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Danger and Dementia: Caregiver Experiences and Shifting Social Roles During a Highly Active Hurricane Season

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Danger and Dementia: Caregiver Experiences and Shifting Social Roles During a Highly Active Hurricane Season

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This study examined disaster preparedness and decision-making by caregivers of community-dwelling persons diagnosed with Alzheimer’s or a related dementia (ADRD). Interviews were conducted with 20 caregivers in South Florida. Twelve of these interviews include caregiving experiences during the highly active 2004–2005 hurricane seasons. Results indicate that persons in earlier stages of ADRD can, and often do, remain engaged in the disaster preparation and planning process. However, during the early stages, persons may also resist evacuation, even if the caregiver felt it was necessary. During later stages of the disease, caregivers reported less resistance to disaster-related decisions; however, with the tradeoff of less ability to assist with preparation.

KEYWORDS qualitative, caregiving, dementia, disaster preparedness

INTRODUCTION

Hurricane Katrina in 2005 was responsible for 1,833 deaths, few of which could be considered random; rather, death and illness followed a pattern that disproportionately affected minority populations and adults over 65 years of age (Barnes, 2007). Although the elderly made up less than 12% of the
New Orleans population at the time, over 64% of Hurricane Katrina deaths were of those 65 years or older (Brinkley, 2006; Brunkard, Namulanda, & Ratard, 2008; Jenkins, Laska, & Williamson, 2007). Although it is unknown how many of these elderly victims might have had Alzheimer’s disease or a related dementia (ADRD), one in eight people over the age of 65 in the United States has such a diagnosis (Thies & Bleiler, 2013), making it likely that some of these elder victims were affected by ADRD.

The experiences of families affected by ADRD during natural disasters are understudied. However, due to population aging, this is an issue likely to increase in the coming decades (Hebert et al., 2010; Hebert, Scherr, Bienias, Bennett, & Evans, 2004). More recently, the risk posed to people with ADRD gained attention after Hurricane Sandy impacted the northeast coast of the United States in 2012. It became clear that increasing numbers of people with ADRD complicated traditional disaster preparedness and response plans, jeopardizing their own safety and that of their caregivers and rescuers (Aleccia, 2012).

Very little research exists on how caregivers assess risk and plan for disasters, such as hurricanes. It has been shown, however, that families are less likely to evacuate if they have an older family member in their household (Cherry, 2009; Cherry et al., 2010; Christensen, Richey, & Castañeda, 2013; Dash & Gladwin, 2007; Eisenman, Cordasco, Asch, Golden, & Glik, 2007; Solis, Thomas, & Letson, 2009). Because ADRD is correlated with age, it stands to reason that disaster-related decisions can be influenced by caring for a person with such a diagnosis.

Symptoms and behaviors of Alzheimer’s and other related diseases (such as Lewy body frontotemporal disease and Parkinson’s-related dementia) are progressive, causing increased cognitive deterioration over time (Ashford & Schmitt, 2001; Caputo et al., 2008; Mhaoláin et al., 2012; Santano, Pérez de Lara, & Pintor, 2011). In the beginning stages of the disease, the person may be acutely aware of his or her cognitive losses, leading to frustration and depression (Cosentino, Metcalfe, Cary, De Leon, & Karlawish, 2011; McLean, 1995; Schinka, Brown, & Proctor-Weber, 2009; Taylor, 2007). Alzheimer’s-type dementia follows a relatively predictable pattern of decline in functioning over time (M. S. Albert et al., 2011; Reisberg et al., 1987; Shimada et al., 2003). The progression of cognitive loss can be scored and categorized within one of the three stages of the disease: (a) early, (b) middle, (c) and late (S. Albert, 2004). The stages, which act as measurements of cognitive loss, are a device for caregivers and healthcare professionals to use in assisting people with ADRD by predicting which types of behaviors can be expected over time. Behavioral symptoms vary with the severity of a probable ADRD patient (Ata et al., 2010; Gauthier et al., 2010; Lopez et al., 2003; Scarmeas et al., 2007). Behaviors such as anxiety, sundowning, pacing, and attempts to exit the home unaccompanied can commonly be triggered if the person with ADRD experiences stress as a result of a change in
environment and daily routine (Gerdner, Buckwalter, & Reed, 2002; Moore, Algase, Powell-Cope, Applegarth, & Beattie, 2009; Rowe & Glover, 2001). Events such as family preparation for disaster, or the disaster itself, can cause environmental changes that trigger anxiety-related behaviors (Christensen, 2012). The type and severity of the behaviors exhibited are generally tied to the stage of the disease. In addition, the staging of the disease can impact how the caregiver makes decisions about planning for and responding to disasters.

In an attempt to better understand how families affected by ADRD make decisions for disaster preparedness, this study interviewed 20 caregivers about their past hurricane experiences (though the experiences of 12 are discussed in depth). This group was selected because they live in hurricane-prone areas in South Florida. Most caregivers reported their most recent hurricane experience took place during the highly active 2004–2005 hurricane season, and the study utilized this as the starting point to discuss future hurricane preparedness plans. A major goal was to explore the challenges that ADRD-affected families might face during hurricanes. As a primarily qualitative, exploratory study, we did not develop formal hypothesis to test, but rather employed an inductive analytical approach informed by grounded theory. The project aim of exploring disaster-related challenges for caregivers was informed by a review of the current scholarship on decision-making and dementia (e.g., Cosentino et al., 2011; Hirschman, Joