
<td>14.7%</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>252</strong></td>
<td><strong>100%</strong></td>
</tr>
<tr>
<td>Missing</td>
<td>1</td>
<td>.4%</td>
</tr>
</tbody>
</table>
Living Arrangements
Most of the caregivers, 94.5% (n=239) physically lived with the PWD. Only 5.5% (n=14) lived in another location.

Table 7.19 Caregiver living with PWD

<table>
<thead>
<tr>
<th>Live with Person with Dementia</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>14</td>
<td>5.5%</td>
</tr>
<tr>
<td>Yes</td>
<td>239</td>
<td>94.5%</td>
</tr>
<tr>
<td>TOTAL</td>
<td>253</td>
<td>100%</td>
</tr>
</tbody>
</table>

Assistance from Others
Most caregivers, 41.0% (n=100), reported that they received help providing care from family and friends. However, 33.2% (n=81) reported no support, either informal or formal. Caregivers who relied on professional, paid caregivers alone consisted of 23.0% (n=56) of the responses. Other types of help (perhaps volunteers) were available to 2.8% (n=7) of the caregivers surveyed.

Table 7.20 Caregiver Help Providing Care

<table>
<thead>
<tr>
<th>Help providing care?</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>No, I am the only caregiver</td>
<td>81</td>
<td>33.2%</td>
</tr>
<tr>
<td>Yes, I have help from family and friends</td>
<td>100</td>
<td>41.0%</td>
</tr>
<tr>
<td>Yes, I have help from professional caregivers</td>
<td>56</td>
<td>23.0%</td>
</tr>
<tr>
<td>Yes, I have access to other types of help</td>
<td>7</td>
<td>2.8%</td>
</tr>
<tr>
<td>TOTAL</td>
<td>244</td>
<td>100%</td>
</tr>
<tr>
<td>Missing</td>
<td>9</td>
<td>3.6%</td>
</tr>
</tbody>
</table>

However, when the caregivers were asked how many hours of help they received per week, most, 40.1% (n=101), reported that it was less than three hours. The second most common response, conversely, was from caregivers who received over 30 hours of help a week 18.7% (n=47). 10-20 hours a week was the third most common response at 15.1% (n=38). Those who received less than 10 hours a week made up 12.7% (n=32) of the
responses. Less than 5 hours a week of help accounted for 8.3% (n=21). Between 20-30 hours was 5.2% (n=13).

7.21 Hours of Help

<table>
<thead>
<tr>
<th>Hours of Help</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Over 30 hours a week</td>
<td>47</td>
<td>18.7%</td>
</tr>
<tr>
<td>Between 20-30 hours a week</td>
<td>13</td>
<td>5.2%</td>
</tr>
<tr>
<td>Between 10-20 hours a week</td>
<td>38</td>
<td>15.1%</td>
</tr>
<tr>
<td>Less than 10 hours a week</td>
<td>32</td>
<td>12.7%</td>
</tr>
<tr>
<td>Less than 5 hours a week</td>
<td>21</td>
<td>8.3%</td>
</tr>
<tr>
<td>Less than 3 hours a week</td>
<td>101</td>
<td>40.1%</td>
</tr>
<tr>
<td>Total</td>
<td>252</td>
<td>100</td>
</tr>
<tr>
<td>Missing</td>
<td>1</td>
<td>.4</td>
</tr>
</tbody>
</table>

Table 7.22 Caregiver Hours of Help
Caregiver Health Issues

Fortunately, fewer caregivers reported health problems that interfered with their ability to provide care for a PWD (26.5% or n=67) than those who did have health barriers (73.5% or n=186).

Table 7.23 Health Barriers to Providing Care

<table>
<thead>
<tr>
<th>Health Barriers?</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>186</td>
<td>73.5%</td>
</tr>
<tr>
<td>Yes</td>
<td>67</td>
<td>26.5%</td>
</tr>
<tr>
<td>Total</td>
<td>253</td>
<td>100</td>
</tr>
</tbody>
</table>

Caregivers were asked how they would rate their level of social support on a scale of 0-10. Some caregivers had trouble answering this question and asked for clarification. A number, however, reported little or no support.

Table 7.24 Caregiver Social Support Rating Bar Graph
Caregiver Burden

In addition to the social support question, the survey included a question, adapted from the Zarit Caregiver Burden scale (described in the methods chapter), which yielded responses to the bottom line question of burden. The most common response, 42.9% (n=25), was that the caregiver “sometimes” felt burdened. The second most common response 25.4% was that the caregiver “quite often” felt overwhelmed or burdened because of their caregiving duties.

Table 7.25 Caregiver Burden Rating

<table>
<thead>
<tr>
<th>Caregiver Burden Rating</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never</td>
<td>25</td>
<td>10.4%</td>
</tr>
<tr>
<td>Rarely</td>
<td>34</td>
<td>14.2%</td>
</tr>
<tr>
<td>Sometimes</td>
<td>103</td>
<td>42.9%</td>
</tr>
<tr>
<td>Quite often</td>
<td>61</td>
<td>25.4%</td>
</tr>
<tr>
<td>Almost always</td>
<td>17</td>
<td>7.1%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>240</strong></td>
<td><strong>100%</strong></td>
</tr>
<tr>
<td>Missing</td>
<td>13</td>
<td>5.1%</td>
</tr>
</tbody>
</table>

Table 7.26 Caregiver Burden Rating Bar Graph
Only 7.1% said that they were “almost always” burdened and 10.4% reported “never” feeling burdened.

**Caregiver Hurricane Experience**

The vast majority of the caregivers, 90.5% (n=229) had experienced a hurricane during the past 20 years.

Table 7.27 Hurricane Experience

<table>
<thead>
<tr>
<th>Hurricane Experience</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>24</td>
<td>9.5%</td>
</tr>
<tr>
<td>Yes</td>
<td>229</td>
<td>90.5%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>253</strong></td>
<td><strong>100%</strong></td>
</tr>
</tbody>
</table>

During this hurricane experience, 70% (n=177) of the caregivers were physically living with the person who has currently has the dementia diagnosis.

Table 7.28 PWD Living with Caregiver during Hurricane

<table>
<thead>
<tr>
<th>PWD Living with Caregiver During Hurricane?</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>76</td>
<td>30%</td>
</tr>
<tr>
<td>Yes</td>
<td>177</td>
<td>70%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>253</strong></td>
<td><strong>100%</strong></td>
</tr>
</tbody>
</table>

However, only 34% (n=86) of care recipients had had a dementia diagnosis at the time of the hurricane. This means that 66% (n=167) have not yet experienced a hurricane while caring for a PWD.

Table 7.29 PWD Diagnoses during Hurricane

<table>
<thead>
<tr>
<th>Was the PWD diagnosed during this hurricane?</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>167</td>
<td>66.0%</td>
</tr>
<tr>
<td>Yes</td>
<td>86</td>
<td>34.0%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>253</strong></td>
<td><strong>100%</strong></td>
</tr>
</tbody>
</table>
Caregiver Perception of Hurricane Likelihood

The next question addressed how likely caregivers thought a hurricane would strike this year, on a scale from 1 to 10 (with 10 indicating great likelihood). The majority of caregivers (33.2%, n=84) stated, on a scale of 0-10, the likelihood of a hurricane hitting would be a “5”. Only 7.1% (n=18) stated that there was 0 chance of being hit by a hurricane this season. Another 13% (n=33) stated that they thought the likelihood of a hurricane hitting this hurricane season was very, very low at “1”. Overall, 35% (n=88) rated the likelihood of a hurricane to be a “4” or below (0-4). In short, these 35% did not feel that the risk of a hurricane impact during the coming season was very high.

Conversely, only 3.6% said there was an absolute chance of being hit by a hurricane this year. Caregivers who felt that the risk of being hit by a hurricane this year was a “5” or higher made up 65% of the responses. The number of individuals who rated the likelihood of a hurricane at a 6 or higher made up only 32%.

The below bar graph illustrates the variation in risk perception among the caregivers. Again, it is clear that most chose the answer that reflected a 50/50 chance of being hit by a hurricane this year.
Table 7.30 Caregiver Risk Perception Bar Graph

Preparedness: Disaster Kits, Hurricane Shutters, Access to Generator
Most caregivers reported that they had a disaster kit (67.6% or n=171); slightly less than one third (32.4%, n=82) reported that they did not. It is unknown why they did or did not have a disaster kit. For example, they might not be able to afford a disaster kit or they might simply not think that a hurricane was likely. This issue was explored further in the caregiver interviews.
Table 7.31 Disaster Kit

<table>
<thead>
<tr>
<th>Do you have a disaster kit?</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>82</td>
<td>32.4%</td>
</tr>
<tr>
<td>Yes</td>
<td>171</td>
<td>67.6%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>253</strong></td>
<td><strong>100%</strong></td>
</tr>
</tbody>
</table>

Table 7.32 Hurricane Shutters or High Impact Glass

<table>
<thead>
<tr>
<th>Do you have Hurricane Shutters?</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>66</td>
<td>26.1%</td>
</tr>
<tr>
<td>Yes</td>
<td>187</td>
<td>73.9%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>253</strong></td>
<td><strong>100%</strong></td>
</tr>
</tbody>
</table>

The majority of caregivers (73.9% or n=187), reported that they had hurricane shutters or high impact glass to protect their home from projectile objects dislodged by high winds. However, only 41.9% (n=106) had access to a generator in the event of a power outage.

Table 7.33 Access to Generator

<table>
<thead>
<tr>
<th>Do you have Access to a Generator?</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>147</td>
<td>58.1%</td>
</tr>
<tr>
<td>Yes</td>
<td>106</td>
<td>41.9%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>253</strong></td>
<td><strong>100%</strong></td>
</tr>
</tbody>
</table>

Home Structure

The vast majority 73.5% (n=186) of the homes inhabited by caregivers were made of cinder block. Eleven point nine percent (11.9%, n=30) of the homes were made with a less sturdy wood frame. Eight point three percent (8.3%, n=21) reported that the frame of their home was made of some other material. The remaining 6.3% (n=16) were unsure what the frame of their home was made of.

Table 7.34 Housing Structure

<table>
<thead>
<tr>
<th>Housing Structure</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wood Frame</td>
<td>30</td>
<td>11.9%</td>
</tr>
<tr>
<td>Cinder Block</td>
<td>186</td>
<td>73.5%</td>
</tr>
<tr>
<td>Other</td>
<td>21</td>
<td>8.3%</td>
</tr>
<tr>
<td>Don’t Know</td>
<td>16</td>
<td>6.3%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>253</strong></td>
<td><strong>100%</strong></td>
</tr>
<tr>
<td><strong>Missing</strong></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Most of the caregivers (61.7% or n=157) lived in free-standing homes. The second most common habitation (19.4% or n=49) was a condo. Another 8.3% (n=21) lived in a townhouse or a villa. The remaining families (7.1% or n=8) lived in an apartment and 3.6% (n=9) lived in a mobile home. The latter type of dwelling is particularly vulnerable to high winds.

Table 7.35 Housing Type

<table>
<thead>
<tr>
<th>Housing Type</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Free standing house</td>
<td>156</td>
<td>61.7%</td>
</tr>
<tr>
<td>Townhouse or villa</td>
<td>21</td>
<td>8.3%</td>
</tr>
<tr>
<td>Condo</td>
<td>49</td>
<td>19.4%</td>
</tr>
<tr>
<td>Apartment</td>
<td>18</td>
<td>7.1%</td>
</tr>
<tr>
<td>Mobile home</td>
<td>9</td>
<td>3.6%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>253</strong></td>
<td><strong>100.0%</strong></td>
</tr>
</tbody>
</table>

Recovery

The final questions in the survey assessed the caregivers’ ability to recover from a hurricane. They were asked about whether they thought they would be able to afford repairs on their home, should it be damaged in a storm. They were also asked about their insurance policies and income.

Most of the caregivers (64%, n=162) reported that they felt they would be able to afford repairs on their home should it be damaged. Only 15.8% (n=40) stated that they did not have the means to repair damages to their home, should they occur. Another 10.7% (n=27) stated that they were unsure whether they would be able to afford the repairs or not. Another 9.5% (n=24) said that they would not be responsible for the repairs, and therefore, the question was not applicable.
The vast majority, 83.4% (n=211), of the caregivers stated that they had insurance on their home, while the remaining 16.6% (n=42) did not.

Table 7.37 Home Insurance

<table>
<thead>
<tr>
<th>Insurance?</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>42</td>
<td>16.6%</td>
</tr>
<tr>
<td>Yes</td>
<td>211</td>
<td>83.4%</td>
</tr>
<tr>
<td>Total</td>
<td>253</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

When asked about more specific types of insurance, such as a wind protection policy or flood insurance, the affirmative responses dropped slightly. 52.6% (n=133) stated that they had a wind protection policy. Twenty seven point seven percent (27.7%, n=70) stated that they did not have a wind protection policy. The remaining 19.7% were unsure whether the or not they had such a policy included in their general home insurance.

Table 7.38 Wind Protection Policy

<table>
<thead>
<tr>
<th>Wind Protection Policy?</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>70</td>
<td>27.7%</td>
</tr>
<tr>
<td>Yes</td>
<td>133</td>
<td>52.6%</td>
</tr>
<tr>
<td>Don't know</td>
<td>50</td>
<td>19.7%</td>
</tr>
<tr>
<td>Total</td>
<td>253</td>
<td>100%</td>
</tr>
</tbody>
</table>

However, only 37.9% of the caregivers surveyed reported that they had flood insurance (while 60.5%, n=153 did not have flood insurance). Most of the caregivers were aware of whether they had a flood insurance policy or not.
Many of the caregivers were uncomfortable answering questions about their income and thus the response was missing from 16.6% (n=42) of the surveys, resulting in a sample of 211. Of these, 10.4% (n=22) stated that they made less than $10,000 a year. On the other end of the spectrum, 3.3% (n=7) reported that they made over $100,000 a year. The most common caregiver income reported was between $20,000 and $40,000 a year at 34.6% (n=73).

<table>
<thead>
<tr>
<th>Income</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than 10k a year</td>
<td>22</td>
<td>10.4%</td>
</tr>
<tr>
<td>between 10k-20k a year</td>
<td>42</td>
<td>19.9%</td>
</tr>
<tr>
<td>between 20k-40k a year</td>
<td>73</td>
<td>34.6%</td>
</tr>
<tr>
<td>between 40k-60k a year</td>
<td>45</td>
<td>21.3%</td>
</tr>
<tr>
<td>between 60k-80k a year</td>
<td>11</td>
<td>5.2%</td>
</tr>
<tr>
<td>between 80k-100k a year</td>
<td>11</td>
<td>5.2%</td>
</tr>
<tr>
<td>Over 100k a year</td>
<td>7</td>
<td>3.3%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>211</strong></td>
<td><strong>100.0</strong></td>
</tr>
<tr>
<td>Missing</td>
<td>42</td>
<td>16.6%</td>
</tr>
</tbody>
</table>

Most caregivers (86%, n=182) report making under $60,000 a year, while only 14% (n=30) made over this amount. As the below bar graph shows, income levels are skewed to the right, emphasizing the tendency for caregivers to fall into the lower income brackets.
Summary of Findings from Caregiver Survey

Most (52.6%) of the PWD who were participating with ACC could walk without help (n=133). This measure is a proxy for the stage of the disease, and suggests that most of the PWD participating in ACC are in the earlier stages of the disease (before mobility is affected). This is likely due to the fact that one of the qualifications for ACC adult day services is that the PWD be able to at least stand and pivot with assistance. Furthermore, at the end stages, other services, such as hospice and respite, are more appropriate for the PWD. The high rates of mobility also suggest a potential for wandering behaviors (which might lead to elopement).

The majority of caregivers, 47.8% (n=121) stated that they were retired, and not employed. The second most common response was for the caregiver to be employed full time. Another 14.7% (n=37) stated that they were not employed, but also not retired; this
means they might have been out of work, on disability or chosen to quit their job to provide full time care, among other possible explanations.

When the caregivers were asked whether they had any health conditions that might interfere with providing care, the majority of the caregivers considered themselves healthy: 26.5% (n=67) reported health problems (that interfered with their ability to provide care for a PWD). Most did not report health barriers 73.5% (n=186).

Overall, it appears that most caregivers live in sturdy, free-standing homes. Most of the caregivers 61.7% (n=157) live in free-standing homes and the vast majority 73.5% (n=186) of the homes inhabited by caregivers were made of cinder block. Eleven point nine percent (11.9%, n=30) of the homes were made with a less sturdy wood frame. This finding can give an insight into the safety of the homes in which families are living. In general, cinder-block homes are more likely to withstand hurricane winds than wood frame homes. The majority of caregivers 73.9% (n=187), reported that they had hurricane shutters or high impact glass to protect their home from projectile objects dislodged by high winds. However, only 41.9% had access to a generator in the event of a power outage.

The vast majority, 83.4% (n=211) of the caregivers stated that they had insurance on their home, while the remaining 16.6% (n=42) did not. The high number of insured caregivers suggests that most would be able to repair their homes and recover from any damage from the storm. Most of the caregivers (64%, n=162) reported that they felt they would be able to afford repairs on their home should it be damaged.

The vast majority of the caregivers, 90.5% (n=229) had experienced a hurricane during the past 20 years. However, only 34% had been providing care for a PWD during
that hurricane experience. This is perhaps one of the most significant findings because it means that most caregivers do not have previous caregiving experience for a PWD during a hurricane.

**Caregiver Interviews**

As reported earlier in this chapter, 20 family caregivers were interviewed about their hurricane experiences and plans in preparation for future hurricanes. I used the demographic information from the baseline disaster plan review to determine how many males and females/Hispanics and non-Hispanics I needed to interview to match the larger population trends. While I was volunteering at the adult day centers, I invited caregivers that fit the needed demographics. If some refused, I asked others. I had only one direct refusal, and two that did not meet me at designated times or did not return phone calls. This section describes the primary findings resulting from these interviews. It is divided into two main parts: “Caregiver Hurricane Experiences” and “Caregiver Hurricane Plans.” The final section covers “Caregiver Concerns” and “Words of Advice” that did not fit into the previous sections.

**Caregiver Hurricane Experiences**

All 20 caregivers interviewed reported that they had experienced a hurricane; however, only 12 of them had the PWD living with them during those hurricanes. From these experiences, analytical emphasis was placed on the 12 caregivers who reported that the (diagnosed) PWD was living with them during a hurricane. This section is divided into the themes that emerged from the caregiver interview analysis: 1) neutral hurricane experiences, 2) hurricane-caused problems for the PWD.
Neutral Hurricane Experiences

For three families, the hurricane was a “neutral” experience for the PWD. Eight caregivers made statements about the PWD faring well or having a neutral response during past hurricanes. Three mentioned that, though their family member had already been diagnosed with dementia prior to the 2004-2005 hurricane season, they were still well enough to assist with preparations and recovery. Most caregivers noted that the level of dementia had been less pronounced during the hurricanes experienced six years ago. This sub-section is divided into the following themes: 1) the PWD Assisted with hurricane preparation or recovery; 2) activities and distractions during the hurricane; 3) the PWD did not notice the hurricane.

The PWD Assisted with Hurricane Preparation or Recovery

Three caregivers specifically mentioned that the PWD helped prepare for the hurricane or clean up after the hurricane. For example, one caregiver, which I will call “June”, stated, “When my mother was with us before [the hurricane], she was not showing too many signs of her disease. She was able to help us prepare” (Adult Daughter, White, Hispanic). Another caregiver, Ken, was more specific about how his wife assisted him in moving furniture and objects from the patio:

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\text{Once she was diagnosed in 2003, I really started minimizing, removing things from the back patio so I would not have to keep bringing things in all of the time during hurricane season. There were those back–to-back storms [2004] and I wore myself out trying to put things away. [My wife] was very able to help me then, though. (White, non-Hispanic Male, Spouse)}
\]

Above, Ken explains how his wife was able to help him remove patio furniture in preparation for a hurricane, thus preventing the furniture from being blown away or becoming projectile objects that might cause damage. Since his wife was in the early

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16 All names provided for caregivers are pseudonyms.
stages of dementia during the 2004 storms, she was still ambulatory and able to take direction. At the time of the interview in April, 2011, however, his wife was no longer weight-bearing and was primarily non-verbal, though she smiled when spoken to or touched. Though it went unsaid, Ken’s wife would not be able to help prepare for any future hurricanes.

A third experience came from Carrie, whose father carried a dementia diagnosis: “We were here during [Hurricane] Wilma, too. We didn't think it would be that bad… Dad was still able to help us clean up back then” (Adult daughter, White, non-Hispanic). In Carrie’s case, her father had been well enough to help with hurricane recovery in the past. He was able to pick up fallen branches and take care of their horses, dogs, and cats. At the time of the interview, however, his dementia and loss of mobility had progressed to the point that he would no longer be able to help.

These experiences all highlight how the progression of the disease can change a disaster plan. During the early stages, the PWD can assist in different stages of the disaster (e.g., preparation or recovery). As the disease progresses, abilities (such as mobility and the capacity to follow instructions) will likely decline. The different stages of the disease indicate that more responsibility for disaster planning and recovery will be placed on the caregiver over time. Caregivers must consider that the support they had from their loved one in the past may not be available in future plans.

**Activities and Distractions during the Hurricane**

Some caregivers said that they provided different activities during the hurricane to keep the PWD calm. For example, one caregiver, Juanita, described making music with her mother, using pots and pans, during the hurricane:
There was a lot of rain. We are in an apartment, on the bottom floor, so we couldn’t really hear the rain pounding on the roof. We heard a lot of wind. We got out pots and pans and played music to drown out the noise. (Adult Daughter, White, Hispanic)

Activities, such as making music with pots and pans, can distract a PWD from anxiety-induced behaviors. The unfamiliar sounds of the wind, in the above case, were drowned out by a competing noise. Other activities, depending on the stage of dementia, can help focus a PWD away from his or her anxieties.

Another caregiver, Bella, who evacuated during the 2004-2005 hurricane season, suggested that the time spent with family during hurricanes also acted as a positive distraction.

She [mother] had dementia at the time and she had just come to live with me. My mom doesn’t get excited. She loves to go where we want to go.... When we say we are going somewhere, she is ready. In the past, when I wanted to stay, she always wanted to get out. It has been our tradition.... The kids always liked hurricane season because, you know why? Because the whole family would all get together. We would cook all the food left in the refrigerator. The church would come in and cook. I think it is the same for mom. (Adult Daughter, Black, non-Hispanic)

This caregiver’s statement hints at one of the more positive aspects of evacuation and sheltering in place, namely, family interaction and sense of community. Her comments show positive aspects that could arise within a stressful situation.

The PWD did not Notice the Hurricane

Four of the eight caregivers said that family members who had dementia during the 2004-2005 hurricane season “didn’t even know there was a hurricane” (Gloria, Adult Daughter, White, Hispanic). A second caregiver, Jorge, echoed this same sentiment, explaining that, “During the 2004 hurricanes, my mother was here [and had dementia] but it didn't bother her. We all slept through it” (Adult Son, White, Hispanic). A third
caregiver, Juanita, mentioned that the hurricane-induced power outage simply acted as a catalyst for sleep: “She was not agitated once the power went out -- she just kind of forgot about it and went to sleep. But around 4 a.m. she was hungry, so I made her a sandwich. (Adult Daughter, White, Hispanic). The fourth caregiver, Christine, explained that, “Mom was living with me but her dementia was not that bad then. I don’t remember any issues” (Adult Daughter, Black, non-Hispanic). This is noteworthy because Christine points to the progression of the disease, suggesting that future plans might be different.

**Hurricane-Caused Problems for the PWD**

Following is the second theme of the hurricane experience analysis, which includes more negative experiences for both the PWD and the caregiver. The concerns include the following sections: 1) the progression of the disease, rendering the PWD less able to assist in preparations; 2) the PWD resisting evacuation; 3) difficulty with recovery.

**The PWD Could not Help Caregiver Prepare.**

One caregiver, Betsy, mentioned difficulty with setting up her hurricane shutters without the help of either her husband or her limited social network:

> In 2004, I had never been in a hurricane and I had no idea what to do. The first hurricane was Charley, and it hit the West Coast. Pictures of the devastation were all over the news. I knew nothing about the shutters, which are big heavy panels. It took two days for me to get them up. My husband was unable to help by this time [he had had the disease for about ten years by this point]. (Spouse, White, non-Hispanic)

Betsy went on to explain that her neighbor, another woman, offered to assist her with the hurricane shutters:

> We watched the video to see how to get them up. It was almost funny. When we went to her house to put her shutters up; it turned out she didn't have any. Her house was built in 1999, and in this county,
houses were not required to have shutters until 2000. Mine was built in 2000.

The above quote also brings up an interesting fact about mitigation: hurricane shutters were only mandated in 2000 in Martin County. In Palm Beach County, however, shutters were mandated for new homes built after 1997.

The PWD Resisted Evacuation

Two of the caregivers who had experienced a hurricane after their family members had been diagnosed reported that they had had resistance from the PWD when they tried to evacuate. The first, Juanita, explained her experience with her sister, the PWD:

Usually, she goes to my brother’s house in Royal Palm when there is a hurricane warning. This last one she stayed here. She refused to leave, so I stayed with her. (Adult Daughter, White, Hispanic)

It is important to note that, in this case, there were no damaging consequences from Juanita’s decision not to evacuate with her sister’s nearby home. However, had the family lived in an evacuation zone, this situation could have been problematic.

Another caregiver, Betsy, who did live in an evacuation zone, had more anxiety surrounding the PWD’s resistance to evacuation.

It was very difficult, though, because [my husband] didn’t want to go. I had to fight with him to get him out of the house. That was my big problem because I couldn’t reason with him. He was totally resistant.

Betsy’s husband was physically larger than she was, and she could not force him to leave. She told me that, eventually, she was able to get her husband into the car for evacuation. However, he continued to be unhappy, even once they reached their evacuation destination.
At the hotel, he spent the whole time in the bed. Not happy. I had to get medications and important papers together. I didn't know how long we would have to be gone or if we would have a house to come back to. Both of those hurricanes made landfall just about ten miles from here.

This situation draws attention to the importance of early planning. If the PWD is resistant, evacuation might be delayed and complicated. Some caregivers might be convinced to stay, even if it is unsafe to do so.

Difficulty with Recovery

One caregiver, Gloria, explained that there were some problems after the hurricane passed, when the electricity was out.

_During [Hurricane] Andrew, she [her mother] had signs of dementia but she was OK. In 2004, she was upset because the electricity was out and the things she was used to were not available [like the TV and radio].”_ (Adult Daughter, White, Hispanic Daughter)

This statement reiterates an ongoing theme—that changes in the environment can be upsetting to the PWD. Having a generator or battery-powered electronics and lighting can assist in creating some environmental continuity.

Another caregiver, Lisa, had a different experience with her mother after a hurricane:

_During [Hurricane] Wilma [2005] she wasn't diagnosed, but she was showing signs of dementia.... The power went out for four days after the hurricane and we didn't have a generator. So all of the food in the refrigerator went bad. I tried to throw it out, but mom refused. We got into a huge argument over the food. She really didn't want to throw it away. It was a huge ordeal. She kept wanting to save it and trying to eat it, but it wasn't safe. There was just no reasoning with her_ (Adult Daughter, White, non-Hispanic).

Lisa told me that she waited until her mother went to bed and then threw out the spoiled food. While her mother had a history of being frugal, she felt that this argument came from her mother’s failure to understand the danger of eating meats and dairy products
that had been in a warm environment for over three days. Lisa went on to clarify that, as her mother’s disease progresses, it might actually become easier to care for her mother during a hurricane:

*Now I think it is easier because, since she was diagnosed, we have found the right balance of medications and she is not as anxious as she used to be. Her disease has progressed so she is more forgetful. I think she would be OK if we had to evacuate. She will be confused maybe, but not resistive (sic).*

Lisa predicts that her mother might be easier to assist before, during, and after a hurricane now that she is in later stages of dementia.

**Shelter Experiences**

Two of the caregivers interviewed, Tina and Betsy, had experiences with evacuation shelters during hurricanes. Both Tina and her mother qualified for special needs shelter (SpNS) services and, though her mother was not diagnosed when they went to one in 2004, her experience does give insight into how one is run. Betsy and her husband attempted to evacuate to a regular shelter shortly after moving to Florida in 2004. Upon arriving at the shelter, Betsy decided it would not be an appropriate environment for her husband (who had a dementia diagnosis at the time). Her experience gives insight into the concerns that caregivers might face in an emergency.

**Special Needs Shelter.**

Only one of the caregivers interviewed, Tina, had experience sheltering in a SpNS. Both she and her mother had physical problems during the 2004 hurricanes that qualified them for the special needs shelter. She explained that, “Mom was living with me then, but she did not have dementia. She had physical problems though, so we evacuated to the special needs shelter” (Adult Daughter, Black, non-Hispanic). She explained that Palm Beach County provided transportation (called Palm Tran) for her and
her mother to get to the SpNS. During the 2004 hurricanes, “We stayed there until the storm went over, the power came back on, and we returned home. It was not too bad.”

She also explained how her role as a caregiver changed within the SpNS context:

*The SpNS... there were a lot of different people there [people with and without dementia]. I basically took care of mother in the shelter. I bathed her... gave her sponge baths. They [shelter staff] changed the bedding but I did her medications.*

She went on to explain that in the following year, 2005, she again evacuated to the SpNS, but was not able to return home right away due to continued power outages in her area:

*The next year, for [Hurricane] Wilma, we did the same [and went to the SpNS]. Except we stayed there for over a week. The power was still out at our place and mom needs a nebulizer, which needs electricity. The power was out at our place for three weeks. So we were transferred out of the shelter and into a nursing home. I am considered “special needs,” too, so they admitted me, too. They treated us like patients. I was transported to my dialysis treatments across town three days a week.*

This experience gives one example of how the SpNS operates in Palm Beach County.

Since Tina’s mother was not diagnosed with dementia in 2005, Tina was not able to report on any of the dementia-specific features of the Palm Beach SpNS, but she did provide insight into how care was provided in the shelter. Tina provided her mother with most of the care she needed. Her experience also illuminates the procedure used for SpNS residents who are unable to return home after the shelter closes. The partnership between long-term care facilities and the county appears to be strong in Palm Beach County, when compared to other surrounding areas.

**Regular Shelters.**

Only one of the caregivers interviewed had attempted to use a non-SpNS evacuation shelter. Betsy, who lived in an evacuation zone in Martin County, evacuated
in both the 2004 and 2005 hurricane seasons. She first attempted evacuation to a regular shelter; however, it was not a special needs shelter.

We went to a [regular] shelter located in a school. I thought, “oh my God!” It was totally unacceptable. There were kids running around. It was crowded. You had to bring your own bedding and I couldn’t let him (the PWD) sleep on the floor. It was loud and chaotic. It just wasn’t well organized at all. Also, they don’t take pets and we have cats. We took one look at it and we realized it wouldn’t work so we just turned around and came home.

This statement introduces some descriptive aspects of a regular shelter -- it can be crowded and “loud and chaotic.” These factors have the potential to over-stimulate a PWD and to exacerbate dementia-related behaviors. Furthermore, bedding placed on the floor can be problematic for people with common medical issues, such as arthritis or bad joints, which might make it more difficult to get up and down off of the floor.

While the environment at a SpNS might be slightly different, such shelters can vary from county to county. Even if Betsy and her husband had gone to a SpNS, there is not a dementia-specific component in their Martin County SpNS (but there is in the Palm Beach County SpNS). This being the case, a SpNS might not have had staff trained to effectively respond to the PWD’s dementia.

**Caregiver Hurricane Plans**

All of the caregivers interviewed provided me with least a basic plan during the interview. These 20 plans, detailed below, are further divided into the most common disaster plan destinations: 1) sheltering at home; 2) evacuating to a family or friend’s home; 3) evacuating to a hotel; 4) evacuating to a shelter; and 5) destination unknown.
Sheltering at Home
At times, caregivers presented a simple plan with little elaboration, such as, “We will stay at home. We have a whole pantry full of our disaster preparedness supplies” (Gloria, Adult Daughter, White, non-Hispanic). One caregiver stated that she preferred to shelter at home because, while her mother’s physical health was strong, “It is bad for her to be out of her comfortable environment.” She added that, “If it were mandatory to go to a shelter, I would. I am scared of the nearby canal” (Juanita, adult daughter, white, Hispanic). Others were a little more elaborate in their disaster plans. June, for example, stressed that they felt safe in their home; however, they also prepared to leave in case the situation were to become acute:

First, I make sure there is water in the bathtubs, get canned food and prescriptions filled. I have a suitcase full of clothes in case we have to leave. We can go to a family member’s house if we need to. I always try to prepare just in case. (Adult Daughter, White, Hispanic)

Luz explained that she would prepare her home to shelter in place but she would also have a contingency plan in case there was a mandatory evacuation or if they felt they were in immediate danger. She also explained in the interview that she, her husband, and her mother (the PWD) had a strong social network they could call upon in such an emergency.

Another caregiver, Joe, also mentioned his informal social network; however, he made it clear that his decision to either shelter in his home or to evacuate depended upon the strength of the storm: “If it were a Category 1 or 2 [on the Saffir-Simpson Scale], we will stay here at home. If it is a Category 3 through 5, we will go out of town.” He then elaborated on his evacuation options:

We have four daughters who live south of here. We have a son up north in the Panhandle. Or, we could just drive up to Georgia. I guess
we would have to leave three or four days ahead of time. You don't want to get caught on the highway (Husband; White; non-Hispanic).

In addition to the importance of his social network (his family), this caregiver also mentions the necessity of early evacuation, so that he and the PWD did not have to spend too much time in traffic. This concern was expressed both by caregivers who were sheltering in place or who planned to evacuate regardless of storm category.

Another caregiver, Liz, echoed the importance of knowing a hurricane’s strength when considering evacuation and concerns about traffic. She, however, also addressed the option of official shelters, “We live across the street from a shelter but it really doesn't look safer than my house. If it is less than a Category 3, I am going to stay in my house” (Adult Daughter, White, non-Hispanic). Liz went on to explain the circumstances in which she would evacuate:

*If it is a Category 4 or 5, we will leave. It is difficult to leave with all of the traffic... leaving with someone with Alzheimer’s disease, and stuck in a car for hours. That is not a good option because they can get anxious. We can go stay with family inland, who live 15 miles inland in a newer home. They have hurricane windows.* (Adult Daughter, White, non-Hispanic)

First, the above statement suggests that some caregivers question the safety of government-provided shelters. Secondly, this caregiver states she will use the strength category of the storm as an indicator of the need for evacuation and will utilize her social network for a safer location. Her statement indicates she feels that her family’s home is safer because of its distance from the coast, newer construction, and the fact that it has impact-resistant glass. This statement also indicates that she trusts in the scientific assessment of the storm and in those who report the news.
Another caregiver who preferred to shelter in place stated frankly, “Well, I have been living here all of my life and I have never even entertained the idea of leaving my home….” He followed with the qualifier, “but things are getting strange. Maybe we will see even stronger storms.” He went on to say the following about his contingency plan:

*If it looked bad, I would start looking for stronger shelter. I would have to talk to the kids about it and coordinate with them. We would not want to go to a shelter, though. Not after Katrina and what happened to those people in the Superdome. It looked terrible.*

(Spouse, White, non-Hispanic).

This final statement hints at the role of media coverage in the aftermath of Hurricane Katrina. The situation at the New Orleans Superdome, though very different from the shelters available in Palm Beach County, has left a lasting impression in people’s minds. The fact that so many vulnerable people publicly suffered left some caregivers distrustful of the services that shelters can provide.

One caregiver, Germaine, who stated that his primary preference was to shelter at home, also said that he would consider evacuating if it were mandated. “If we had to evacuate, if it were mandatory, we have friends in Port St. Lucie and in Orlando. If we had to leave, we have options.” He explained, however, that he preferred to stay because, in addition to caring for his mother, who has dementia, he is also was in a profession that served a large number of people:

*So, I go and buy plywood and put them up at other people’s homes before the storm. There is a lot to do after we secure our own home. My wife is a nurse, so she has to work during a hurricane. I have to get the place ready.* (Adult Son, Black, Caribbean)

This example illustrates that some caregivers have responsibilities that extend beyond their role of providing care for the PWD. This caregiver is also a spiritual leader in his community and takes responsibility for the more vulnerable people in his social network.
These other obligations could potentially delay a mandatory evacuation and could result in the family being stuck in traffic if he eventually attempts to leave town. The fact that his wife is a nurse and, therefore, must report to work during a hurricane is also noteworthy. Though none of the primary caregivers interviewed were obligated to report to their place of employment during a hurricane warning, this situation did present itself in the disaster plan review (discussed later in this chapter). These caregivers (present in 2% of the total disaster plans) stated that they would bring the PWD with them to their place of employment.

Another caregiver also mentioned how her plan had changed since her previous experience with hurricanes:

_The plan has changed. I don’t have a husband around anymore. I want to get shutters. We wanted to use impact-resistant glass, but it was prohibitively expensive. The glass we ended up using is thick and heavy, but it is not impact-resistant. We recently renovated the home here. We have a lot of windows._ (adult daughter, White, non-Hispanic).

Since her divorce and with the progression of her father’s disease, preparing for a hurricane had become more difficult. While she had a sturdy home, in which she felt safe, she did not have hurricane shutters. She also mentioned the extremely high cost of impact-resistant glass. She went on to explain her plan for evacuating.

_I don’t think I would stick around for a Category 4 storm. I would go to Virginia to my sister’s home. She has a ranch [for my horses]. We could pack up the trailer and head north. It is a whole different ball game with horses. We have two horses, two cats, and two dogs, which make evacuation more difficult._

This caregiver, though she would prefer to stay in place because of her menagerie, would evacuate if the storm were strong enough. Though she told me that her horse barn was
rated for a Category 3 hurricane, she did not feel comfortable staying there, with the animals and her father, caring for them on her own.

The most important point to note, from the caregivers who plan to shelter at home, is that most will consider evacuating if it is “necessary.” Only three caregivers stated that they planned to shelter at home, regardless, and they did not discuss any contingency plans.

Most of the caregivers who planned to shelter in their own homes stated that they did have a social network they could tap into for support, if it were necessary. Necessary, for some caregivers, meant that a mandatory evacuation had been declared. For others, necessary evacuation is when the strength of the storm reaches a certain category on the Saffir-Simpson Scale, usually above a category three or four. While these two definitions of “necessary” are not mutually exclusive, one depends on the government’s assessment of risk, while the other depends on the caregiver’s own assessment.

Evacuating to a Family or Friend’s Home

The second most common disaster plan (after sheltering at home) was to evacuate to a family member’s home.

*My plan is to go to my son's house. He has high-impact glass on his windows and he has two generators. Also, his home is on higher land. I drive my husband there and we bring food. My son's place is a safe place. Even his neighbors come to shower there. Usually, with hurricanes, you have enough time to get everything together. As soon as there is a hurricane warning, I go to my son's house. He only lives a mile away. Just to be safe. (Wife, White, non-Hispanic)*

The above caregiver assessed her son’s home as safe because of the high-impact glass, access to generators, and the elevation of his home.

The next caregiver is the sister of the PWD. While she does not live with the PWD, their mother does. This caregiver shares the care of both her mother and her sister
with dementia with another sister. They explained how they would partner to keep their family safe during a hurricane:

*My sister and I will come to the condo, pick up mother and (our) other sister [with dementia]. If it is a Category 1, 2, 3, then we will take them to my condo or my sister's house. My sister has shutters at her house and we would go there if it were a 4 or 5. She has an extra room for us.*

She went on to say that, “We never go to a shelter because we don't like it. It is more for people who live alone… There are six of us siblings who live in the area, so we have choices” (Sister, White, Hispanic). This quote illustrates a reluctance to utilize shelters when there is access to social networks.

Another caregiver, who had previously experienced a hurricane with her husband, diagnosed with dementia, told me that her plan had changed. Previously, her husband had been highly mobile and very resistant to evacuating:

*Things are a little different now. My husband's not as ambulatory as he was before and I don't think he would be as resistant [to evacuating]. I also know more people here. My plan is to go to a friend's house, which is on the same grid as the jail, so power comes back on quickly. He offered for us to stay there because he is out of town for the summer.* (Spouse, White, non-Hispanic)

The above statement illuminates several important ideas: 1) the progression of the disease in the PWD, 2) the importance of established social networks, and 3) status of power grid restoration.

Another caregiver, Bella, who lives near Lake Okeechobee, expressed concern about the safety her home: “I have relatives in Orlando we stay with. The reason we leave here now is because we are afraid of the flooding. It hasn't happened yet, but we never forget the '28 storm.” The reference to the 1928 storm, which had devastated the southern areas around the lake, was interesting, especially since Mykle, author of the book, Killer
‘Cane, (2006) had suggested that survivors of the storm did not talk about it much with their families. When I asked this caregiver how she knew about the 1928 storm, she responded, “I used to work with children and we took them to the Chamber of Commerce and we learned all about it.” The awareness of past storms being raised, this caregiver then went on to explain her plan:

So, we fortify the house. If it is over a Category 3, we will pack up and go to my cousin's house in Orlando. In Clewiston, the flooding is worse there. If I couldn't get to Orlando, I would go to Belle Glade. (Adult Daughter, Black, non-Hispanic)

This caregiver was strongly attached to her church group as well as to her extended family, all of whom lived throughout the Okeechobee and greater Florida areas. She was well-informed of the differential risks to the different areas around the state.

Evacuating to a Hotel
The following caregiver, Denise, had sheltered in place at her home during the 2004 and 2005 hurricane season. Since that time, her mother had been diagnosed with dementia and came to live with her; she states she would evacuate if the storm were strong enough. “With my mom here, I think we would stay for a Category 1 or 2 hurricane, but a 3 or above, I'm out of here.” Denise explained her evacuation options as first, to try to get a hotel room and, if that was not possible, to go to her father’s home on the west coast of Florida:

Maybe we could stay with my dad on the west coast... it is kind of a haul in traffic...with mom. That would only be if we could not get a hotel room in the area. We do reserve rooms early when there is any sign of a hurricane coming our way. We work in the hotel business so we can usually get a reservation. But dad's place is a backup. (Adult Daughter, White, non-Hispanic)

Denise expressed awareness of the difficulty of traveling in traffic with her mother, who has dementia. In addition to having home insurance, this caregiver also worked in the
hotel industry which, with planning, usually gained her family access to a hotel room. Many insurance companies cover the costs of hotel rooms. However, the option of staying at a hotel usually requires access to disposable income, which not all caregivers have.

Evacuating to a Shelter

Only one of the caregivers interviewed had experience in a special needs shelter and planned to return there in the future. In this case the caregiver, Tina, had medical problems herself, which qualified her for SpNS placement. Though she would be receiving medical care at the SpNS, she would also act as her mother’s caregiver. Tina’s decision was based on their (her own and her mother’s) medical status and the proximity of their home to Lake Okeechobee:

*The plan this year would be the same. Take Palm Tran [bus] to the special needs shelter.... If a storm is coming anywhere near Lake Okeechobee, we are out of here. I worry about that Hoover Dike [on Lake Okeechobee].* (Adult Daughter, Black, non-Hispanic)

Tina is aware of the disrepair at Hoover Dike, which was also a concern raised by one of the staff members during the staff interviews. Tina further elaborated upon her plan, which built on her past experiences:

*This year, I will bring the insurance papers with me, I think. I used to put the papers up high, in case it flooded. But we don’t have hurricane shutters on these homes [HUD housing]. They tell us that if we want them, we need to pay for them. But it is government housing... a rental. How are we going to afford that?* (Adult Daughter, Black, non-Hispanic)

Tina and her mother live in federally subsidized housing (also known as US Department of Housing and Urban Development, or HUD, housing). This housing was built in an area prone to flooding during hurricanes. In the past, Tina had put important documents in a safe place so that they would not be destroyed if her home flooded. This year,
however, she planned to bring important documents with her. What was most striking about her statement, however, was that HUD housing does not provide hurricane shutters. Though this was a hurricane-prone area, the homes were built in the 1980s, prior to any county building codes. When this caregiver asked for shutters, she was told they would not be provided, but that she could install them herself. This put her in a difficult position, considering both she and her mother received disability as their only income and could not afford this important safety measure. Additionally, the lack of shutters left their homes vulnerable not only to broken windows due to the hurricane, but from theft should any of their belongings survive. This will be discussed further later.

Other residents in HUD housing who planned to shelter in place also lacked hurricane shutters; however, they did have generators. FEMA had reimbursed residents for generators they had purchased after the 2004 and 2005 hurricane seasons. This seemed to be a strange prioritization of government benefits to the participants.

Destination Unknown

During the interviews, three caregivers were unsure of their plans. One caregiver, Hannah, who lived in a rented condo, was unsure of how well the building would stand up to a hurricane. She was also concerned about evacuating because of her mother’s tendency to become disoriented and wander.

_Honestly, I don’t really know. I think I would try to stay in place. She kept leaving the hotel room when we traveled. I think she might get lost._ (Adult Daughter, Black, Hispanic)

Fear of the PWD getting lost and uncertainty about building structures make it difficult for caregivers to make an informed decision about whether to evacuate or shelter in place. This caregiver, who had recently moved back to Florida to care for her mother and who worked full-time, did not have a social network available to offer support. After I
presented her case to the FNC in charge of her case, she was signed up for a special needs shelter in Palm Beach County. This was deemed appropriate because the Palm Beach County SpNS was set up for dementia-specific care, in addition to care for physical ailments.

Another caregiver, Lena, said she had been contacted by hospice before previous hurricanes to see if she planned to attend the SpNS. She had declined in the past, but used this previous contact to suggest that she might be signed up for it already: “I think we might be registered in a special needs shelter, but I don't know. We are stocked up, we have shutters, so we want to stay if we can.” (Adult Daughter, Black, non-Hispanic).

One caregiver, Lisa, was unsure of what her disaster plan would be when I interviewed her. In addition to her mother (the PWD), she was also concerned about her pets:

> We have five pets so it makes it hard [to evacuate]. I know my husband would not want to evacuate. If we really had to leave, we would have to find a hotel that accepts dogs and cats...or arrange to have them boarded somewhere. My husband would not want to do that but we should think more about that. We need to think more about family or friends out of town. I would want to go. (Adult Daughter, White, non-Hispanic)

The above caregiver later contacted me through the adult day center to tell me she had researched evacuation options for her mother, her husband, her dogs, and herself. She told me that her insurance would cover the costs of a hotel room and that American Automobile Association (AAA) listed hotels that were animal-friendly. She had located several hotels that they could evacuate to if the strength of the storm were enough. This caregiver, however, lived in a sturdy home in a location that was not near any major body of water. The home was also equipped with a generator and hurricane shutters.
Regardless of whether a caregiver planned to shelter at home or evacuate, there were several consistent themes that factored into caregiver decision-making.

**Caregiver Risk Communication and Risk Assessment Preferences**

I asked caregivers how they preferred to get information during hurricane season. By far the most common source of information was television (18 out of the 20 caregivers; 90%). Only two caregivers did not have access to televisions and therefore did not use them. Instead, they used the internet or applications on their phone. (Most preferred the local news, which will be discussed in detail later). Eight of the 20 caregivers (40%) mentioned more than one primary source of information. For example, one caregiver claimed to get most “news from TV… but, also phone calls from family” (adult male, white Hispanic). Another also mentioned social networks as a primary information source, “Comcast has local channel in Clewiston. Also, friends call. We discuss whether to evacuate or not. But, if it is over a Category 3, we pack up and go” (adult daughter, Black, non-Hispanic). Three other caregivers explained that once they hear about a storm on the news, they then confirm it on the NOAA website, via the internet. Only one of the caregivers reported getting their information exclusively from the radio (900 AM, a local channel) and from texts on her phone. Finally, only one of the caregivers mentioned reliance upon the information put out by ACC, “The information is everywhere. ACC gives the best and the most information. But, sometimes it is too much. They gave a packet [several inches thick] but it was mostly a waste of ink. I really didn’t look at it.” (adult daughter, Hispanic). None of the caregivers listed newspapers as a primary source of hurricane information.
I then asked which available news sources they felt were the most reliable (local TV, radio or newspapers versus national sources of the same medium). The answers indicated an overwhelming preference for the local news. Nineteen of the twenty caregivers (95%) reported that they trusted the local news over national sources. The one caregiver who preferred the national news said, “I trust the national news. The local news is too emotional” (spouse, White, non-Hispanic male). Three of the caregivers reiterated the fact that they used more than one news source, namely, the internet. Two of these said that they double-checked with the NOAA website specifically, “I always go to the NOAA website. They give the local news the information” (adult daughter, Black, non-Hispanic). These two caregivers, though they preferred local news, also used the internet to check the national-level weather specialists.

**Disaster Kits**

I asked caregivers whether they had a disaster kit for sheltering in place. If so, they were also asked to provide a freelist of supplies that they had included or thought should be included. I then asked them what they would take with them should they have to evacuate (to see if the items were different). Finally, I asked them how they decided what was important for a disaster kit.

Only 25% (n=5) reported that they had a disaster kit set aside in case of emergency. Another 50% (n=10) reported that they had necessary supplies, but they were not all in one place or in a box that would be easy to take with them in the case of an emergency. The remaining five reported not having a disaster kit or adequate supplies should a disaster strike. Only two of the caregivers interviewed had written their plans for future reference.
Even though five caregivers did not have a disaster kit, two of these were still aware of what they needed and knew where to obtain further information. These two caregivers cited the lists put out by grocery stores (Publix) and hardware stores (Home Depot) around hurricane season. Out of the 20 caregivers interviewed, seven cited the lists distributed by Publix (n=4) and Home Depot (n=3) as the primary source for deciding what to put into a disaster kit. Three of the caregivers reported that knowledge about what to include in disaster kits was “common sense”. Another three stated that “previous experience” had informed their decisions about what to include in the disaster kit. Two of the caregivers cited materials provided by ACC as their primary source for planning their disaster kits. One cited the internet and broadcasts from “channel five”. The remaining five did not have a disaster kit and did not provide rational for what would go into one. These five were able to list at least three items that would need to be included in their disaster kits.

**Caregiver Concerns and Words of Advice**

This section addresses caregiver concerns that did not neatly fall into the structured themes of hurricane experiences or planned evacuation destinations. One of these concerns (raised by two different caregivers) was the level of crime that can occur in the area – specifically the Lake Okeechobee area – after a hurricane. The second theme was the reoccurring advice independently discussed by three different caregivers: if the caregivers keep calm, then the PWD will emulate their calm behavior.

**Issues Unique to Lake Okeechobee Area**

Two of the caregivers interviewed lived in government-subsidized housing (HUD housing) near Lake Okeechobee. The concerns about lack of hurricane shutters were
present for both of these caregivers. Christine reported on the Lake Okeechobee area after the 2004 hurricanes:

*There was a lot of crime after the hurricanes. It was hard because it would be people you know, your neighbors. They would break into your place while you were gone. It didn’t happen to me because I was here the whole time. But they broke into my son’s house and stole all of his groceries. All the electronics. They tried to take his big screen TV, but it was too heavy.*

Crime in an area spikes after a hurricane, largely due to the number of homes left vacant by people who have evacuated. Christine went on to predict that crime might be even higher should a hurricane hit in 2011.

*Now, things are different. The economy is so bad. The prison [a major local employer] is shutting down and the sugar company, which was seasonal anyway, is pulling out, too. If a hurricane came now, we are in trouble. People might break into your house even while you are home. I don’t know.*

Christine expressed concern that the current economy and increase in job loss in the Lake Okeechobee area might exacerbate the crime rates after a hurricane. A similar concern was raised by an ACC staff member during the staff interviews.

Unlike Christine, Carrie did not live in the Lake Okeechobee area; however, she did work in the school system there. She discussed the impact of the previous hurricanes on the people she worked with in the area:

*The people in Pahokee did not fare well. There is a little community out on Muck City Road, by the sugar rail tracks. Someone broke into their homes and stole everything -- a lot of the victims were my students.*

She also discussed the long-term impacts of the 2004-2005 hurricane season in the Pahokee area:
The grocery store was damaged and it closed down. Now they have to
drive to Belle Glade for groceries. More and more people are leaving.
Sugar is pulling out and they are giving land back to the Everglades. It
is expensive out here. Land is pricy. No place to build, really. You
have to use special foundations for the homes because it is all on the
muck, and your house will sink.

What both Christine and Carrie are describing is a community in crisis. The pre-existing
vulnerabilities, such as poverty and the high cost of land, have been exacerbated by the
damage wrought by past hurricanes. Carrie went on to discuss the impact that the
hurricanes had on the children she worked with:

When the kids came back after the hurricane, a lot of them were
traumatized. Those who didn’t evacuate, the kids talked a lot about the
damage, the leaking, broken windows. A lot of those building were
built in the 20s and 30s. They just can’t withstand the wind.

Indeed, on my weekly drive to Pahokee, I was continually struck by the number of
dilapidated, cinder-block structures that must have once been someone’s home or
business. It is clear that poverty, the age of the buildings, the disrepair of the dike, and the
proximity of Pahokee and Belle Glade to Lake Okeechobee have the potential for
disaster. There are echoes of the structural vulnerability that existed before Hurricane
Katrina hit New Orleans; there, concerns were well known, but little was done to
mitigate. The result was catastrophe.

In addressing more immediate potential concerns of a caregiver during a
hurricane, three different caregivers emphasized the importance of remaining calm during
a crisis. Ken offered the following words of advice:

The important thing is to stay calm. The changes in the environment
can be stressful for someone with dementia [e.g., when putting up
shutters, it gets very dark]. We try to pay attention to her comfort level
and explain things. We tell her what is happening. I think on a basic
level, she understands.
Ken stressed that explaining environmental changes to the PWD might help keep him or her oriented and more comfortable with changes. Ultimately, he believed that staying calm was key to a disaster response while caring for a PWD. This statement was echoed at a more explicit level by Luz:

*I think, next time, she will respond how we respond. She will respond to what she sees. If she sees a lot of commotion, she will likely be nervous. We will stay calm.*

June clearly stated this same sentiment, “She would respond to a hurricane depending on how we react. If we panic, she will panic, too. If we are calm, she will be calm.” While the dementia diagnosis is somewhat fluid, changing over time and in different environments, the idea that the PWD will emulate the caregiver’s behavior is an important concept. A measured response (as much as possible) will help both the caregiver and the PWD when faced with hazards, such as hurricanes.

**Summary of Findings from Caregiver Interviews**

Of the 20 caregivers interviewed, 12 had the PWD living with them during a past hurricane experience. Of these, two primary themes emerged from the data: a) the hurricane was a non-event, neutral hurricane experience and b) the hurricane caused problems for the PWD. Three mentioned that, though their family member had already been diagnosed with dementia prior to the 2004-2005 hurricane season, they were still well enough to assist with preparations and recovery. Most caregivers noted that the level of dementia had been less pronounced six years ago, which means their disaster plans are likely to change.

Caregivers reported several different actions and reactions to hurricanes. The primary reports were about a) the PWD assisting with reparation or recovery; b) activities
and distractions during the hurricane; c) or that the PWD did not even notice there was a hurricane happening. Families that had trouble during the hurricane reported the following a) the progression of the disease, rendering the PWD less able to assist in preparations; b) the PWD resisting evacuation; c) difficulty with recovery. All of the caregivers interviewed provided at least a basic plan in the event of a future hurricane threat to their area. These plans included sheltering at home, evacuating to a family or friend’s home, evacuating to a hotel, or evacuating to a shelter.

Fear of the PWD getting lost and uncertainty about building structures make it difficult for caregivers to make an informed decision about whether to evacuate or shelter in place. Those that preferred to shelter at home reported concerns about the PWD health and wellbeing if they were to evacuate. Without dementia specific care, shelters are difficult places for PWD because of all of the commotion (children, sleeping on the floor, noise).

It is noteworthy that only two of the caregivers interviewed had a written disaster plan. While ten of the caregivers claimed to have the supplies needed for inclusion in a disaster kit, only five of the total twenty have a disaster kit set aside for emergencies.

Disaster Literacy Assessment

In the Newest Vital Sign (NVS) procedure, individuals are asked to read health-related materials (e.g., a medicine bottle) and then demonstrate the ability to use that material by answering questions (Weiss et al, 2005). The procedure developed by Brown (2010) is similar to the NVS, but with the following changes: 1) she incorporated a Wide Range Assessment Test (WRAT), which is a brief and basic assessment of literacy, and 2) she supplemented the “health related information” with disaster preparedness
materials. As with the NVS, we asked participants to demonstrate their ability to comprehend and use the information we provided by answering questions about specific materials. The disaster literacy aspect of the interview consisted of two parts: 1) a short reading test (WRAT) (see below) and 2) a disaster literacy evaluation. I incorporated this literacy test into the qualitative interviews, with the goal not of generalizing literacy levels across the ACC population, but rather to yield rich, detailed data about each participant’s understanding and perceptions of the disaster preparedness materials.

The reading subtest if the WRAT includes the recognition and naming of letters and the pronunciation of out-of-context words. I used the WRAT to ensure that each participant had basic English literacy skills. This prevented illiteracy from being a confounder for disaster literacy. The WRAT is not a measure for health literacy or disaster literacy on its own.

I asked participants to read one side of a two-sided pamphlet on SpNS, produced by the Palm Beach Board of County Commissioners, entitled “Palm Beach County Special Needs Program” (2009). The pamphlet is disseminated in public places and is also accessible online. When each participant finished reading, I recovered the pamphlet and then proceeded to ask six questions about the article. During each caregiver interview, I handed the caregiver the document as a flat piece of paper, with the primary text side facing up. I then immediately asked six questions about the information the caregiver had read in the pamphlet. I recorded their answers and transcribed the results into a Microsoft Excel spreadsheet file.
**Document Description**

The document used to assess disaster literacy is two-sided and has three columns on each side, which is designed to be folded into a pamphlet. On the side that is designed to be the front, it reads:

Column 1: The title is “Palm Beach County Special Needs Program”. Below the title is an image of a woman in a white coat, which denotes her role as a medical professional, presumably a doctor.

Column 2: “Palm Beach County Department of Public Safety Division of Emergency Management”. It then provides contact information (phone, fax and website) and contains a logo for Palm Beach County

Column 3: “What is the Special Needs Program?”

Beneath, in italics:

> “Palm Beach County has established a Special Needs Program to provide care for citizens with certain medical problems during a major emergency. The Special Needs Shelter is a facility with physicians and nurses on staff. It has auxiliary electrical power, is wind resistant, and is not flood-prone.”

On the other side of the pamphlet, side two, there is the primary informational text. Like the previous side, there are three columns, however, they are meant to be read as one document. There are seven subheadings that break up the three columns: 1) How to Qualify for the Special Needs Program; 2) What to Bring to the Special Needs Shelter; 3) May I Bring a Pet to the Special Needs Shelter; 3) Transportation; 4) After the Hurricane; 5) What if I only Need Transportation to a Regular Shelter; 6) Alternatives to the Special Needs Shelter. At the end of the final column there was a photograph of a man wearing a white coat (presumably a doctor) and wearing a stethoscope. He is using the stethoscope to listen to another man’s chest.
Document Evaluation
The document was evaluated by assessing the number of letters in a word and the average sentence length to determine its approximate readability (using the Flesch–Kincaid Grade Ease test). The three columns contain 544 words and 43 paragraphs. There are 1.3 sentences per paragraph and 12.1 words per sentence. Each word contains an average of 5.5 letters. None of the sentences uses the passive voice. According to the Flesch Reading Ease calculation, this document scored a 38.0. Since the Flesh Reading Ease score is rated on a scale of 0-100 (100 being the easiest possible to read) this document is considered to be a semi-difficult one to read. The associated grade level was 10.9, meaning that this document was geared toward people who had at least an 11th grade high school education in English.

Caregiver Responses and Scores
During each caregiver interview, I handed the caregiver the document as a flat piece of paper, with the primary text side facing up. Only four of the caregivers actually turned the paper over to read the other side, which contained both the title and the description of the special needs program. The results might have been different if I had handed it to them as a folded pamphlet (which was not done because of the way the pamphlet printed off the website). I could have folded the document but decided against it because I suspected that people would most often see the pamphlet unfolded when they printed it off of the EOC website. Furthermore, the way the document was printed, when folded, part of the double sided text was upside down when the pamphlet was folded (perhaps in error). I have not encountered the pamphlet at the EOC, Area Agency on Aging, Department of Elder Affairs or ACC, suggesting that its primary distribution is
via internet access. For this reason, I assumed the primary exposure to the pamphlet would be on the county website. Unfortunately, this assumption means that individuals without computers would not have access to this information at all.

After caregivers read the pamphlet, I immediately asked six questions about the information they had read in the pamphlet. The answers were recorded and transcribed into an Excel file. I then scored the accuracy of each caregivers answer to each question. The answers to the first five questions were scored on a scale of 0-3, however, the final question was scored as either a 0 or 1. The total score possible was 16 points, which would indicate a higher level of disaster literacy.

None of the caregivers scored a perfect 16 in their answers. The highest score was 15 and the lowest score was 5. The most common score (five of the caregivers) out of the total twenty was 11. This mode of 11 corresponded with the average score, 11.1. The first question, “What is the topic of this article?”, had the highest average of correct answers at 2.45. All of the caregivers gave at least a partially correct answer to this question (none received a “0” or a “1”). Though the majority of the caregivers did not turn the document over to read both sides, the average score of 2.45 indicates that most were able to assess the primary focus of the article correctly.

The second question, “How do you get special needs shelter services if you need them?” had an average score of 1.9 (~2). This number indicates that most caregivers offered a partially correct answer. Only one caregiver was unable to answer the question at all. The average score of 1.9 for this questions suggests that most caregivers were only able to identify one qualifying criteria for the SpNS.
The third question, “What services are provided at the SpNS?”, received the lowest average correct answer at 1.8. The average score of 1.8 for this question indicates that caregivers are unclear about the services provided at the SpNS. This may be because they tended not to read the description of the SpNS on the other side of the pamphlet. Even if they did read the other side, it did not guarantee a correct response.

The fourth question was, “Who qualifies for a special needs shelter?” for which the correct answer rate was 2.35, which was the second highest response rate out of all of the questions.

The fifth question, “how do you get to a special needs shelter” had an average score of 2.15. A caregiver was assigned a score of “3” if they specifically mentioned the county transportation “Palm Tran” or “DTAP” to get to the SpNS.

Finally caregivers were asked whether their loved one would qualify for a SpNS. This question was scored on a 0 or 1 scale because all of the PWD would, technically, be eligible for SpNS services. Of the 20 caregivers, 60% (n=12) recognized that they would be eligible for SpNS services if they needed them. The remaining 8 (40%) did not believe they or their family member qualified for SpNS based on dementia alone. One caregiver explained his affirmative answer, “Yes, we would qualify if we had no other place to and it was over a Category 3 storm… but I don’t want to be like those people during Katrina… Stuck in the [New Orleans Super] Dome like that” (spouse, White, non-Hispanic).

**Disaster Literacy Correlations with WRAT/Reading Times**

The highest possible score on the WRAT literacy testing is 70. The average caregiver score was 55 (54.85, to be exact). This means that, on average, most caregivers
were unable to recognize 15 words on the word list. Since the WRAT word list begins with simple words (i.e. cat, book) and becomes progressively difficult (i.e. bibliography, covetousness) the most commonly missed words were in the final 20.

After administering the WRAT literacy test, the caregivers read the pamphlet on SpNS. The average reading time for the pamphlet was three minutes and three seconds. Average educational level of participants was high school plus two years of college (or a two year technical degree). This is a higher than the national average reading level of 8th grade (National Adult Literacy Survey) The lowest grade level completed was 9 and the highest was 22 years of formal education (or a PhD).

I ran crosstabulations in SPSS to see if factors such as years of education, age, language or the WRAT score were correlated with a higher comprehension score; none of the factors were significantly correlated, which might be due to the small sample size of 20.

Responses about the Quality of the Document.

At the end of the interview, I asked each caregiver if they felt that the document had enough information to make a decision for using a special needs shelter. I also asked them if they felt there was anything that might improve the document or make it easier for them to use. One response, which was echoed by four other caregivers, was that, “it did not say anything about nurses or doctors being there. I did not know that until you told me.” The prevalence of comments like this is likely because most caregivers did not turn over the document to read the description of the program. However, there was a photograph of a doctor and patient on this side of the pamphlet as well. People were unclear on the difference s between SpNS run by the county, which provides doctors and
nurses, and the Red Cross-run “regular” shelters. In fact, one caregiver asked me, “What makes it different from a regular shelter?” (Spouse, White, non-Hispanic)

One caregiver, Betsy, suggested that, “They could make the print a bit bigger,” but went on to say, “I like that they tell you to get the medications ahead of time. People just don't think about this.” (Spouse, White, non-Hispanic). This indicates that this caregiver felt that, overall, the caregiver felt the pamphlet was helpful.

Another caregiver, Denise, was slightly more critical: “Well, they tell you that you need to bring a can opener [to the SpNS] but they do not tell you if they provide the can of food.” She went on to point out that, “The alternatives that they list are not realistic for elderly people. Who is the audience? If you need a shelter you probably can't afford these alternatives” (Daughter, White, non-Hispanic).

**Summary of Findings from Disaster Literacy**

It is important to note that data is only useful as a qualitative snapshot of how well caregivers understand informational pamphlets about SpNS. Most caregivers did not understand the difference between a regular shelter (run by the American Red Cross) and the SpNS, which is run by the county. The associated grade level was 10.9, meaning that this document was geared toward people who had at least an 11th grade high school education. Average educational level of participants was high school plus two years of college (or a two-year technical degree). This is a higher than the national average reading level of 8th grade (National Adult Literacy Survey) The lowest grade level completed was 9 and the highest was 22 years of formal education (or a PhD).

I have not encountered the pamphlet at the EOC, Area Agency on Aging, Department of Elder Affairs or ACC, suggesting that its primary distribution is via
internet access. ACC family nurse consultants provide these pamphlets to families they feel are eligible.

I ran crosstabulations in SPSS to see if factors such as years of education, age, language or the WRAT score were correlated with a higher comprehension score; none of the factors were significantly correlated, which might be due to the small sample size of 20. Unfortunately, this means that this component of my research had very little to add. It simply gives an exploratory insight into how well caregivers understood the pamphlet.

**Tying it All Together: Final Group Interview with Administrators.**

In December 2011, I met with three ACC administrators to discuss findings that had been emerging from the data. Participating in the group interview were some of the primary decision makers in the organization, who are also deeply involved with the day-to-day functions of the adult day centers and other services. I asked them to reflect on some of my findings and to use their experience to explain them as one of the ways of triangulating the data.

Questions and themes I specifically asked them to reflect upon included:

1) the history of the disease (senility, dementia and AD);
2) the narrative of a person with AD as being “a shell” of who they once were;
3) how, in an ideal world, they would like to see AD and related dementias addressed in the public and policy spheres;
4) initial findings on the increased difficulty with caregiver disaster response when the PWD was in the early stages of the disease;
5) the concept of “retrogenesis” and the parallels between the progression of AD and childhood development;
6) how SpNS should be utilized and if it is possible to improve the system.

Several other topics came up unprompted, such as the role changes between spouses and adult caregivers with the PWD. The administrators argued that, in their experience, the disease can actually bring children closer to their parents because it leads to a breakdown in inhibitions and thus allows for a more honest relationship. They also discussed how music therapy operated as a means for families to unlock the relationships and to emphasize the creative abilities of those with AD and related dementias.

History of AD and Personhood

I asked ACC administrators to reflect on the language of personhood and the loss thereof over the course of the disease. I used the example of a person with AD being considered a “shell of who they were”. Radcliff responded that, though he could see how an outsider might think there was less of a person there at first glance, he felt this was not ultimately true:

*I think there is much more inside that we are not aware of. When you start looking at the creative modalities through the music, tactile stimulation. There are so many things we don’t understand with this disease. It is almost arrogant to think that there is not a person there. It is an arrogant assumption to make that there is a loss of personhood at the end stage of the disease.*

Indeed, the progression of AD is not linear. As described in Chapter 2, the stages were constructed as a shorthand to explain the general changes in a person with AD over time. Lucidity can wax and wane over the course of days or weeks. There can be fluctuations over the course of a day (frequently becoming more confused in the evening, i.e. sundowning) (Volicer et al., 2001). The administrators discussed how these fluctuations demonstrate that while “there is always a person there,” they are not always able to access the things (memories) that others see as a marker of “personhood”.

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They did note, however, that medical professionals, legislators, and sometimes even families feel differently. One shared that, “A doctor told me that, no matter what stage of the disease they are in, they will eventually become a vegetable. Why would you try to save them?” Another added, “There is an assumption that they no longer have a quality of life, which I don’t believe to be true”. One administrator distinguished between child and spousal caregiver responses to the disease: “Some caregivers think that [the PWD] is gone or has little quality of life too. The spouses not too much. The husbands and wives have much more ownership of their relationship.” They paused the discussion to ask me if I had noticed a difference in how spouses and adult child caregivers responded to this issue. Though not been part of my analysis, I had noticed a difference: four of the caregivers were moved to tears when discussing the change in their loved one over the course of the disease. All of these were spouses. Three of them were male.

The change in shift in social roles brought on by assuming a caregiving role was something of which the ACC administration was highly aware. On administrator told me that, “the leap from husband or wife to caregiver is awesome. And that is something else that the system does not understand.” Another suggested the following:

As children, we go through life thinking we will outlive our parents. It is more expected... You are not quite sure, with your partner who may or may not go first. Maybe it is not as traumatic as an adult child [rather than as a spouse caregiver] because it is more expected.

This observation can have implications for caregiver burden. For example, Cho, Zarit, and Chiriboga (2009) found that wives and daughters responded differently to role burden, which ultimately impacted length of time to nursing home placement.
Special Needs Shelters

I asked the administration to explain the ambivalence that staff seemed to have about the use of SpNS. They explained that the acceptance of PWD into SpNS is a relatively recent development in Palm Beach County, as, to their knowledge, the latter is the only county that provides dementia specific shelters. One administrator explained that during previous hurricane warnings (before the 2004 hurricane season),

Unless there was a need for electricity or refrigeration [of meds], they[PWD] couldn’t go [to the shelter]. We were told that it is a special care unit, not a “special needs shelter”. We had to go back and read the statutory language. We came back and said, ‘you are required to house people with special needs. And here is the definition of people with special needs, which includes people with dementia.’ They didn’t even have what they classified as a SpNS in Palm Beach County.

One administrator gave a pointed example of the dilemma that this interpretation of SpNS caused. “There was a police officer who was taking care of his mother who had AD and his aunt had emphysema. The [SpNS] took the aunt, but wouldn’t take his mother. What was he going to do? He had to work during the hurricane.” Currently, Palm Beach county is the only in Florida that offers dementia-specific services in their SpNS. Even this is a recent development that took an extensive amount of negotiation between local governments. ACC provides specially trained volunteers to assist in the SpNS, including FNCs.

When ACC attempted to create the same arrangement in Martin and St. Lucie counties, they were told it would be “impossible” to accommodate people with dementia in the SpNS. One administrator I interviewed agreed with this assessment, “that is really the thinking with government agencies in general. They really do not want to deal with PWD. They feel, number one, it is too expensive. Then they think they are going to have
to work harder.” As another ACC administrator mentioned, when one revisits the Florida Statutes, people with cognitive difficulties should be included. She went on to say, “Different counties operate so differently. It should be standardized. Same rules, same regulations. We talked to St. Lucie and Martin counties, they said, “They couldn’t open up to PWD. ‘We can’t open it up! We wouldn’t be able to house these people’”.

Even in Palm Beach County, where there was ACC involvement, however, SpNS were considered to be a “last resort,” because, due to the high levels of activity and layout, they tend to be stress inducing. One administrator explained,

*Is there potential for the patient to experience significant distress and anxiety? Absolutely, and they probably will. What we do is try to minimize that as much as we can by carving out a section that is just for them, putting them in the back corner of the gym, having staff that is knowledgeable.*

One administrator also addressed the concept of post-traumatic stress syndrome in older veterans. “You can imagine, some of our veterans, they walk into a big gymnasium with cops lined up. That must be a horrifying experience.”

Both caregivers and ACC administration stressed that if the care provider remains calm during a disaster, the PWD would likely respond in kind. The CEO echoed the caregiver sentiments when she said, “You have to approach [PWD] with this calmness. If you have an anxiety level, they are going to have an anxiety level.” Radcliff connected this to the use of the SpNS, “If you think about it, the shelters are just oozing with anxiety anyway”. Another administrator agreed, “I don’t care how trained you are, everyone is just very anxious. The adrenaline is up.” Barnes explained that the layout of the SpNS was anxiety-provoking: “that room was huge, they put us in the middle of the room. I ask them to put us against the wall, because it is less overwhelming…. In spite of the
anxiety that a PWD can experience in an unfamiliar, noisy, and chaotic environment, some anxiety producing situations can be contained by properly trained staff. One administrator shared her experience in the SpNS during a 2004 hurricane:

*I saw a man [with a form of dementia] heading toward the bathroom area. I said to [non-ACC staff], “You know when that person has to go to the bathroom, they may not know how to get back”. Sure enough, this one man walked out of the bathroom, which is a nice enclosed area, the ceiling is a normal ceiling. And you walk out, and there is this huge open space and you are disoriented it. Sure enough, he was supposed to go straight and he took a left. We can anticipate that. That is our job. We can anticipate those kinds of behaviors. People who are not as educated might not be able to do that.*

Staff trained in the nuances of dementia care can anticipate potential anxiety producing scenarios and see the situation “through the eyes of the patient”. In an attempt to understand what the SpNS was like without ACC involvement, I asked a program manager who had experience in one of the unstaffed SpNS:

*I cannot imagine any of my folks being in a special needs shelter. The special needs shelters up here are not dementia specific. It can be so crazy. The only people I would recommend the special needs shelter only if they have electricity... or live in a trailer, have no family or friends in the area and no money for a hotel. I don’t think they would do well. They would not be able to see outside.(Program Manager, informally interviewed during disaster plan evaluations).*

Caregivers indicated that they had a negative view of shelters, special needs or otherwise. This program manager was referring to a shelter in Martin or St. Lucie County, which has not collaborated with ACC in providing dementia-specific care. This illustrates the importance of counties collaborating with dementia-specific service providers during storms. Without such partnerships, PWD are systematically excluded from government safety measures. They become a burden that local officials fail to recognize.
Early Stages more Resistant to Evacuation
Caregivers reported that they had more resistance to disaster response and recovery when the PWD was in the earlier stages of the disease. When I asked ACC administrators to explain this trend, one explained that, during the early stages of the disease, intellectual capacity may be maintained, but “judgment” (being able to process multiple risk factors and apply them appropriately) is impaired.

>You can talk about judgment and intelligence. You can lose your judgment without losing your intelligence. I think that it creates the perfect storm behaviorally. In that case, the judgment doesn’t allow me to understand the ramifications of not going somewhere in a disaster, but your intelligence is there saying, ‘You are trying to tell me to do something I don’t want to do.’ That is there. And boom. That is very common in the early stages especially.

When asked about the concept of retrogenesis, the administrators agreed that conceptualizing a PWD as a child as potentially negative ramifications. However, they also found the parallels compelling.

>When you are going through puberty you are struggling to gain your autonomy independence. When you are adult and starting to lose that... In the early stages you are going to see that person rebel against the loss of independence and autonomy. Maybe they are trying to protect their independence. I wonder how much of that would be psychological versus behavioral, social.

The administration referred back to the concept of retrogenesis when explaining why people in the earlier stages resisted evacuation or refused to throw away spoiled food after a hurricane. They suggested that these behaviors are part of a larger struggle to maintain autonomy and assert their personhood.

Future Directions in AD Services
Though the risk for dementia increases as one ages, it is not purely a disease of the elderly. ACC administrators stressed that AD, especially, is being diagnosed earlier in the life cycle. In the 1980s, early onset AD (before the age of 60) meant that many people
were not eligible for federal support until they reached “retirement” age. This illustrates the implicit assumption that AD is still a part of aging.

One administrator suggested that rather than pushing AD into a preexisting category, a new category should be forged, drawing upon the fields of biomedicine (including neurology and psychiatry), psychology, social work, and gerontology: “You need the whole combination!” I argue that anthropology is also a central part of this whole combination.

One administrator explained, “We talk a lot about the hospice model which was, at least at its inception, for cancer. It created a very distinguished model of care for that one disease process”. Hospice was developed to provide palliative care for people with terminal cancer in the end stages of the disease. Though the hospice model has expanded to other illnesses, and has attempted to envelop AD, “they have consistently fallen short” because the progression of AD is often unpredictable. People with AD can sometimes physically “revive” and live several more years, which goes beyond the scope of the hospice model. Another administrator explained the parallel between the hospice model and what is needed for long-term, home and community-based care for AD is “in some ways very appropriate and in some ways not”. He went on to explain that:

Hospice is there to really help someone with a terminal disease process die with dignity and support. We support that too, but the difference is that we want to create support systems so that families with a disease can live in the community. That they have the support from when they first see the symptoms, though diagnosis, the death process, and the grief process those caregivers sometimes experience afterwards. The reason I am drawing link with hospice is inclusive that they have public policy, it is inclusive with the medical community and it is inclusive of the human services and social services. So they have done a good job of packaging that all up and making a distinction. We have a little bit more of a continuum with this disease (AD).
In essence, ACC would like to see people with AD and their families be able to, as much as possible, lead a fulfilling life in the community. They hope to aid them through the naming of the disease, thus approaching the role changes and the conflicting sense of personhood with dignity.

**Administrative Interview Summary**

ACC administrators helped to explain several of the phenomena that had emerged from the results. They presented their conceptions of “personhood” and social roles in the families they served. They argued that lucidity can wax and wane over the course of days or weeks. The administrators discussed how these fluctuations demonstrate that while “there is always a person there,” they are not always able to access the things (memories) that others see as a marker of “personhood”.

They discussed how, in the past, PWD have been excluded from SpNS services in Palm Beach County. This trend continues in many other Florida counties. This is due, in part, in the wide variance in SpNS services from county to county.

They also provided further history of PWD in SpNS. Finally, they attempted to explain why caregivers had more resistance to disaster response during the early stages of the disease. They argued that, during the earlier stages of the disease, people try to maintain their autonomy by asserting their preferences. PWD retain their intelligence, even if their judgment is impaired. These factors can lead to conflict in high stress situations, such as disaster response and recovery.

ACC staff would like to see an expansion of the services that are available for PWD. Ideal future directions would be based on the cancer paradigm, including hospice services. This ideal would include medical teams that would work in tandem to provide
accurate diagnosis and treatments. Home and community-based services, such as ACC, ought to be expanded to help aid families through the naming of the disease, thus approaching the role changes and the conflicting sense of personhood with dignity.
Chapter 8: Discussion- Danger, Disasters, and Dementia

I designed this chapter to synthesize the historical context and theory (presented in Chapters 2-5) with my research findings (outlined in Chapter 7). The role of anthropological theory is central to my research design and the analysis of my data. Participant observation, the long-term embeddedness with the people I seek to learn about, gives me unique insight into the reality that caregivers face. While surveys and interviews are common instruments in research, my participation in their lives allowed me to tailor the questions to be relevant to issues facing caregivers in the Treasure Coast of Florida.

In the following pages, I will reiterate the primary theoretical concepts and explain how they relate to my research findings. I specifically explain how concepts from A) Biomedicine, B) Anthropology, C) Medical Anthropology, D) Anthropology of Dementia, E) Critical Medical Anthropology and Health Policy, F) Anthropology of Disasters contextualize my data.

Secondly, I present theoretical concepts that can be built into a framework for the Anthropology of Dementia and Disasters. Concepts from A) Disability and Disasters/Critical Disability Theory, B) Public Health and Risk Identification are used to inform and explain my findings within larger trends.

In the next section, I compare national demographics to my findings about ACC families’ demographics. I then specifically compare what they reported about their home safety and disaster preparations to those reported in the FEMA Citizen Corps (2007).
Critical Medical Anthropology, with its emphasis on gendered health disparities, becomes central because within caregiver demographics lay impressive gender disparities. I argue that feminization of dementia care impacts disaster planning and response. Drawing upon arguments made in Chapter 5, I suggest that social roles within families change as the disease progresses, which can pose challenges to a caregiver who is not comfortable taking on the decision making role in the relationship.

Continuing to the next section, I discuss how the staging of AD can have several impacts on disaster planning: 1) whatever experience a caregiver might have had during hurricanes in the past might be negated by changes in the PWD cognitive status in the future; 2) PWD remain self-aware of their preferences throughout the early disease, which means they may not share as the caregivers assessment of risk during disasters; 3) in the early stages, especially, PWD might feel the need to assert their independence and individuality to combat the sense of loss of social status and social roles (as adult, husband, wife, mother, father). These findings are informed by theory from Medical Anthropology and the Anthropology of Dementia as discussed in Chapter 5.

The next section addresses how AD is defined in the policy arena and how ACC has influenced state policy. Anthropological theories, such as liminality, are deeply important this analysis. Since PWD are in a liminal space, they are often excluded in a policy arena. In this section, I discuss the political actions that ACC caregivers have used to advocate for dementia-specific services and community-based care. Next, I discuss reoccurring issues surrounding the use of SpNS in the Treasure Coast and in Florida in general. I reflect on the ways that county governments have discouraged the use of SpNS
by either excluding people with dementia or withholding information about services (for example, caring for pets).

In the next section, I explore the tensions between home and community-based care paradigms (which are somewhat decentralized) with centralized disaster planning and response. I explore the challenge that the relatively small number of community based support systems face when providing individualized, dementia specific disaster planning. Disaster response is, by necessity, largely a top down response that is not yet equipped to assist these special needs populations.

Continuing, the next section explores the unique vulnerabilities that remain in the Lake Okeechobee area. I apply the pressure and release (PAR) model to this area to explore these vulnerabilities. The location, financial status of the area and the racial disparities all contribute to making the area extremely vulnerable to a hurricane. The sixth part is a discussion of “risk society” and how it applies to disaster planning. I consider hurricane warnings and use of the “cone of uncertainty” as a risk communication device. I also discuss how caregivers obtain information about impending storms. Of anthropological significance is the continued neglect of this area, which echoes Paul Famer’s (2004) concept of structural violence.

Next, I present the concept of “risk fatigue”, which might explain why the population in general (and perhaps caregivers, specifically) might be resistant to evacuation orders. This concept is defined by a person failing to guard against a risk because the sheer number of risks they face overwhelms him or her. Rather than shifting through all of the potential risks and preparing against them, they might choose to ignore some, including hurricanes.
Finally, I present some of the limitations of this research. The primary limitation is the fact that this research was not equipped to examine the situations of PWD who live alone and do not have a social network. Secondly, this research did not incorporate the perspectives of people with dementia.

**Future Directions of Anthropology, Health Policy and Dementia Care (including during disasters).**

**Relevant concepts from Biomedicine**

Biomedical frameworks give us several important concepts and guidelines that help to improve our understanding of the process of dementia causing diseases and how to treat them. The salient concepts from biomedicine include: 1) diagnosis and measurement of symptoms; 2) treatment and cure seeking; 3) the biological process of the disease in the brain and the correlated behavioral symptoms. Medical anthropologists draw upon cross cultural examples to contend that the biomedical framework is just one way in which to understand the cause and expression of the disease. They use these comparative methods to illustrate how things are done differently in different places. This can erode assumptions that might otherwise limit the ways in which we treat people with dementia causing diseases. Nonetheless, the scientific method, which drives much of biomedicine, yields deeply important information about the functioning of the human body. It is how this information is utilized that constitutes the cultural variation in responses to dementia causing illnesses and diseases.

i. **Biological Components of the Disease.**

Biological progression of the Alzheimer’s disease throughout a person’s brain changes over time. Therefore, disease related behaviors are likely to change over time. In the DSM-IV, a constellation of symptoms are defined and codified as the recognizable
Alzheimer’s disease. Once the disease is identified, a treatment and, ideally, a cure is sought. The diagnosis of the disease, the biological process, and the related behaviors can have a significant impact on disaster planning.

**ii. Diagnosis.**
A diagnosis, according to medical anthropological theory, gives a reason for aberrant behaviors (Helman 2001; Womack 2010). It legitimizes a disease and gives it a category in which it can be placed and addressed. With this categorization, comes a change in social roles (Kleinman 1973; 1980). The caregiver is expected to take on more of the decision making roles over time, especially in disaster scenarios (Loboprabu 2006). Depending on how the disease is affecting the PWD’s brain, a wide range of behaviors might be observed. Some of these behaviors might make disaster response more difficult for the caregiver.

My research found that disease related symptoms (such as increased stubbornness, judgment impairment) can impact disaster planning and response. Furthermore, whatever experience that caregivers might have had with the PWD during a past hurricane are likely to be very different in the following years. It is very difficult to predict how a PWD might respond during different stages of the disease.

**iii. Treatment.**
Biomedical treatments, such as behavior modification interventions or medications (such as antipsychotics, antidepressants, cholinestrase inhibitors, memetamine and anxiety medications) can assist families with some dementia related behaviors (Gauthier et al. 2010). Dosage varies depending on the person and type of dementia causing disease they have. For example, the medical regime and treatment
strategies might be very different for Parkinson’s related dementias than Alzheimer’s type dementia.

Caregivers have to work with their general practitioner, neurologists, psychiatrists, social workers, psychologist and anthropologists to find the right treatment regimen before a disaster strikes in order for them to be useful. Otherwise, knowledge of behavioral interventions, such as redirection, validation, and singing need to be used. Preferably, these techniques are used in tandem (discussed in greater detail under recommendations).

iv. Measurement.

Biomedicine also gives us tools that we can use to measure the cognitive loss. This also helps us predict what kind of behaviors might be observed over time. Though AD does not affect everyone in the same ways, organizing the illness into stages and in terms of a time structure “improves the caregiver’s ability to predict and supervise the development of the illness” (Poveda 2003). This organization allows me to discuss general differences that caregivers might experience during the early stages of the disease and the later stages. These stages and the severity of the disease affect disaster planning. Symptoms that might influence disaster planning include memory impairment and the inability to learn new information. The symptoms used to diagnose Alzheimer’s type dementia are the following:

- Aphasia- difficulty with language comprehension (inability to tell people who they are or where they are going or who their family members are).
- Apraxia- difficulty performing movements in response to verbal commands (difficulty walking).
- Agnosia - difficulty recognizing familiar faces, objects (risk of becoming disoriented, separated from family and possibly lost).

- Executive function - difficulty planning or sequencing activity or difficulty completing a task (judgment - impaired ability to determine risk).

- Loss in ADL’s also measure increased dependency on others (Katz et al. 1963; Lawton & Brody 1969).

When these symptoms are reflected in the “stages of Alzheimer’s disease” (either the three stage or more detailed seven stage framework) they are more accurately thought of as hermetic devices for explaining the process of the disease. Conceptualizing the disease in that way can be useful for anticipating what issues caregivers might face during a disaster. In the earlier stages of the disease, the social roles might not have shifted in the PWD and caregiver dynamic. Especially if a PWD has not been diagnosed, caregivers might not have fully accepted the “caregiving” role of primary decision maker (Loboprabu 2006). Even if the caregiver has accepted this role, the PWD might be fully aware of the social changes and respond with frustration, anxiety and/or depression.

Caregivers need to find ways to respond that minimize these feelings and work towards keeping everyone safe. Suggestions for meeting these ends are made in the recommendation section.

**Anthropological Concepts**

There are many relevant anthropological methods and data analysis techniques available. Here, theoretical concepts from the field of cultural anthropology are discussed: i) liminality and symbolic pollution and, more specifically, how it contributes
to stigma; ii) time as a social construction. I explain how these concepts are relevant for caregivers during disasters.

i. Liminality and Symbolic Pollution.

People who do not fit categories are considered potentially dangerous and are avoided as if they are polluted (Douglas 1967). Anthropologists have argued that there is a profound discomfort with people and things that do not conform to preordained categories and are therefore “between categories” or in a liminal place (Turner 1969). This concept has several areas of significance for my research: 1) the benefits of a diagnosis, which can give both people with a disease and their family members a sense of control; 2) people with dementia are frequently in a liminal position that is somewhere between being “fully alive” and “as good as dead”, which impacts how they are treated in the medical and policy arenas; 3) the lack of a category for Alzheimer’s disease in policy and funding streams, which can lead to inadequate support and exclusion. The liminal position of people with dementia causing diseases has multiple policy implications illuminated during disasters, especially in the special needs shelters. This exclusion is deeply related to the outcome of a liminal status or “symbolic pollution”. A similar concept is that of stigma, which is when a trait, such as wheelchair use, creates a cognitive discomfort and reduces the disabled person “from a whole and usual person to a tainted, discounted one…” in the minds of people around them (Goffman 1963: 3). Not all disability is as easily recognized as wheelchair use. Mental disorders or other “invisible illness” (such as diabetes), might also be stigmatized and seen as a personal failing (Goffman 1963: 4). Once a person is identified as having an undesirable difference they might be categorized in extreme cases as “a person who is quite
thoroughly bad, or dangerous, or weak” (Goffman 1963:3). People with Alzheimer’s disease are frequently stigmatized and, at times, feared, because of the unusual behavior patterns associated with it. Goffman explains that, “By definition, of course, we believe the person with stigma is not quite human. On this assumption we exercise varieties of discrimination, through which we effectively, if often unthinkingly, reduce his life chances” (5). This is painfully clear when county emergency management officials exclude people with dementia from disaster relief services. The data from my research that supports these theories are found in the caregiver interviews and the ACC administrative interviews.

ii. Time as a social construction.

When a PWD becomes disoriented to time, it is important to remember that our measurement of time is somewhat arbitrary anyway. Techniques to pacify the PWD during times of time disorientation create less conflict between the caregiver and PWD than reality orientation. During a disaster, caregivers can incorporate the time that the PWD is experiencing into the plan (i.e., if needing to evacuate, say, “let’s go pick up the kids from school” or “time to go to work”). Further suggestions are discussed later in the chapter.

This concept also has other applications when considering the stigma with which people with chronic diseases are treated. As discussed in Chapter 5, chronological age can be divided into stages: 1) childhood, 2) adult citizenship, and 3) post-adulthood or old age (Fry 2002). Conceptions about age-specific roles and responsibilities can vary across societies; in the United States, adulthood is when a person is capable of “full citizenship” (Fry 2007), as demonstrated by roles taken on in family relations and work (or the provision of goods). As a result, when one reaches “post-adult” status, a person often
relinquishes responsibilities such as working full time. Thus, there are different social roles and responsibilities (or lack thereof) associated with different stages of the human life. These theories are used to explain some of the difficulties that caregiver interviews who reported difficulty with evacuating for hurricanes.

**Medical Anthropological Concepts**

Medical Anthropology has offers a contextual and comparative perspective on the medical system. The power of the diagnosis to alter social roles is important for understanding caregiver responses during disasters. The anthropological perspective on i) diagnosis, ii) chronic illness and social roles, iii) the political economy of chronic illness, iv) social status and chronic illness, are briefly reviewed. The significance of these concepts for my research findings is explained.

i. **Diagnosis and Social Roles.**

In summary, a diagnosis creates a shift in social roles that can impact disaster response. Bio-medicine, though based in science and biological processes, has an impact on social processes. Social frameworks influences where and how scientists look for answers (consider a market driven system vs. a social welfare state). The naming of the disease makes it “legitimate” and allows a caregiver to recognize a constellation of behaviors in their loved one as “pathological”, yet, something that can be dealt with. However, in the early stages of the disease, the caregiver is not necessarily a “caregiver”. Their social role or identity is that of a spouse, or adult child (or other relationship) (Loboprabu 2006). Once a loved one’s forgetfulness is classified as a disease process, social roles begin to shift. During these early stages, especially if a professional has not legitimized the behaviors (forgetfulness, judgment problems) by
naming it “Alzheimer’s disease” or “Lewy Body disease”, then family members might have more difficulty taking on a decision making role during disasters. Conversely, they might argue with the PWD to the point of frustration.

ii. Chronic Illness.

Anthropologists deconstruct how the loss of mental capacities frequently equate a loss in social status, adult status and sometimes, even the distinction of being alive (Estroff 1993; Estroff 2004). Ultimately, PWD are in what anthropologists consider a “liminal” space that defies categorization. In Western societies, “adults with incurable chronic illnesses such as schizophrenia frequently fail to retain the expected roles of student, employee, spouse, and parent” (Estroff 1993: 259). If one fails to retain said “expected roles” then the chronic illness “contributes to simultaneous loss of valued, competent role experiences and increase in devalued, incompetent roles and experiences” (Estroff 1993: 259). One result of chronic illness is that it leaves people unable to provide for themselves and, therefore, often dependent on family and on society for subsistence. One of the values promoted as an American cultural ideal (and in capitalist systems in general) is that “adults should have and produce more resources than needs, have or earn more money than is spent” (Estroff 1993:259).

With the role of “adulthood” comes responsibilities and “full citizenship” (Fry 2007:14). When one can no longer fulfill their responsibilities, citizenship is lost. When they lose this role, they may experience stigma and social isolation (Goffman 1963; Estroff, Penn and Toporek 2004; Hashmi 2009). This finding largely comes from discussions with caregivers, staff, and participant observation in the adult day centers.

iii. Political-economy and Chronic Illness.
There are also *political-economic consequences* to the bio-medical designations of who is legitimately sick. For example, funding in Florida is determined by how disabled a person is. A PWD might not be able to be left alone, but if they do not need help going to the bathroom (which is an activity of daily living or ADL), then they might not qualify for care. I suggest that the Florida “Prioritization Assessment Form” does not capture the needs of PWD and therefore, needs to be reevaluated. This finding stems from the staff interviews and informal discussions I had with staff during participant observation.

iv. Social Status.

Social Status is tied to one’s ability to be productive in society. A person with a chronic disability (such as schizophrenia, as described by Estroff 1993- or, I argue AD) loses their “adult” status because they become dependent on others (and therefore, are more childlike). This shifts their social value. It begs the question, who deserves/ is worth saving during a disaster? I argue this explains some of the reasons why people with dementia are left out of disaster planning and have been excluded from special needs shelters at the county level.

v. Legitimacy and Categorization.

Categories and the legitimacy of the disease are linked with stigma and exclusion. Diseases, even when named can cause fear and mark the “ill” as “the other”. Discomfort with the difficulty of discerning whether a PWD is “human”, “dead” or “alive” adds to the fear, stigma, and exclusion.

Disease, no matter how based in biology it is, can be understood differently in other societies. Many examples illustrate how dementia is interpreted in different places-illuminating the cultural aspects (constructions) of disease. Not everyone understands the
disease in biological terms. In the U.S., shortcuts, such as the stages of AD, are used to
define and explain the disease to caregivers so they can anticipate possible behavioral
issues in the future. Hashmi “medical anthropologists do not dispute that biological
disease occurs, but are more interested in the reasons why scientifically demonstrable
physical pathology should appear and be treated in such different ways around the world
(2009:207). Our conception of the disease is based in loss of productivity (DSM-IV;
Crowe 2001). Measures such as ADL’s and IADL’s are also indicating a loss of the
ability to take care of one’s own needs. These latter measures do not include indicators
that capture loss in cognitive ability. Cognitive loss is only captured when it interferes
with a person’s ability to be self-sufficient. When considering whether someone is able to
toilet themselves independently but is unable to find their way to the kitchen, these
measures might fall short. In emergency shelters, these nuances are more likely to be
overlooked by untrained staff. An example of this is provided by ACC administration
when they describe a PWD becoming disoriented when trying to return from the
bathroom.

Anthropology of Dementia

The Anthropology of Dementia has offered critical examinations of the
biomedical approaches to dementia causing diseases. This sub-field critiques the
definition of what it is to be “alive” in biomedical terms (Kaufman 2006). This section
will review the concepts of: i) recognition and the prevalent rhetoric of the “living dead”,
ii) Bio-social death, iii) the “firsts”, iv) caregiver social roles.

i. Recognition and the ‘Living Dead’.
A person’s ability to recognize the person caring for them allows for basic reciprocity (Taylor 2008). When that fails, some caregivers consider the “person” dead (Cohen 1994 & 1998). The concept of recognition also alludes to identity politics. Are people with dementia recognized as a group deserving of care? I argue (based on Mary Barnes’ and other ACC administration’s emphasis and my observations) that PWD are difficult to categorized, and therefore, they are not easily recognized in the political or social arena.

ii. Death- Biological and Social (tied to liminality and stigma).

Many anthropologists write about the social transitions and allude to “death”. I divide the ways in which they discuss death into four categories (1. biological death, 2. living death, 3. biosocial death, 4. relational death). These categories all highlight the liminal state of PWD and how they are neither fully alive nor dead. I argue that the difficulty with categorizing PWD leads to their exclusion from social safety nets, such as special needs shelters, during disasters.

iii. ‘The Firsts’.

Taylor 2008 turns the concept of loss on its head and considers the things the more enriching experiences she had with her mother after the diagnosis (tucked her mother into bed with stuffed animals, held hands with her mother on a walk). Taking a step back and reexamining assumptions illuminate positive aspects in the caregiver/PWD relationship after a diagnosis. This view is also supported by statements made by both caregivers and the ACC administration during interviews. The shifts in social roles are not always negative and, in fact, can shift some relationships in positive ways.

It is helpful to be aware of the potential shifts in social roles between PWD and the caregiver when considering disaster planning. Especially in the early stages of the
disease the caregiver might not be comfortable taking on the role of primary decision maker. If they are, they might not be equipped to redirect behaviors and instead might be caught in an argument or power struggle with the PWD.

**iv. Caregiver Role.**
Loboprabu (2006) describes the caregiver’s transition from “their family role as spouse or adult child to caregiver, and ultimately from the caregiver stage to that of care manager” as a necessary response to the progressive cognitive deterioration of the PWD. She argues that these steps allow for separation from the impaired PWD as he or she is less able to reciprocate (2006: 95). In the earlier stages, this transition might not yet have taken place when a disaster is threatening.

**Critical-Medical Anthropology and Health Policy**

Critical Medical Anthropology “balances concern for unbiased social science with an awareness of the sociohistoric origin and political nature of all scientific knowledge” (Castro and Singer 2004; xiv). For this reason, I highlighted the history behind the concept of senility, dementia and Alzheimer’s disease. The fact that Alzheimer’s disease is correlated with aging means that there is a continued debate about what is “normal” and “abnormal” aging. The categorization of the dementias is also a contested and politically charged debate. Funding streams for the study of the biological origins of the disease are also tied to the knowledge base. Critical Medical Anthropology includes an analysis of i) historical context, ii) health policy, iii) the feminization of caregiving, iv) political economics of Alzheimer’s disease, v) political economics of caregiving.

**i. Historical Context.**
In chapter 3, I outlined the history of senility, dementia as a “normal” part of aging and the naming of Alzheimer’s disease. I did this to contextualize the current issues
in surrounding dementia causing diseases and to highlight the questions that continue to be asked today: Is aging pathological? If it is pathological, what does that do to personhood and social status of older adults? Science, though seemingly objective, is in reality a contested and politically laden process.

ii. Health Policy and Critical Medical Anthropology.
This concept is mentioned as background for Critical Medical Anthropology. While there is a great deal of literature on Anthropology of Policy coming out of Britain, I don’t believe it is useful for this research largely because, policy itself is inadequately defining policy. Since this work is not as applicable as other theories, it is not discussed in detail. There is a brief mention of the field to lead into critical medical anthropology and health policy. I have added this justification as a footnote. Critical medical anthropology also “acknowledges the fundamental importance of class, racial and sexual inequity in determining the distribution of health, disease, living and working conditions, and health care” (Castro and Singer 2004; xiv).

iii. Caregiving is Gendered.
The vast majority of caregivers are female. Since there is a high rate of caregiver burden among people who provide care for someone with dementia, and this caregiver is more likely to be female, more women are bearing the increased morbidity and mortality. Critical Medical Anthropology sees to examine why these patterns exist. I argue that the gendered nature of caregiving can impact disaster planning and response. Female caregivers, who have operated within traditional social roles, might be more reluctant to contradict their fathers or husbands, especially in the early stages of the disease. Furthermore, size differentials between males and females can make evacuation and care
more difficult, as was demonstrated by concerns raised by some of the female caregivers interviewed.

iv. Political Economics of Alzheimer’s.

Anyone can get AD but people with more education have a “cognitive” reserve… at least, they tend to score better on the tests designed to measure loss (Albert 2004; Stern 2006). It is important to note, however, that how a person performs on the MMSE is influenced by socio-cultural and economic factors, such as age and level of formal education (Albert 2004). Those with more education, for example, tend to have higher median scores regardless of dementia status, suggesting that these influences must be considered when interpreting scores (Albert 2004:140; Stern 2006). Lower education levels are often linked with lower socio-economic status and higher morbidity rates in general (Muller 2003). Education as a confounding factor highlights one of the many bio-social aspects of dementia and highlights the difficulties in measuring interactions between biological processes, social factors and disease (Stern 2006). Nonetheless, researchers have used the MMSE to measure the severity of dementia. They have found that psychiatric symptoms, such as wandering and fecal smearing (scatolia), vary with the severity of dementia with probable AD (Lopez et al. 2003; Scarmeas et al.2007; Ata et al. 2010.

v. Political economics of Caregiving.

One concern with a decentralized, community based approach to long-term care, is that there is very little oversight or regulation of the quality of care. During disasters, caregivers might not be equipped to keep their family member safe. Conversely, nursing homes are required to have comprehensive emergency management plans that keep the residents’ safety as the utmost priority. It is possible that PWD might be safer with an
organized and centralized plan, such as those found in nursing homes than in the
decentralized, community based setting.

However, not everyone is capable is willing to be an informal caregiver. There are
situations where caring for PWD in the home can put both caregiver and PWD at risk.
Medicaid funded nursing home beds are necessary for when a person’s medical needs
extend beyond the informal caregiver’s capacity. The shift toward home and community
based care comes with it a dismantling of necessary social services such as Medicaid/
Medicare and Social Security which have been put in place as a safety net for aging
Americans (Polivka and Estes 2009; Polivka 2011). The emphasis on home and
community based care has many connections with deinstitutionalization of the 1980’s,
which stripped down social supports without adequate support in the community to help
transition those with special needs. Some people may be providing care in the
community simply because they do not have the resources to pay for institutional care but
cannot find a Medicaid funded placement.

**Anthropology of Disasters**

Anthropology of disasters contributes two primary concepts that are applicable to my
research: i) the use of the pressure and release model (PAR) to analyze risk and
vulnerability and ii) considers how age and ethnicity might factor into the decision
making and disaster response.

1. **Adopting the PAR models.**
   The pressure and release mode (PAR) allows for a conceptualization of the
different kinds of social factors that might impact vulnerability (Wisner et al. 2005).
When the structural conditions create a vulnerable population, then this collision creates a
disaster (Appendix V). The authors of this model suggest that risk is defined by a hazard (such as a hurricane) multiplied by vulnerability (or R=H x V). This tool is used to demonstrate how disasters have a differential impact on vulnerable populations.

This model considers “root causes”, which include economic, demographic and political processes, are the most important factor in determining vulnerability (Wisner et al. 2004: 52). The next phase (or layer) of vulnerability is conceptualized as “dynamic pressures”. Dynamic pressures “are processes and activities that ‘translate’ the effects of root causes both temporally and spatially into unsafe conditions” (Wisner et al. 2004:53) Examples include skills, learning, and local institutions as well as other macro-level factors, such as rapid population growth and urbanization.

I believe this conceptual model is an excellent way to explain how complex structural vulnerabilities that translate into differential risk and unequal mobility and mortality. I used this model to explain the ongoing vulnerabilities that exist in the Lake Okeechobee area.

ii. Age/ ethnicity and Disaster decision making during disasters.

Older populations have been found to be less willing to evacuate than younger populations. Eisenmen, Cordasco, Asch, Golden and Glik (2007) found that elderly may have refused to evacuate and therefore, younger family caregivers chose to stay behind with parents. This illustrates how family members can influence each other’s decisions about how to respond to a disaster. My research also showed that some caregivers decided to stay in their home during a storm because the PWD refused to leave. I argue that this might be related to the social roles that people take on within their family network. In the earlier stages of the disease, caregivers might still be attached to their social roles as “son” or “daughter” and, as such, might be uncomfortable challenging
their older parent. Some spousal caregivers might have had a pattern of deferring to their spouse and have not yet transitioned into a caregiver role who manages important household decisions. Loboprabu (2006) describes the caregiver’s transition from “their family role as spouse or adult child to caregiver, and ultimately from the caregiver stage to that of care manager” as a necessary response to the progressive cognitive deterioration of the PWD. She argues that these steps allow for separation from the impaired PWD as he or she is less able to reciprocate (2006: 95). In the earlier stages, this transition might not yet have taken place when a disaster is threatening.

**Toward an Anthropology of Dementia and Disasters**

Working towards an “Anthropology of Dementia and Disasters” must include A) current theory from the disability and disasters and B) concepts from public health. Disability and disasters incorporates critical disability studies. These theories include: i) the critique of the “vulnerability” concept; ii) “shifting vulnerability” and moving toward “vulnerable situations” rather than “vulnerable populations. I revisit these concepts in the following pages and argue for an aware use of the term of “vulnerability”. I posit that researchers should seek to educate and engage the policy makers about the meaning behind vulnerability and what can be done to reduce factors that cause it.

The second set of components come out of Public Health. Important concepts from public health include: i) lay conceptions of risk and ii) Risk communication.

**Disability and Disasters/ Critical Disability Theory**

Adams et al. (2011) found that after hurricane Katrina, there was a “lack of government infrastructure for caring for the evacuees, particularly the elderly” (254).
Anthropologists argue that the failure to include mechanisms for keeping the elderly (and other vulnerable populations) safe is rooted in a “one size fits” all disaster planning paradigm (Fjord 2007). This paradigm includes only those who are “able bodied” that have the means (such as money and access to a) to prepare and evacuate. This type of overarching plan excludes any person who “temporarily or permanently cannot see, hear, move, cognize, and cope during and after a disaster (Fjord 2007:53). This is particularly true for people with Alzheimer’s disease or related dementias as is illustrated by my finding that they are excluded from special needs shelter services.

i. The Vulnerability Concept Critiqued.

Fjord 2007 argues that the vulnerability concept might be used to justify differential losses by presenting the public images of the “expected dead”. For example, presenting images of hurricane victims dead in their wheel chairs might imply that they are dead because of their disability, not the systematic social exclusion and lack of proper planning. Fjord and Manderson (2009) argue that it is the social environments that are disabling, not the impaired body of the individual. This is known as the social model of disability. Many individuals with a disability can function within society as long as there are alterations made to restrictive environments. Fjord (2007) implicitly references the social model of disability when she argues that disaster planning policies are disabling large segments of the population because they are not “normal” and are “special needs”.

While I agree that the vulnerability concept might be misconstrued by lay populations, I argue that it is still a very important concept. Researchers working in the realm of disability and disasters must be cognizant of the potential for vulnerability to be misconstrued. I argue that it is the researcher’s job to connect the concept of vulnerability to the social, political, economic, and historical context that placed them there.
Communicating these connections are central to the Social Sciences in general and Anthropology in particular.

ii. Vulnerable populations versus Vulnerable Situations.

Fjord and Manderson argue that “vulnerable persons” ought to be conceptualized as “vulnerable situations”. They use Wisner’s (2007) concept of “shifting vulnerabilities” to argue that vulnerability is a situation “which people move in and out of over time” (Fjord and Manderson 2009: 67). The benefit of thinking of “vulnerabilities” as “shifting” is that one can then “split apart the embodied or social characteristics of an individual or group from the social situation that cause differential burdens of harm” (2009: 67).

I find the concept of shifting vulnerabilities particularly helpful because a disease, such as Alzheimer’s, also shifts over time, thereby changing a person’s relationship to the social and policy environment. Shifting vulnerability fits nicely with the fact that AD is progressive and changes over time. Therefore, a family’s situation, and correlating vulnerability, can also change over time. Disaster plans and services need to reflect those changes. Nonetheless, some populations continue to bear a greater burden of morbidity and mortality than others. The reasons behind this disproportionate loss must be examined, highlighted and communicated to the population at large. This is because Critical Medical Anthropology, “asserts that its mission is emancipatory: it aims not simply to understand but also to change culturally inappropriate, oppressive, and exploitative patterns in the health arena and beyond” (Castro and Singer 2004; xiv). In short, Critical Medical Anthropology “sees commitment to change as fundamental to the discipline” (Castro and Singer 2004; xiv). As suggested by the Critical Medical
Anthropology’s mission, this information must be used to address the structural inequalities that exist within the social, political, and economic frameworks.

Fjord and Manderson argue that the population at large can benefit from an expansion of disaster response services, not just “special needs populations” (2009: 64). FEMA is now requiring that all shelters, not just special needs shelters, are equipped to accommodate people with functional disabilities (FEMA 2010). I feel that this move toward inclusive disaster shelters is ultimately a good one. I believe that all Red Cross Volunteers should be trained in the unique needs of disabled populations, especially frail elderly, since this is a rapidly growing population. There are some concerns that will need to be addressed for a successful implementation of this plan, especially the chaotic environment. People with dementia might benefit from a separate room or area with less stimulation. Furthermore, it may be difficult to find enough volunteer nurses to staff all of the shelters since many nurses are required to report to duty for their primary employer.

Public Health/Risk Identification/ Risk Perception

There are two primary concepts that are relevant for my research findings: 1) disability and disasters, 2) risk communication. Many people do not perceive themselves at risk even if, in epidemiological terms, they have a high probability of being impacted by an illness/ disaster event.

In public health, “risk” is often used as synonym for “danger” (Lupton 1999). Lupton, however, recognizes that there are two different kinds of risk: 1) environmental (over which individual has very little control) and 2) risk behaviors, resulting from lifestyle choices (where individual supposedly had a lot of control (Lupton 1999; Nichter 2003). During Katrina, people were blamed for not taking the precaution of evacuating
the city. Little consideration was given as to why people might not have evacuated, such as physical illness, frail elderly who have difficulty with mobility, or lack of financial resources.

i. Lay Conceptions of Risk.
   People must believe the risk exists before they engage in risk reduction procedures, such as creating a disaster plan. 1) believe the information provided by governments is valid and that safeguards will be in place.

ii. Risk Communication.
   It is the role of public health professionals to communicate risk to public. The Cone of Uncertainty is often used to communicate risk about a hurricane’s trajectory. People seem to have a good amount of trust in this “expert generated” picture. The Saffir-Simpson Wind Scale is also used for people to determine the level of risk they think they face. When interviewing caregivers about their hurricane plan, they reported that the category, or expected strength of the storm, influences their decisions about whether they should evacuate or not.

Behavioral Modification

There are several approaches to behavioral symptoms associated with Alzheimer’s disease and related dementias (such as anxiety, pacing, and aggression). Pharmaceutical interventions are commonly used. Here, I will discuss interventions, i) Medical, ii) Validation Therapy and Therapeutic Activities, iii) Reality Orientation, and iv) Music Therapy.

i. Medical and Behavioral Interventions.
   As discussed under the biomedicine section, there are a number of pharmaceutical approaches to dementia related behaviors (antipsychotics, antidepressants, cholinesterase
inhibitors, memetamine). Most of these interventions are only available with a medical consultation and official diagnosis. If behaviors begin to emerge during a disaster event, it is unlikely that access to these medications will be possible.

ii. Validation Therapy and Therapeutic Activities
Though validation therapy, time disorientation and other therapeutic activities (such as playing with dolls) might not fit with generally accepted responses to dementia, I believe that they are less stress inducing than other alternatives (James 2006). The PWD remains happy when you address their reality and are willing to work with them. I recommend trying these methods in stressful situations to avoid confrontation and escalating behaviors

iii. Reality Orientation and “Age Appropriate” Activities.
Some scholars, such as Salari (2001; 2005) argue that age appropriate activities should be implemented over other therapeutic activities. While, this argument is well intended, I believe that it can also be denying PWD several other therapeutic options. For example, allowing PWD in the late stages of dementia to play with dolls can be a soothing activity. To deny people soothing activities, in my opinion, is linked with “reality orientation”, which can cause more anxiety and agitation (Feil 1985; Feil 1993; Morton and Bleathman 1991). I argue that whatever activities a PWD prefers (as long as it is safe and not encroaching on the rights of others around them) they should be allowed to do it. If a person with dementia thinks they need to go to work, tell them it is Saturday, or tell them that they “just got home from work” and that they can relax now. If the PWD is trying to engage in a dangerous activity, try to redirect with another activity. If the activity is not dangerous, pacify and allow it. Ultimately, the PWD’s happiness should be the first priority in a therapeutic care setting such as a specialized adult day center.
iv. Music Therapy.

Music therapy has shown statistically significant changes in problem behavior (Kong et al. 2009). I recommend singing a familiar song in stressful situations to distract and redirect when there are anxiety related behaviors (including violence, pacing, and yelling).

v. Stages of Alzheimer’s Disease.

During various stages of the disease, symptoms such as wandering, pacing (potentially leading to elopement), impaired judgment (wearing clothing inappropriate for the weather, which can lead to dehydration or, conversely, hypothermia), and/or agitation (possibly leading to violence) might become a concern. These symptoms, should they happen during a disaster event, can be exponentially dangerous. In the conclusions and recommendations (at the end of this chapter) I outline techniques and preventative measures that caregivers can use to appropriately reduce negative outcomes for both themselves and the PWD.

Comparison to National Demographics and Disaster Preparedness

In this section, I contextualize the ACC population within national and state trends. First, I will compare the ACC caregiver demographics against the national caregiver statistics. Secondly, I will review national disaster preparedness trends (which are not caregiver-specific) and compare them to the ACC caregiver’s disaster preparedness indicators (such as having a disaster kit or needing shelter).

An estimated 5.4 million Americans had a diagnosis of Alzheimer’s disease in 2011 (450,000 of whom live in Florida), and there are 1.4 million unpaid caregivers providing for their needs (Alzheimer’s Association 2011). Nationally, fifty percent of unpaid caregivers of people with Alzheimer’s and other dementias live in the same
household as the person for whom they provide care (Alzheimer’s Association 2011). Conversely, 92.9% of the caregivers surveyed in this study reported that they lived in the same location as the PWD, which is nearly double than the national average. This may indicate a higher level of personal involvement overall. There may be a kind of participation bias because people with greater involvement might be in greater need of support services. Conversely, this arrangement might be out of necessity, reflecting a lack of resources, which would allow for partially supervised assisted living facility placement. These topics were not drawn out in the interviews in any detail as they were not the primary focus of the study. None of the caregivers I spoke to indicated that they would prefer to have their family member in a nursing home. By the end of the study, however, two of the twenty families I had interviewed had enrolled the PWD into a nursing home (because the caregiver was no longer able to provide care in the home). Two other families lost the PWD in the end stages of the disease in their own home.

In the US, 60% of family and other unpaid caregivers of people with Alzheimer’s disease and other dementias are women (Alzheimer’s Association 2011). My research confirmed this gendered caregiving trend. According the to the caregiver survey (which included families who were receiving services such as family nurse consultants, case management, and adult day services), this population was 62% female and 38% male, which is only 2% higher than the national average of female caregivers. When considering only the participants utilizing adult day care services (the population from which the disaster plan review was drawn), 74.1% of the caregivers were female, which is 14.1% higher than the national average (of female caregivers).
While it is possible that male caregivers are less likely to utilize adult day services than female caregivers, it is also possible to speculate that gendered nature of this finding might be tied to: 1) relationship to the PWD or 2) caregiver employment status. In an attempt to tease out some of these associations, I ran a chi-square (cross-tab) analysis to explore the caregiver relationship to the PWD and gender. Female adult children were more likely to provide care for a parent than a male child at nearly a 3:1 ratio. This skew is far greater than would happen by chance, indicating that other factors are at play.

Critical Medical Anthropology calls for an analysis of the reasons behind these gendered trends because it “…acknowledges the fundamental importance of class, racial and sexual inequality in determining the distribution of health, disease, living and working conditions, and healthcare” (Castro and Singer 2004). Normative gender roles, which often relegate women to “domestic” tasks such as childrearing and caregiving, are likely underlying reasons for these trends. This study confirms that, whatever the reasons, there is unequal sharing of caregiving responsibilities (United Nations Expert Group Meeting 2008).

Since adult child caregivers are overwhelmingly female, it is likely that adult day service use is primarily used by female adult children. Adult children are more likely than spouses to be younger than retirement age (and therefore, more likely to be employed than spousal caregivers). Employment might be a reason for the high use of adult day centers by adult children, and, therefore, might explain some of the results.

Nationally, over half of the caregivers were adult children of the PWD (52.1%) followed by spouses at 32.8% (Alzheimer’s Association 2011). The caregiver survey (which, again, was sampled from families receiving a full range of services through ACC,
not just the adult day centers) revealed a different demographic pattern. The most common relationship between the caregiver and the PWD in this population was that of spouse (48.6%), followed by adult child (38.7%). This is likely because the sample population for the survey was older than those who only utilized the adult day services. Older caregivers might choose not to send their family member to adult day centers because they are retired and do not need to go to work, however, they may find other types of respite services offered by ACC useful. Nationally, 44% of caregivers for PWD are employed full or part-time (Alzheimer’s Association 2011). The data from caregivers surveyed (those using all services, not just adult day care) indicated that fewer than 37.5% ACC caregivers worked full- or part-time (which is 6.5% lower than the national average). It is possible that the populations utilizing the adult day centers are more likely to be employed than those who chose not to; however, this will take further analysis to be certain.

Research has pointed to the different levels of caregiver stress experienced by spousal caregivers and adult children, which also might elucidate reasons for different service utilization. For example, Cho, Zarit and Chiriboga (2009) found that wives tended to become more overwhelmed than daughters and, therefore, were likely to seek nursing home placement earlier. By contrast, the use of adult day centers among daughters delayed admission to nursing homes (Cho et al. 2009). If one considers concepts such as risk fatigue, female spousal caregivers might be more at risk than adult daughters (again, pointing to the importance of social roles within the caregiving dynamic). The concept of risk fatigue will be explored later in this chapter; however, further research is needed to explore associations.
It is possible that there are differences from the national average because different subsets of the population are using different types of services through ACC. Nonetheless, understanding which caregivers utilize which services can be useful, and might lead to further insights in disaster planning. Research has shown that adult child caregivers tend to get more benefits from interventions and formal support than do spouses (Sorensen, King, and Pinquart 2006).

An important consideration is that female caregivers are most likely to be making the disaster planning decisions in their household. Those participating in adult day care centers are more likely to be adult daughters and those who are utilizing FNC or case management services only are more likely to be wives. Thus, it would be important to understand if there are gendered differences in disaster planning and response decisions. For instance, men might tend to be more able with tasks such as loading cars, lifting supplies, and physically supporting the PWD. This was evident in one of the caregiver interviews, where one woman partnered with her neighbor to put up hurricane shutters. Secondly, predetermined gender roles might make more difficult for wives or daughters to take on the role of dominant decision maker in an emergency, at least and especially when the PWD is in the early stages of the disease. As was illustrated in the caregiver interviews, some female caregivers were met with resistance when they felt that it was time to evacuate. One spousal caregiver in particular described how difficult it was to convince her much taller and larger husband that they needed to evacuate from the path of a storm. She contended, however, that in the later stages of the disease, there would be less resistance.
ACC Caregiver Preparedness Compared with National Averages

According to the 2007 FEMA Citizen Preparedness Review, 57% of the general population reported that they had absolutely no emergency preparedness plan. Similarly, according to the baseline disaster plans at ACC only 46% (n=134) were without a hurricane plan. This means that ACC caregivers appeared to be better prepared by approximately 11% upon the initial review. By June 2011, however, nearly all of the families attending the adult day centers had an emergency contact and basic disaster plan. Similarly, 50% of the general (national) population said that they have a disaster kit. The number of caregivers surveyed at ACC who reported having a disaster kit was higher than the national average at 67.6%. The raw statistics, however, might be deceiving, however. During the caregiver interviews, I asked the caregivers whether they had a disaster kit for sheltering in place, and how they decided what was important for such a kit. During the interviews only 25% (n=5) had an actual disaster kit that was specifically set aside for an emergency. Most other caregivers had supplies on hand, however, they were not designated to be used only during an emergency. The advantage of having a disaster kit set aside specifically for a hazard event means that the supplies are less likely to be used before an emergency strikes. Furthermore, a kit might allow for people to easily grab the needed supplies should a late evacuation become necessary. However, most of the caregivers were knowledgeable about what ought to go into a disaster kit, or at least, where to find pertinent information (i.e. local grocery stores). Of the general population, 11% said that they would not evacuate, even if they were ordered to do so (FEMA Citizen Corps 2007). During the baseline disaster plan review, over half of
caregivers, 51.7%, said they would not leave, even if ordered to do so. This is much higher than the general population, and yet in a geographic location especially vulnerable to hurricanes. During the follow-up review, the number dropped to 32% who would not evacuate. During the follow-up review, caregivers were asked to specify whether they would evacuate for a category 1-3 storm or a 4-5 storm. More individuals said they would evacuate if mandated when they were asked to consider the strength of the storm. However, the 32% who said they would not evacuate, regardless of category, remains higher than the national average (11%). Why these families did not want or could not evacuate, even if mandated. It is possible that they felt that their home was strong enough to withstand a category 5 storm, (which is why the caregiver survey was designed to assess the safety of caregiver’s homes). Others might simply not know what the alternatives are.

Some staff felt that their clients’ disaster planning improved because of their involvement with ACC. During my observations at the center, many caregivers were initially resistant to staff asking them to draft a disaster plan. They seemed initially overwhelmed by the prospect of something that seemed either unlikely, or at least, not immediate. However, the ACC policy to ask for basic plans did seem to force caregivers to think about the possibility of a hurricane createa basic plan. I would also posit that disaster plans were more likely to be thorough when the staff believed that it was an important document. If they shared a caregiver’s skepticism, then they might be less likely to probe for answers.

The caregiver survey also gave some insight into the types of housing that the majority of the caregiving population lived in. The safety of the home and having funds
set aside for recovery suggest that most caregivers will be likely to recover from hurricane damage.

Overall, this study revealed that ACC caregivers appear to be more prepared than the general US population (in terms of having a plan and disaster kit readiness), even though a much higher percentage said they would not evacuate in the event of a hurricane, even if ordered to do so.

**Stages of AD and Related Dementias, Personhood and Disaster Planning**

Though the staging of AD might be a social construction, as outlined in Chapter 2, it remains an important and useful tool for understanding caregiver concerns before and during a disaster. In this study, caregiver interviews revealed a significant change in PWD response to risk associated with disasters over time, for which an understanding of the stages of the progressive disease is especially useful. This research revealed that the staging of AD can have several impacts on disaster planning: 1) whatever experience a caregiver might have had during hurricanes in the past might be negated by changes in the PWD cognitive status in the future; 2) PWD remain self-aware of their preferences throughout the early disease, which means they may not share as the caregivers assessment of risk during disasters; 3) in the early stages, especially, PWD might feel the need to assert their independence and individuality to combat the sense of loss of social status and social roles (as adult, husband, wife, mother, father).

Anthropologically speaking, the aspects of personhood and social roles are powerfully present in this finding. As the ACC administration stated:

*You can lose your judgment without losing your intelligence... In that case, the judgment doesn’t allow me to understand the ramifications of not going somewhere in a disaster, but your intelligence is there saying, ‘You*
are trying to tell me to do something I don’t want to do. That is there. And boom. That is very common in the early stages especially.

Throughout the early and middle stages of AD, people are still self-aware. They know what they want and do not want, which can impact disaster response.

Table 8.1 Anthropological Concepts

- Biomedicine
  - Diagnoses and Measuring Loss of Cognitive Abilities
  - Stages of Alzheimer’s Disease (MMSE/FAST)
  - Increased Dependence Upon Others
- Anthropology
  - Deconstructs the historical, political-economic context.
  - Loss of Personhood/Social Roles (adult, citizen, spouse)
- My Research
  - As the disease progresses, disaster planning needs will change.
  - The social dynamics within a family response to a disaster is more difficult in the early stages.
  - Liminal Space of People with Dementia in Biomedicine and Policy

Contrary to what I had assumed, caregivers reported that they had more difficulty when someone was in the early stages of dementia, rather than the later stages. PWD were resistant to evacuating even if, according to the cone of uncertainty, the hurricane was predicted to be a direct hit. This was because caregivers had more trouble negotiating with a person in the early stages when judgment is impaired (however, the ability to argue is not). Caregivers did not expect to have the same problem with people in the later stages in the early stages of AD. I had assumed, initially, that the later stages -- with more medical problems, more equipment to rely upon, and less mobility -- would be more difficult for them. This research contradicted this assumption. While I was collecting data
in 2011, there was not a hurricane and so I did not have an opportunity to observe this process. I did, however, discuss hurricane experiences with 20 caregivers.

A PWD may have many strong emotional and cognitive reasons for resisting evacuation or challenging caregiver’s decisions before, during, and after a disaster. They might be uncomfortable with the prospect of leaving familiar surroundings, where they can still maintain a sense of control. When I asked ACC staff and administrators why this changed in the later stages, they speculated that the PWD’s capacity to argue becomes less. Further research on PWD in the early, middle, and late stages is necessary to explore this finding further.

In the middle stages of the disease, a PWD dementia may experience time disorientation. The desire to “go to work” or find something or someone that the PWD perceives as lost can be an antecedent to wandering, elopement and becoming lost. This is something that caregivers must consider when evacuating with a PWD during a chaotic event.

Older populations have been found to be less willing to evacuate than younger populations. Eisenmen, Cordasco, Asch, Golden and Glik (2007) found that elderly may have refused to evacuate and therefore, younger family caregivers chose to stay behind with parents. This illustrates how family members can influence each other’s decisions about how to respond to a disaster. I also found that some caregivers decided to remain in their home because the person they were caring for refused to leave. This might be related to the social roles that people take on within their family network. In the earlier stages of the disease, caregivers might still be attached to their social roles as “son” or “daughter” and, as such, might be uncomfortable challenging their older parent. Some
spousal caregivers might have had a pattern of deferring to their spouse and have not yet transitioned into a caregiver role who manages important household decisions. Loboprabu (2006) describes the caregiver’s transition from “their family role as spouse or adult child to caregiver, and ultimately from the caregiver stage to that of care manager” as a necessary response to the progressive cognitive deterioration of the PWD. She argues that these steps allow for separation from the impaired PWD as he or she is less able to reciprocate (2006: 95). In the earlier stages, this transition might not yet have taken place when a disaster is threatening.

During various stages of the disease, symptoms such as wandering, pacing (potentially leading to elopement), impaired judgment (wearing clothing inappropriate for the weather, which can lead to dehydration or, conversely, hypothermia), agitation (and possibly violence) might become a concern. These symptoms, should they happen during a disaster event, can be exponentially dangerous. In the conclusions and recommendations (at the end of this chapter) I outline techniques and preventative measures that caregivers can use to appropriately reduce negative outcomes for both themselves and the PWD.
Anthropology of Policy and the Liminal Position of Alzheimer’s disease in the Policy and Public Spheres

The anthropological concept of “loss of personhood” or “bio-social death” was not explicitly addressed by caregivers because the focus of the study was on hurricane preparedness, not the emotional experience of caring for someone with dementia. They were, however, poignantly aware of the progressive nature of the disease and its implications. They spoke positively about the services offered through ACC, which allowed them time to work, run errands or have some alone time. They often told me (and legislators) that these services allowed them to continue to care for their loved one in their home.

Several of the caregivers became politically involved, writing letters to legislators or joining the advocacy trip to Tallahassee to visit with lawmakers. The requests they made of legislators were usually very specific, about the Silver Alert legislation, Alzheimer’s disease Initiative funding, or legislation to improve state standards for dementia-specific adult day centers. The concept of personhood was often implicit in their appeals to legislators. For instance, on the trip to Tallahassee (November 2011), caregivers spoke passionately about how the adult day center programs helped them continue to give care in the community (and how this was more economical for the state) and the positive effect for the PWD. They stressed the importance of socialization, such as the activities and exercises that were incorporated into the adult day center programs that increased their family’s (both PWD and caregivers’) quality of life. They noted that
it allowed people with AD to have some latitude to “be themselves”, in spite of the disease.

These activities expand the recognition of AD within the biomedical and political arenas, thus improving recognition on both interpersonal level and the larger scale social, political and economic levels. ACC has helped caregivers and PWD become recognized as an identifiable and politically important group, both at the local county level and, increasingly, at the Florida state level. However, several challenges remain. ACC struggles to convince leaders in surrounding counties to adopt more dementia friendly policies. The most salient example is the exclusion of PWD from many SpNS.

As noted in the theoretical background chapter (Chapter 5), people with dementia are often in a liminal position because family, friends, and legislators have trouble categorizing them as either fully “alive”, though they breath and observe, or fully “adult”, though their age defines them as such17 (Douglas 1967; Turner 1969; Kaufman 2005; Taylor 2008). ACC administrators have repeatedly expressed frustration about the inappropriate pigeonholes in which AD has been placed (such as aging, mental health, or disability rights issues). For example, monies from the Alzheimer’s Disease Initiative (ADI) are administered through the Area Agencies on Aging. Agencies need to compete for the designation of “lead agencies” to receive these funds for individuals in need. The fact that Alzheimer’s disease can strike a person as young as 40 suggests that the Area Agencies on Aging may not always be the best providers for dementia care.

Funding for AD and related dementias is frequently relegated through the Department of Elder Affairs, Mental Health Services and the Agency for Persons with

17 See Behuniak (2011) for an analysis of comparisons between people with Alzheimer’s disease and zombies.
Disabilities. Though aging, mental health and disabilities are associated with AD, none of these categories alone are equipped to address the complexity of AD. Waivers filtered through these programs often fall short of meeting the specific needs for people with dementia. As discussed in the History and Background chapters, Florida Medicaid Alzheimer’s Home and Community-Based Waiver Program failed to be implemented because of the way in which “home and community-based” and “nursing home admissions” were defined.

As legislators increasingly cut funds for skilled nursing care in institutionalized settings, it is important that organizations such as ACC continue so that families are supported and have access to resources. Without careful planning and funding for community-based safety nets (such as adult day centers, family nurse consultants and caseworkers), caregivers will be less able to provide quality care in the community.

Classical Medical Anthropology, as exemplified by Kleinman (1978; 1980), and Helman (1981), distinguishes between the categories such as “illness” and “disease”. In The naming of the disease legitimizes it and allows for a disease process to be organized into categories and understood as a process. Sometimes, these categories and named diseases continue to instill fear and discomfort in other “well” people in society. The ability necessity of categories is explained by Goffman (1963) in terms of “stigma”. Douglas describes a similar phenomenon of “symbolic pollution”, which is the result of a person or thing that does not fit neatly into clear categories. While this may seem abstract, the fact that Alzheimer’s disease remains difficult to categorize has concrete, observable consequences in practice (as is seen in public and policy responses).
Special Needs Shelters and the Anthropology of Health Policy (Critical Medical Anthropology)

The theme of liminality emerges again when examining dementia care in SpNS. Initially, as participants in this study noted, people with dementia in Palm Beach County were not allowed to use the SpNS. However, there were also no other alternatives. Thus, people with dementia are in a liminal space: they might have special needs, but they are not physically “sick”, which some local governments have used to exclude them from services. It seems that local governments’ view of PWD is that they are neither dead, nor fully alive, but they are most certainly threatening to the order of hurricane shelter efforts. Initially, the SpNS in Palm Beach County was also resistant to allowing people with dementia into the shelters unless they also had a physical disability. While this has changed with ACC coordination, there are not provisions for PWD in Martin or St. Lucie counties (not to mention the rest of Florida).

This has a major impact on caregiver disaster plans. The baseline disaster plan review revealed that 40 caregivers reported that they planned on going to “a shelter”. When compared to number signed up for a special needs shelter (SpNS), there is a disparity: only 10 of these 40 individuals were actually signed up for a special needs shelter. Some of these individuals lived in Martin or St. Lucie counties, where the SpNS did not actually offer any support for a PWD. Others were located in rural and underserved Pahokee. Staff explained that most families preferred to go to the local shelter at the school, because they could evacuate as a family (the SpNS only allows the person with a disability and one caregiver to attend). They also preferred to stay close to their property, which was vulnerable to crime if left unattended.
Local government seemed to have a great fear of “being overwhelmed” and did not seem to want people to know about the full range of services available. For example, the Palm Beach county informational pamphlet clearly states that they do not accommodate pets at the SpNS. I was told by EOC staff, however, that if someone arrives with pets, they have an arrangement with a local kennel to house them (as long as they bring the supplies). The county consciously withholds this information, according to one participant, to prevent people from (over-)utilizing this service. Research has shown, however, that people might choose to remain in unsafe conditions rather than abandon their pets (Solis et al. 2009). According to the American Red Cross (2007), only 37% of the populations who have pets have a plan for their pets in case of disaster. However, only 4% said they would not comply with an evacuation order and stay at home with their pet (FEMA’s Citizen Corps Report 2007). The vast majority “would bring pet along if ordered to evacuate, regardless if they were accepted in hotels” (ARC 2007); however, there is not any information about what people would do with their pets if they were in need of shelter services. Two of the caregivers I interviewed had seriously considered the plight of their pets when crafting their disaster plans. Both of these, however, were financially stable enough to afford accommodations for their animals. The county’s policy of withholding this service might influence people who cannot afford pet-friendly alternatives to stay in their home in unsafe conditions. This runs the risk of marginalizing the not only those who are innately frail (if they qualify for SpNS) but also from lower socio-economic backgrounds. In other words, they run the risk of discouraging those who might need the services the most.
The trend of excluding PWD from social safety nets is not unique to special needs shelters. PWD are also systematically excluded from clinical trials for a wide range of illnesses (Taylor, DeMerse, Vig and Borson 2012). Taylor et al. (2012) reviewed articles in the Journal of the American Geriatrics Society and determined that persons with cognitive impairments are frequently excluded from research “often without rationale or mention of exclusion as a limitation or any discussion of its potential effect of the evidence base in geriatrics” (1). When a PWD is excluded from clinical trials for cardiac medication, for example, the outcomes might be slightly skewed, especially for those with a vascular dementia. Nonetheless, cognitive impairments pose a challenge to offering services and medical services that are not explicitly designed for PWD. For this reason, identity politics may have an increased importance for PWD to stress the necessity of their inclusion in medical treatments and social safety programs, such as SpNS.
Tensions between home and community based care paradigm and centralized disaster planning and response

Disaster response emphasizes working in tandem with multiple organizations (American Red Cross) and levels of government (Federal, state and county). Though these organizations are working toward common goals, community dwelling families with dementia have been frequently ignored in Florida. Nursing homes, conversely, have gained some attention in the Gulf Coast states during recent hurricanes. PWD living in nursing homes are more likely to be met with a centralized response to disasters because they are staffed with trained caregivers who are required to report for duty. As community dwelling caregivers have a sharp learning curve and the disease process in the PWD is constantly changing, they may not realize the difficulties they might encounter during a hurricane. Professional caregivers in nursing homes usually have some co-workers seasoned in care during hurricanes, and specialized training.

Furthermore, all nursing homes are required to have a comprehensive emergency plan (in Florida). These plans require contracts and agreements with other skilled nursing facilities and bus companies in case evacuation is necessary. There are no such supports for community dwelling families with dementia. The push for home a community based care, though it has many benefits, has the potential to increase vulnerability during disasters. However, the centralized care in nursing homes is not infallible. As reported during recent hurricanes, these contracts are not always observed (Dosa et al. 2008; Hyer et al. 2007). Furthermore, nursing homes are not always on the priority power restoration list, even though they are providing medical services to vulnerable populations (Hyer et
al. 2009). The advantage of nursing homes in Florida is that they are represented by the Agency for Health Care Administration (AHCA) who has worked towards improving the conditions of nursing homes during hurricanes. Nursing home administrators now know they need to communicate with the providing power company about their skilled nursing status and the need for priority power restoration to care for the residents.
Vulnerability and Structural Violence: Ongoing Concern in the Lake Okeechobee Area

Vulnerability is defined by Tobin et al. (2006) as a systematic circumstance measured by the degree of potential and actual loss of an attribute of individuals or groups characterized by a range of variables that influences exposure and coping abilities. Though, thankfully, a hurricane did not strike this area in 2011, the root causes of vulnerability in this area have remained, namely dynamic pressures and unsafe conditions.

Nestled on the banks of Lake Okeechobee, the towns of Pahokee and Belle Glade still stand as a monument to the large sugar companies that brought prosperity to the area. Upon entering Belle Glade, a sign declares that, “Her Soil is her Fortune”. However, her fortune has lost some luster. The primary sources of employment, “Big Sugar” and the county jail, are both closing down. Unemployment rates are high.

A combination of physical damage from storms and the damaged economy appears to have left entire strip malls and buildings dilapidated and empty. The cinderblock skeletons of what must have once been apartment buildings line the road that leads to the adult day center in the Glades. Canals designed to bring water from Lake Okeechobee to the sugar cane fields crosscut the roads, but few of these canals have rails or barriers to keep a car from slipping in.

Pahokee’s City Hall in sits at the bottom of the dike, with hurricane shutters pulled half shut (I was told that officials have relocated to Belle Glade). A steep climb up the dike and a view of the lake becomes visible. On the other side of the dike is pay-by-
space camping, a boat dock, a restaurant, bar and swimming pool. I asked residents and staff about this area. The locals do not use it, they said. They used to swim in the deeply grooved canals, but the alligators got to be too much of a problem.

Staff members and caregivers alike commented on the accentuated vulnerability of the Lake Okeechobee area, which fit well into the pressure and release (PAR) model of disaster (Wisner et al. 2004). Using the PAR model, which considers the collision of structural factors with a hazard, one can begin to see the tinderbox of factors waiting to be ignited by a direct hit from a hurricane. There are a number of potential root causes, which include lack of access to knowledge, political power, social capital, mobility, resources and acceptance. Staff presented very little information about informal support networks when they were asked directly about them, however, though this did emerge through other questions. One staff member, when describing the population he served referenced the 1928 Hurricane but said, “I don’t think it would be that bad again because we have better warning systems and better shelters. Also, people have cars and family in West Palm Beach that they can go to. The younger generation is relocating, so the other folks have a place to go.” This suggests that extended family can act as a protective factor.

Caregivers were generally knowledgeable about past hurricanes and knew where to get information. One of the caregivers told me that the local community center had an educational display on the 1928 hurricane, and schoolchildren were brought there regularly. Most of the caregivers I visited in the area had a television and/or a radio with which to get information about upcoming hurricanes. Those that did not have a television (n=2) did have access to the internet and a phone. However, most of the caregivers I
spoke to who lived in the Glades were out of work and lived in government housing and had few resources.

Dynamic pressures are also accounted for in the model and include age, mobility, income, and geophysical location. The geophysical location of the area on the banks of Lake Okeechobee (with a weakened dike) contributes dynamic pressure to those living in the area. Most have low income or are unemployed. The program manager that served this area described it as “impoverished” and that many people lacked a high school education. He also explained that, juxtaposed against the poverty in the area, there was also a good deal of money which belonged to the plantation owners. In this area, the leadership tended to be white, while the local population was largely black. This was confirmed with a review of the census data: The majority of the local population is black, at 62.5% (the statewide average is 15.4% of the population) (U.S. Census Bureau 2009). Educational attainment in people aged 25 and older is low; 15.6% have less than a 9th grade education level. Another 17.5% have 9th grade -12th grade educations. This means that a full third of the population (33.1%) does not have a high-school diploma (U.S. Census Bureau, 2009). This is more than double the estimated number of people in the US (over 25 years of age) who do not have a high school diploma (14.4 %).

The number of families living below the poverty level in this area is 21.5%, over twice the number of impoverished families in Florida at 9.5% or the US (9.9%). Though the city of Pahokee is located on the edge of a failing dike, 20% of the population lives in mobile homes, compared with 10% in the state of Florida and 7% in the US, in general) (U.S. Census Bureau 2010).
According to the model, unsafe conditions include gender, race/ethnicity, educational attainment, and physical-structural attributes like housing type (renter vs. ownership). When these factors are combined, they determine levels of vulnerability. Three of the caregivers I interviewed lived in HUD housing. (The survey did not track whether a person lived in HUD housing or not, so this information is not available for context). Though the HUD building were constructed out of cinderblock, they are located in flood zones and do not have hurricane shutters. The federal government does not provide this safety measure to maintain its property or to protect the people who use its service. All but one of the caregivers I interviewed in the area was black. They all had at least a high-school education or equivalent (although only one of the five had a college degree). The crime rate increased after the hurricanes in 2004-2005. Some families are reluctant to evacuate because they fear the loss of their property to theft. Caregivers interviewed expressed concern over the escalation in crime after future hurricanes in deteriorated economy. This means that this population is vulnerable to the damages not only of the hurricane, but to violence and loss that results from the dynamic pressures of poverty. Many may choose not to evacuate (or at least not to evacuate a great distance) because they want to be able to return and protect their belongings from the anticipated looting that has followed hurricanes in the past. Hurricane amnesia might also be a factor in lack of future response to hurricanes. As one staff member said, “it has been a few years since we have had a hurricane and people are becoming more lax.” Additionally, the number of risks that this population faces on a daily basis, especially for people who are caring for a family member with AD, hurricane preparedness might seem superfluous.
Risk Society, the Media, and the Cone of Uncertainty

According to caregiver interviews, most preferred to get their information from the local news. They trusted the local news to provide area-specific information, although some would also double-check with National Oceanic and Atmospheric Administration (NOAA). Based on observations during Hurricane Irene (which approached Florida during the course of data collection for this study), there seemed to be a great deal of trust in the “cone of uncertainty”. Though Irene was only 100 miles of the coast of Florida, there were few preparations or responses because Florida did not fall within the projected path generated by scientists. Schools and adult day care centers were still in session and business carried on as usual. ACC administration told me that they began to take action only when there was a hurricane watch. NOAA defines a hurricane watch as, “an announcement that hurricane conditions (sustained winds of 74 mph or higher) are possible within the specified coastal area. Because hurricane preparedness activities become difficult once winds reach tropical storm force, the hurricane watch is issued 48 hours in advance of the anticipated onset of tropical-storm-force winds” (NOAA Hurricane Preparedness, 2011). Action is taken only when experts have determined that the area in question is at risk. However, hurricanes can change directions (as it did with Hurricane Charley) and in intensity. In short, the experts can be mistaken, however, constant warnings can cause “hurricane fatigue”.

However, the situation is more complex: while there is trust in experts, there were many examples in the data that diverged from this and participants reported assessing risk for hurricanes based on “feeling” and “intuition”, or because the area was “due one”. This
was most often explicitly expressed during the staff interviews. As one staff member explained her perception of a hurricane hitting the area in the 2011 hurricane season,

*It isn’t based on science... it is women’s intuition. We haven't had a good smack in the face in several years. You see all of the other problems going on Australia, New Zealand, Japan... Catastrophic disasters. It is about our turn. I feel uneasy (FNC).*

Nonetheless, during another phase of the project it was clear that little (if any) visible action was taken to respond to a hurricane 100 miles off the coast because the scientists said it would miss the area. It is important to remember that communicating risk requires an understanding of the complex social psychology behind disaster response.

When a population has been repeatedly bombarded by an event, they may become simply overwhelmed, exhausted, and fatigued. Though the result can appear the same – people may not fully prepare or respond, as seen in the lack of evacuations after Hurricanes Jeanne and Wilma – the reasons for lack of action are complex. Some of the data presented here supports previous findings that caregivers might fail to adequately prepare for hurricanes because they have successfully weathered previous storms (Cherry et al. 2010). They may not consider, however, the possible changes in the PWD; for instance, caregivers may not expect resistance or the level of anxiety that can accompany a PWD during a storm.

Factors that influence low levels of disaster planning include lack of information, not understanding the information, a lack of means to respond to warnings, or distrust of agencies or scientists providing the information (Sorensen and Vogt Sorensen 2007). The caregivers interviewed for this study had adequate access to information about how to prepare for hurricanes (e.g., disaster kits) and how to obtain information about a hurricane’s path, but had less information about appropriate shelters should they need
them. Further, some caregivers faced significant financial strain, which prevented them from stocking up on supplies and might make it more difficult to plan for evacuations.

As I argued in the theory chapter (Chapter 5), “disaster fatigue” is only one reason why people might not respond to a hurricane. Instead, I proposed that “risk fatigue” is a concept more suited to the situation of caregivers of PWD, since it describes a type of cumulative risk as the result of multiple exposures to risks of different kinds. In other words, caregivers experiencing high caregiver burden, anticipatory loss, financial stressors, and hurricane fatigue are more likely to have “risk fatigue” resulting in lack of preventative action. It is likely that caregivers living the Lake Okeechobee area are even more vulnerable than most because of the constant stressors of poverty, unsafe housing, and crime they face on a daily basis. Higher caregiver burden can lead to risk fatigue in general, making an adequate response to a hurricane more difficult.

Mental health issues, including posttraumatic stress disorder and depression, have been well documented after hurricanes (Norris et al. 2002; Moore and Moore 1997; Galea et al. 2008). Mental health concerns can also become physical safety concerns, as people who may have evacuated to safety for earlier storms might fail to evacuate after experiencing multiple storms.

18A particularly important aspect of risk is its cumulative nature, when exposure to a hazard occurs repeatedly over time. The degree to which people understand cumulative risk has important theoretical and social implications. Slovic 2000. What does it mean to know a cumulative risk. Journal of Behavioral Decision Making 12 (2) pp 259-266
Application of findings to other disasters

Hurricanes are semi-predictable events in that forecasters can narrow the zone of possible impact down based on a number of environmental factors (i.e. temperature of the ocean, wind direction). These predictions give populations a certain amount of lead-time in order to gather their supplies, prepare their homes and/or evacuate. Other semi-predictable events based on weather patterns include blizzards, heat waves and, often, wildfires. Many of the findings of this research might be applicable to these disasters in particular.

Semi-predictable events.
Blizzard/ Coldwave/ Heavy Snowfall: According to Landesman (2005), “a major winter storm can be lethal”. Most deaths associated with winter storms are related to transportation accidents and hypothermia (3). Hypothermia is defined by dangerously low body temperatures (less than 90 degree Fahrenheit) (4). People with disabilities are particularly at risk for hypothermia since they might not be physically mobile and therefore, less able to generate body heat. As with the hot Florida summers, people with dementia might not be able to judge temperature or choose appropriate clothing for harsh winters. Caregivers who do not live with the PWD might consider staying with the PWD during a blizzard storm to ensure that the PWD does not exit the house without appropriate clothing.

As with the long power outages after a hurricane, winter weather can cause power loss due to snow covered branches breaking and falling on power lines. People relying on electric heating systems might have trouble heating their homes. Homes with wood burning stoves require the ability to lift heavy logs into the fire place.
Water pipes might freeze, making running water unavailable. Families with a wood burner stove can melt snow into water, however, those with central heating might not be able to (unless they have a gas stove). Furthermore, blizzards can be a barrier to accessing necessary supplies.

When reviewing the hurricane disaster plans, several caregivers who did not actually live with the PWD, indicated that they would have the PWD come stay with them during a hurricane. Winter storms should also be taken with the same seriousness.

Wildfires: Can be sudden onset because they often begin unnoticed and then spread, feeding on brush, trees and homes. There are three different classes of wildfires: 1) surface fire; 2) ground fire; 3) crown fire. Common injuries associated with wild-fires include “burns, inhalation injuries, respiratory complication, and stress-related cardiovascular events” (Landesman 2005:22). The direction of forest fires can sometimes be predicted based on wind direction. Evacuating to shelters is often possible. Concerns about PWD being evacuated to shelters without appropriate facilities are applicable in this situation.

Heat wave: A heat wave is a prolonged period of humidity without nighttime temperatures doping significantly. Older adults and infants are highly vulnerable to the deleterious impact of heat waves because (as mentioned in chapter X) older adults have more trouble regulating body temperature. Furthermore, people with dementia might not be able to respond appropriately to the heat and are likely to become dehydrated and suffer from heat stroke.

Sudden onset events.

Many disasters have very little lead-time and, therefore, populations do not usually have much time to gather supplies in case displaced, prepare their homes or
evacuate. Examples of these disasters include earthquakes, thunderstorms, flash floods, mudslides, tornadoes, and volcanic eruptions. While most of the findings of this research are applicable to semi-predictable disaster events, many of the findings related to displaced populations living in shelters after a disaster can be applicable. Disaster survivors who have found their homes destroyed by earthquakes, flooding, mudslides, tornadoes or volcanos may need to spend time in shelters during the recovery phase. The need for dementia specific services with staff trained to respond appropriately to dementia related behaviors remain necessary.

**Limitations**

There are several limitations to the current study. People who lack social networks are very vulnerable, however, this research only considered those who had caregivers. “Live-alones” are at increased risk for injury if they should try to shelter in their homes alone during and after a storm, but they are also at risk if they are relocated to a shelter. This study was not designed to assess the situation of live-alones; however, they will be an important focus for future research.

I also did not interview people with dementia, which might have provided their insight, especially during the early stages of the disease. Finally, ethnicity is ill defined in this study. There were many subcategories tracked in the charts, and ethnicity was not tracked in the caregiver survey. Even if there are trends within and across ethnic groups, this research is not equipped to tease these out in the quantitative data.

This is just a snapshot of one region; other areas might have different concerns.

Other methodological limitations include the small sample size. Even with the best efforts of ACC staff, we were unable to get enough surveys to be able to generalize
about the approximately 1,000 families who participate at ACC. The study does, however, give an exploratory “snapshot” of this particular region of Florida. Other areas in Florida and other states might have different concerns, and disaster planning, especially for those with special needs, can vary widely from county to county.

Another limitation was the fact that this study was conducted in a “hurricane-free” season, so therefore I was unable to observe actual behavior (had to go by what people say, rather than what they actually do in the face of a disaster). In spite of these limitations, I offer preliminary suggestions which, based on my findings, can improve the disaster planning for PWD and their caregivers.

**Conclusions and Recommendations**

The first conclusion derived from this research is that the stages of AD can influence the kind of decisions a caregiver makes in response to a disaster. There is a great deal of ambivalence surrounding the use of SpNS. Furthermore, caregivers have a poor understanding of what unique services are offered at the SpNS, so they often cannot make an informed decision about whether it would be appropriate for their family or not. Informing caregivers of the existence of the SpNS and exactly what they are for should be standard procedure, even if the family is not signed up for this service.

Local government seemed to have a fear of being overwhelmed. As a result they did not want people to know about the full range of services available. While I have not seen how the SpNS operate in action, it seems that they can be improved by collaborating with organizations like ACC, which can augment services for unique populations in need.

Applied anthropology uses anthropological knowledge, methodology, and theoretical approaches to address societal problems (Kedia and Van Willigen 2005). In
essence, it is the goal of applied anthropology to translate findings into tangible goals to improve conditions for stakeholders and the populations we study. Frequently, this translation comes in the form of policy recommendations. My findings and conclusions lead me to make the following recommendations at the federal, state, county and organizational (ACC) levels. The recommendations are grouped as recommendations from, first, the federal level, then the State of Florida, county and, lastly, the ACC level.

My suggestions are based in my participant observation. While volunteering in the adult day centers, I learned what worked and what did not work when trying to manage violence, yelling, or attempts to exit unaccompanied from the building. I had initially thought that my training in the emergency room and with people with cognitive developmental disabilities would prepare me for working long-term with people with dementia, however, I was mistaken. People with dementia do not retain short-term memory. If they burn their hand on a hot stove, it will hurt, but they are likely to forget what caused the hurt. They cannot learn to avoid the stove, while many people with cognitive disabilities can learn and respond to basic conditioning. For this reason, I learned, it does not benefit anyone (the PWD or the caregiver) to argue, yell, or set arbitrary boundaries. Rather, redirection is the most useful technique. When dealing with a client who became very agitated with me (for reasons I could not discern), I eventually learned to take a defensive posture and apologize, regardless of the perceived indiscretion. I also learned that starting to sing a familiar song would distract and redirect. Above all, I learned to remain calm. I learned this by doing, and not without making some mistakes (the techniques I had learned for dealing with aggressive behavior in the emergency room were not at all appropriate here and left me powerless- and the PWD
more aggravated). I did not learn these techniques from a book or even an interview. I learned because I volunteered for 10 months, two to three times a week. I also began to learn about the frustrations that caregivers face when trying to manage their lives and provide care. I learned this through the interactions I had with them when they came to pick their loved one’s up from adult day care, at the social events to honor them and on the trips to Tallahassee. I heard their stories, their successes, their trials with their families and with obtaining support. Overall, I heard their gratitude for a program that offered to support them as they cared for their loved one in their home, in the community.

**Federal-Level Recommendations.**

1. The federal government should provide hurricane shutters in hurricane-prone areas to protect those who require HUD housing. Hurricane shutters would also protect the government’s own assets (the physical structure). The shutters might also help prevent the rampant break-ins after hurricanes when people evacuate.
2. The federal government should continue to fund veterans for community-based services, such as adult day centers.

**State of Florida Level Recommendations.**

1. The state of Florida needs standardized regulations for SpNS to include the care of PWD.
2. The state of Florida needs a more accurate assessment form that captures the unique needs of PWD, rather than simply physical abilities. The DOEA form does not adequately capture the needs of people with Alzheimer’s disease.
3. The state of Florida needs to adequately support community-based care. Inadequate support of community-based care while removing resources for Medicaid-funded
nursing home beds (Van Gieson 2011) means that the mistakes from the
destitutionalization movement will be repeated and leave many families stranded.

4. Medicaid funded skilled nursing beds should not be further eliminated. Not all families have the capacity to care for people with dementia in the community.

**County-Level Recommendations.**

1. Counties need to be invested in the accommodation of dementia-specific care in SpNS, especially in Martin and St. Lucie counties, which have ACC as a resource.

2. The county should advertise that they will help place pets in a safe place if brought to the shelter.

3. Special needs materials should be written to clearly distinguish the SpNS from regular shelters.

4. Caregivers are unlikely to find out about SpNS on their own. Even after reading the pamphlet, most caregivers did not understand the difference between a regular shelter and run by the American Red Cross) and the SpNS, which is run by the county. They did not know that medical personnel were available at these special needs shelters. ACC staff needs to have a clear sense of who ought to be informed about the SpNS. Informing caregivers of the existence of the SpNS and their exact purpose should be standard procedure, even if the family is not signed up for this service. Since AD and related dementias are progressive and change over time, the family might not need a SpNS now, but will in the future. SpNS in Florida (outside of Palm Beach County) either explicitly or implicitly exclude PWD from their services; implicitly, by failing to consider alternatives for PWD, and explicitly by turning PWD away from SpNS.
This is especially negligent when there are organizations, such as ACC, who are willing to coordinate and volunteer staff and services in an emergency.

5. When evaluating the disaster checklist (during the disaster plan review), staff were uncertain about what qualified as a “last resort”. It was also unclear if staff adequately probed caregivers about the safety of their location, or whether their evacuation plan led to safety. As the results show, there were more people who said they needed shelter than were signed up for SpNS. A decision tree ought to be created to help staff identify who should be signed up for shelters.

ACC-Level Recommendations.

1. These counties (and ACC) should have a more specific protocol to determine who needs SpNS. A decision tree would be a helpful tool to assist in this process. Factors that need to be included in the decision tree include:

1) Does this person require a medical treatment that requires electricity? (For example, is this person on O2, use a C-pap machine or is he or she on dialysis?) If yes, sign up for a special needs shelter. If “no” continue on to the next question.

2) Does this person have a disease that causes dementia? If “no”, continue to question 4. If “yes”, continue to next question.

3) Is this person oriented to time and place? And/or, is this person able to manage their own medications? If “no”, continue to question 5. If “yes”, continue to next question.

4) Does this person need help with any of their ADLs/IADLs? If “no” then no other action is needed. If “yes”, continue to next question.
5) Does this person have a caregiver to assist with daily needs, medications and safety management? If “no”, sign up for Special Needs Shelter. If “yes”, continue to next question.

6) Do the PWD and Caregiver have a safe place to go (a family or friend’s house that is not in a flood zone and is made of cinderblock and equip with hurricane shutters or impact resistant glass)? If “yes”, no further action is needed. If “no”, sign up for special needs shelter.

2. Staff should be educated on what is a “safe” dwelling and location. Factors can include proximity to large bodies of water, access to hurricane shutters, generators, building materials (wood vs. cinderblock frame).

3. Education for caregivers: Discuss strategies for negotiating with a PWD if evacuation seems necessary. (Additionally, suggest dementia specific items for disaster kits.)

4. Change the intake planning form to reflect differential decision making for different storm categories. This suggestion was completed during the study, and yielded improved caregiver disaster plans.

Caregiver Level Recommendations

According the Mayo Clinic, the following symptoms might be experienced by a person with Alzheimer’s disease: 1) Depression; 2) Anxiety; 3) Social withdrawal; 4) Mood Swings; 5) Distrust in others; 6) Increased stubbornness; 7) Irritability and aggressiveness; 8) Changes in sleeping habits; 9) Wandering (Mayo Clinic 2011)\textsuperscript{19}.

While a number of pharmacological interventions exist to reduce anxiety, depression, and behaviors related to forgetfulness and delusions (see Gauthier, Cummings, Ballard Brodaty, Grossbert et al. 2010 for a review), medical treatment might be limited during a

\textsuperscript{19} available: http://www.mayoclinic.com/health/alzheimers-disease/DS00161/DSECTION=symptoms
disaster event. Most caregivers will therefore, be limited to non-pharmacological interventions. Hulme, Wright, Crocker, Oluboyede and House (2010) found that music therapy, touch (massage) therapy and exercise were effective interventions for reducing agitation in people with dementia. Modified techniques might be used during stressful events, such as an evacuation. For example, singing familiar songs, massaging the PWD’s hand, and guiding the PWD in a walking around an evacuation shelter might help reduce anxiety related behaviors. This is an area where clinical specialists might make specific suggestions for each possible behavior that might be encountered.

Table 8.2 Potential Problem Behaviors During a Disaster

<table>
<thead>
<tr>
<th>Potential Problem Behaviors During Disasters</th>
<th>Caregiver Recommendations Based on Literature Reviewed in this Research</th>
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<tbody>
<tr>
<td>Time disorientation-</td>
<td>Validation therapy. Use the time they think they are in to direct them to evacuation or preparation activities (for example, “we need to go pick the kids up from school” or “we have to make the cruise ship, so let’s hurry and get packed”).</td>
</tr>
<tr>
<td>Spatial disorientation-Wandering- Becoming lost</td>
<td>Enroll in Safe Return. Locks on doors. Alert neighbors of PWD’s condition. Walking can be healthy and reduce anxiety if the PWD is supervised during this activity.</td>
</tr>
<tr>
<td>Anxiety induced behaviors- Violence</td>
<td>Don’t argue and remain calm. Take submissive posturing (head down, hands up). Start singing a familiar song and encourage the PWD to join you. Try helping the PWD get regular exercise. Give a soft massage to the PWD hand or neck once they are calm.</td>
</tr>
<tr>
<td>“Increased stubbornness”- refusal to evacuate</td>
<td>Don’t argue. Entice with other options (dinner, visiting family). Make preparations (pack) or throw out food when they are not in the room to avoid confrontation.</td>
</tr>
</tbody>
</table>
Levels of Caregiver Preparedness

1. Basic Plan
   a. Safe Return Program: All caregivers should enroll their family member in the Safe Return program. It does not take a disaster for this program to become useful. People with dementia can become lost at nearly any time during early and middle stages of the disease. During the chaos of a disaster, the risk of becoming separated and lost increases.
   
   b. Techniques for redirection: As the disease changes, behaviors rooted in anxiety, such as yelling or hitting, might become a problem. Techniques sitting on the floor, apologizing (even if you have done nothing wrong), and start singing a song familiar to the person with dementia to diffuse and distract.
   
   c. Disaster Kit: Everyone should have a box set aside with supplies that are designated ONLY for a disaster. It should be easy to pick up and carry should evacuation become necessary. This kit needs to include basic supplies, such as canned goods, water, flashlight, a radio and batteries. Most of these supplies can be purchased at discount stores such as the Dollar Tree at a low cost (a dollar an item).

2. Moderate Plan

   Dementia Specific Disaster kit: For those families who opt to shelter in place, a dementia-specific disaster kit could be created as an educational tool. Ice packs and information about hydration should be included, since part of “normal aging” is a decline in temperature regulation. Depending on the stage of dementia, include incontinence supplies, such as wet wipes and adult diapers. Include a change of “easy on/off” clothing (i.e. pants with elastic bands, shoes with Velcro). If either the
caregiver or the person with dementia wears prescription glasses, include a spare pair in the disaster kit.

The following is a recommended list of items to include in the dementia specific disaster kit. Items marked as “education/reminder” are targeted toward organizations that might choose to provide this kit to caregivers. These items might require a label explaining the purpose.

Table 8.3 Dementia Specific Disaster Kit Contents

<table>
<thead>
<tr>
<th>Item</th>
<th>Goal/Objective</th>
</tr>
</thead>
<tbody>
<tr>
<td>Activities: Early: Cards</td>
<td>Goal #2: Stress Reduction</td>
</tr>
<tr>
<td>Activities: Early: Crossword Puzzle Book</td>
<td>Goal #2: Stress Reduction</td>
</tr>
<tr>
<td>Activities: Late: Colored pencils</td>
<td>Goal #2: Stress Reduction</td>
</tr>
<tr>
<td>Activities: Late: Memory Book</td>
<td>Goal #2: Stress Reduction</td>
</tr>
<tr>
<td>A</td>
<td>Goal #2: Stress Reduction</td>
</tr>
<tr>
<td>Activities: Early: Puzzle</td>
<td>Goal #2: Stress Reduction</td>
</tr>
<tr>
<td><strong>Pill Box with Reminder (refill meds)</strong></td>
<td>Goal #3: Education and Reminder</td>
</tr>
<tr>
<td>Basic First-Aid Kit</td>
<td>Goal #1: Safety</td>
</tr>
<tr>
<td>Batteries</td>
<td>Goal #3: Education and Reminder</td>
</tr>
<tr>
<td><strong>Battery powered fan</strong></td>
<td>Goal #1: Safety-Heat</td>
</tr>
<tr>
<td>Battery powered radio with cell phone charger</td>
<td>Goal #1: Safety-Communication</td>
</tr>
<tr>
<td><strong>Gloves</strong></td>
<td>Goal #3: Education and Reminder</td>
</tr>
<tr>
<td>Door Hanger: (with caution statement)</td>
<td>Goal #1: Safety-Communication</td>
</tr>
<tr>
<td>Flashlight</td>
<td>Goal #1: Safety</td>
</tr>
<tr>
<td>Gatorade</td>
<td>Goal #1: Safety-Heat</td>
</tr>
<tr>
<td>Hand sanitizer</td>
<td>Goal #3: Education and Reminder</td>
</tr>
<tr>
<td><strong>Instant Icepack X2</strong></td>
<td>Goal #1: Safety-Heat</td>
</tr>
<tr>
<td>Large Zip-lock bags for medical documents with reminder label</td>
<td>Goal #3: Education and Reminder</td>
</tr>
<tr>
<td>List of other Activities (printing)</td>
<td>Goal #2: Stress Reduction</td>
</tr>
<tr>
<td><strong>Wash Cloth</strong></td>
<td>Goal #1: Safety-Heat</td>
</tr>
<tr>
<td><strong>Backpack</strong></td>
<td>NA</td>
</tr>
<tr>
<td>Water bottle w/ reminder label</td>
<td>Goal #1: Safety-Heat</td>
</tr>
<tr>
<td>Wipes w/ reminder label</td>
<td>Goal #3: Reminder</td>
</tr>
</tbody>
</table>

Things for the Caregiver to do with their loved one when sheltering at home during a hurricane that do not require electricity\(^{20}\):

---

\(^{20}\) Adapted from Forest Pharmaceuticals, Inc. “The Alzheimer’s Activities Guide” 2008
1. Play Cards  
2. Make with Holiday Cards  
3. Sort Buttons  
4. Sing songs and play instrumentals (pots and pans)  
5. Read Stories Aloud  
6. Find Countries on the globe  
7. Go through old photos  
8. Play cards  
9. Modeling clay/ Play-Doh®  
10. Polish silver (spoons)  
11. Make the bed  
12. Help at meal time  
13. Fold Laundry (if you have running water)  

3. Total Preparedness Plan  

All the above plus:  

Choose to live in a home that is up to code for wind resistance (usually a cinder block home that is not in a flood zone). Ensure that this home is insured. Harden the home- install easy to use hurricane shutters or impact resistant glass. Get a generator and get gas well before the storm. If planning to evacuate, evacuate early. Introduce PWD to the evacuation cite before the storm/ during a non-emergency. During the early stages, especially, this might be a useful technique for reducing the stress of an unfamiliar environment.
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Fry, Christine
Fry, Christine


Fry, Christine


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Appendix I: ANNUAL DISASTER PLANNING CHECKLIST

ALZHEIMER’S COMMUNITY CARE, INC.
ANNUAL DISASTER PLANNING CHECKLIST

Date: ____________________

Patient Name: ____________________________________________

Caregiver Name: __________________________________________

Safe Return # ______ Locator ID Bracelet Frequency ______ Verichip? Y N

In the event of a disaster where evacuation is recommended, do you plan to evacuate your home?

Yes    No

If yes, please explain your plan of action:

________________________________________________________________________________________

Are you in need of a shelter?

Yes    No

If yes, registered for shelter on __________________________

Are you in need of transportation to your designated place of safety?

Yes    No

If yes, registered for transportation on ______________________

Please list the address and phone number (including cell phone) where you can be reached:

Address: ____________________________________________

City: ______________________ State: __________ Zip: __________

Phone: ______________________ Cell Phone: ______________________

In case of an emergency, please list the name and phone number of the closest relative not residing with you:

Friend/Relative Name: __________________________________

Phone: ______________________________________________

Do you rely on medical equipment requiring electricity? Yes    No

If so, please specify:

________________________________________________________________________________________

Do you have all medical information (advanced directives, medication list, physician contact information, etc.) ready to take with you in the event that you must evacuate your home?

Yes    No

Have you called the Safe Return program to ensure that all information and records are up to date? (1-888-572-8566)?

Yes    No    Safe Return # __________

Where will you go if damages prevent you from returning to your home?

Address: ____________________________________________

City: ______________________ State: __________ Zip: __________

Phone: ______________________ Cell Phone: ______________________

Alzheimer’s Community Care, Inc. 24-Hour Crisis Line: 1-800-394-1771
### Annual Disaster Planning Checklist

**Patient Name:** ____________________________  **Caregiver Name:** ______________________________________

**Safe Return #:** __________  **Locator ID Bracelet Frequency:** __________  **Date of Plan Review:** __________

**Do you live in an evacuation zone?**

<table>
<thead>
<tr>
<th>Cat. 1,2 or 3</th>
<th>Cat 4 or 5</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Will you evacuate your home?</strong></td>
<td>Yes ___  No ___</td>
</tr>
<tr>
<td><strong>If evacuating, explain plan:</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Do you need a shelter?</strong></td>
<td>Yes ___  No ___</td>
</tr>
<tr>
<td>If yes, registered on: ______</td>
<td>If yes, registered on: ______</td>
</tr>
<tr>
<td><strong>Do you need transportation to the shelter?</strong></td>
<td>Yes ___  No ___</td>
</tr>
<tr>
<td>If yes, registered on: ______</td>
<td>If yes, registered on: ______</td>
</tr>
<tr>
<td><strong>List address/phone (including cell phone) where you can be reached:</strong></td>
<td></td>
</tr>
</tbody>
</table>

In case of an emergency, please list the name and phone number of the closest relative not residing with you:

**Friend/Relative Name:** ____________________________  **Phone:** ____________________________

**Do you rely on medical equipment requiring electricity?**

| Yes ___  No ___ |

If so, please specify: ______________________________________

**Do you have all medical information (advanced directives, medication list, physician contact information, etc.) ready to take with you in the event that you must evacuate your home?**

| Yes ___  No ___ |

**Where will you go if damages prevent you from returning to your home?**

**Address:** ______________________________________

**City:** __________  **State:** __________  **Zip:** __________

**Phone:** ______________________________________  **Cell Phone:** ____________________________

---

**Appendix IV: Cone of Uncertainty and Spaghetti Models for Hurricane Irene**
Appendix III: CAREGIVER SURVEY

A. About the person with dementia (Alzheimer’s Community Care Member)
   1. How old is the person you care for (year of birth)? _________________________
   3. What year was the person you care for diagnosed with dementia? _______________
   4. How long has this person been enrolled ACC?______________________________
   5. How mobile is this person?
      a. Can walk without help   c. Can bear weight but needs a wheelchair
      b. Can walk with a walker or cane   d. Needs total assistance
   6. Does this person have medications that need to be refilled regularly?
      a. No     b. Yes

B. About the Caregiver
   1. Caregiver year of birth? _________________
   3. What is your relationship to person with dementia (please circle)?
      a. Spouse  c. Other family member  f. Self (live alone)
      b. Child   d. Other arrangement
   4. Are you employed?
      a. Yes, full time  b. No, because I am retired
      b. Yes, part time  c. No, because of another reason
   5. Do you physically live with the person you care for?
      a. No  b. Yes
   6. Do you have family, friends, or professional who help you provide care for the person with dementia? (Circle primary support - do not include ACC)
      a. No, I am the only caregiver  b. Family/ friends help  c. Professional caregivers  d. Other
    7. If yes, approximately how many hours do they help you a week?
      a. Less than 3 hours a week  d. Between 10-20 hours a week
      b. Less than 5 hours a week  e. Between 20-30 hours a week
      c. Less than 10 hours a week  f. Over 30 hours a week
   8. Do you have any health problems that make it difficult to provide care for the person with dementia?
      a. No  b. Yes (please write):
  9. On a scale of 0 to 10, 0 being no support and 10 being extremely well supported, how would you rate the social support you usually have in caring for the person with dementia?
      10. Overall, how often do you feel burdened in caring for the person with dementia?
      g. Don’t Know  h. Refused
   8. Have you ever been in a hurricane?  a. No  b. Yes
   10. If yes, which hurricane(s) (circle all that apply)?
      g. Ivan (2004) h. Other __________________
   11. Was the person you care for with you during any of these hurricane experiences?
      a. No  b. Yes
C. Disaster Preparation

1. Do you have a disaster kit?  
   a. No  
   b. Yes  
   c. Don’t know

2. On a scale of 1-10, how likely do you think Palm Beach County will be hit by a hurricane this year?  
   1 2 3 4 5 6 7 8 9 10

3. Do you have hurricane shutters or impact resistant glass on your windows?  
   a. No  
   b. Yes

4. Do you have access to a generator in case the power goes out?  
   a. No  
   b. Yes

5. Is your home a wood frame or is it made of cinder block?  
   a. Wood frame  
   b. Cinder Block  
   c. Other  
   d. Don’t know

6. What kind of a housing do you live in?  
   a. Freestanding house  
   b. Townhouse/ Villa  
   c. Condo  
   d. Apartment  
   e. mobile home  
   f. Other

7. Does your home have one story/floors or multiple stories?  
   a. Single story/floor  
   b. Multiple stories/floors

8. Do you rent or own?  
   a. Rent  
   b. Own  
   c. Other

9. Do you live near a body of water: (if you live east of I-95, or near Lake Okeechobee put yes).  
   a. No  
   b. Yes, East of I-95  
   c. Yes, Lake Okeechobee  
   d. Yes, a canal  
   e. Yes, Intercostal  
   f. Yes, Lake or Pond  
   g. Yes, Other  
   h. Don’t know

10. Approximately what year was the building you live in built? Please write year built:

11. Zip Code: _______

D. Disaster Recovery

1. If your home were severely damaged in a hurricane, would you have the financial means to have it repaired (or meet the insurance deductible)?  
   IF you rent, circle NA  
   a. No  
   b. Yes  
   c. Not applicable  
   d. Don’t Know

2. Do you have home insurance or renters insurance?  
   a. No  
   b. Yes

3. Do you have a wind protection policy (or is it included in your plan)?  
   a. No  
   b. Yes  
   c. Don’t Know

4. Do you have flood insurance?  
   a. No  
   b. Yes

5. What is the head of household’s approximate income? -  
   a. Less than $10,000 a year (Less than $800 per month/ less than $200 a week)  
   b. Between $10,000-20,000 ($800 to $1,600 per month)  
   c. Between $20,000- 40,000 ($1,600 to $3,300 per month)  
   d. Between $40,000-60,000 ($3,300 to $5,000 per month)  
   e. Between $60,000-80,000 ($5,000 to $6,700 per month)  
   f. Between 80,000-100,000 ($6,700 to $8,300 per month)  
   g. Over 100,000 a year
Appendix V: PRESSURE AND RELEASE MODEL
Appendix VI: ADLS and IADLs

### KATZ BASIC ACTIVITIES OF DAILY LIVING (ADL) SCALE

<table>
<thead>
<tr>
<th>Activity</th>
<th>Independent</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Bathing (sponge bath, tub bath, or shower)</td>
<td>YES</td>
</tr>
<tr>
<td>Receives either no assistance or assistance in bathing only one part of body</td>
<td>NO</td>
</tr>
<tr>
<td>2. Dressing - Gets clothes and dresses without any assistance except for tying shoes</td>
<td></td>
</tr>
<tr>
<td>3. Toileting - Goes to toilet room, uses toilet, arranges clothes, and returns without any assistance (may use cane or walker for support and may use bedpan/urinal at night)</td>
<td></td>
</tr>
<tr>
<td>4. Transferring - Moves in and out of bed and chair without assistance (may use cane or walker)</td>
<td></td>
</tr>
<tr>
<td>5. Continence - Controls bowel and bladder completely by self (without occasional &quot;accidents&quot;)</td>
<td></td>
</tr>
<tr>
<td>6. Feeding - Feeds self without assistance (except for help with cutting meat or buttering bread)</td>
<td></td>
</tr>
</tbody>
</table>

### LAWTON - BRODY INSTRUMENTAL ACTIVITIES OF DAILY LIVING SCALE (I.A.D.L.)

<table>
<thead>
<tr>
<th>Activity</th>
<th>Independent</th>
</tr>
</thead>
<tbody>
<tr>
<td>A. Ability to Use Telephone</td>
<td></td>
</tr>
<tr>
<td>1. Operates telephone on own initiative looks up and dial numbers, etc.</td>
<td>1</td>
</tr>
<tr>
<td>2. Dials a few well-known numbers</td>
<td>1</td>
</tr>
<tr>
<td>3. Answers telephone but does not dial</td>
<td>1</td>
</tr>
<tr>
<td>4. Does not use telephone at all</td>
<td>0</td>
</tr>
<tr>
<td>B. Shopping</td>
<td></td>
</tr>
<tr>
<td>1. Takes care of all shopping needs independently</td>
<td>1</td>
</tr>
<tr>
<td>2. Shops independently for small purchases</td>
<td>0</td>
</tr>
<tr>
<td>3. Needs to be accompanied on any shopping trip</td>
<td>0</td>
</tr>
<tr>
<td>4. Completely unable to shop</td>
<td>0</td>
</tr>
<tr>
<td>C. Food Preparation</td>
<td></td>
</tr>
<tr>
<td>1. Plans, prepares and serves adequate meals independently</td>
<td>1</td>
</tr>
<tr>
<td>2. Prepares adequate meals if supplied with ingredients</td>
<td>0</td>
</tr>
<tr>
<td>3. Heats, serves and prepares meals, or prepares meals but does not maintain adequate diet</td>
<td>0</td>
</tr>
<tr>
<td>4. Needs to have meals prepared and served</td>
<td>0</td>
</tr>
<tr>
<td>D. Housekeeping</td>
<td></td>
</tr>
<tr>
<td>1. Maintains house alone or with occasional assistance (e.g. &quot;heavy work domestic help&quot;)</td>
<td>1</td>
</tr>
<tr>
<td>2. Performs light daily tasks such as dish washing, bed making</td>
<td>1</td>
</tr>
<tr>
<td>3. Performs light daily tasks but cannot maintain acceptable level of cleanliness</td>
<td>1</td>
</tr>
<tr>
<td>4. Needs help with all home maintenance tasks</td>
<td>0</td>
</tr>
<tr>
<td>5. Does not participate in any housekeeping tasks</td>
<td></td>
</tr>
<tr>
<td>E. Laundry</td>
<td></td>
</tr>
<tr>
<td>1. Does personal laundry completely</td>
<td>1</td>
</tr>
<tr>
<td>2. Launders small items - mines stockings, etc.</td>
<td>1</td>
</tr>
<tr>
<td>3. All laundry must be done by others</td>
<td>0</td>
</tr>
<tr>
<td>F. Mode of Transportation</td>
<td></td>
</tr>
<tr>
<td>1. Travels independently on public transportation or drives own car</td>
<td>1</td>
</tr>
<tr>
<td>2. Arranges own travel via taxi, but does not otherwise use public transportation</td>
<td>1</td>
</tr>
<tr>
<td>3. Travels on public transportation when accompanied by another</td>
<td>1</td>
</tr>
<tr>
<td>4. Travel limited to taxi or automobile with assistance of another</td>
<td>0</td>
</tr>
<tr>
<td>5. Does not travel at all</td>
<td>0</td>
</tr>
<tr>
<td>G. Responsibility for Own Medications</td>
<td></td>
</tr>
<tr>
<td>1. Is responsible for taking medication in correct dosages at correct time</td>
<td>1</td>
</tr>
<tr>
<td>2. Takes responsibility if medication is prepared in advance in separate dosage</td>
<td>0</td>
</tr>
<tr>
<td>3. Is not capable of dispensing own medication</td>
<td>0</td>
</tr>
<tr>
<td>H. Ability to Handle Finances</td>
<td></td>
</tr>
<tr>
<td>1. Manages financial matters independently (budgets, writs checks, pays rent, bills, goes to bank), collects and keeps track of income</td>
<td>1</td>
</tr>
<tr>
<td>2. Manages day-to-day purchases, but needs help with banking, major purchases, etc.</td>
<td>1</td>
</tr>
<tr>
<td>3. Incapable of handling money</td>
<td>0</td>
</tr>
</tbody>
</table>
Appendix VII: SAFFIR-SIMPSON HURRICANE WIND SCALE (SSHWS)

http://www.nhc.noaa.gov/aboutsshws.php

NOTICE: The Saffir-Simpson Hurricane Wind Scale (SSHWS) is undergoing a minor modification for 2012 in order to resolve awkwardness associated with conversions among the various units used for wind speed in advisory products. The change broadens the Category 4 wind speed range by one mile per hour (mph) at each end of the range, yielding a new range of 130-156 mph. This change does not alter the category assignments of any storms in the historical record, nor will it change the category assignments for future storms. The reasoning behind this change and a tabulation of the old and new scales is available here (PDF). The new summary table is shown below:

<table>
<thead>
<tr>
<th>Category</th>
<th>Winds</th>
<th>Summary</th>
</tr>
</thead>
</table>
| 1        | 74-95 mph  
64-82 kt  
119-153 km/h | Very dangerous winds will produce some damage |
| 2        | 96-110 mph  
83-95 kt  
154-177 km/h | Extremely dangerous winds will cause extensive damage |
| 3        | 111-129 mph  
96-112 kt  
178-208 km/h | Devastating damage will occur |
| 4        | 130-156 mph  
113-136 kt  
209-251 km/h | Catastrophic damage will occur |
| 5        | 157 mph or higher  
137 kt or higher  
252 km/h or higher | Catastrophic damage will occur |

More Information
- About the Saffir-Simpson Hurricane Wind Scale (PDF)
- Saffir-Simpson Hurricane Wind Scale Extended Table (PDF)

During the open public comment period for the draft of the Saffir-Simpson Hurricane Wind Scale in 2010, many people suggested that the National Weather Service develop a storm surge specific scale as well as improve its forecasting of storm surge. It is acknowledged that there are some researchers who advocate developing another scale for hurricanes specifically geared toward storm surge impact by incorporating aspects of the system's size. However, the National Hurricane Center does not believe that such scales would be helpful or effective at conveying the storm surge threat. Read more... (PDF)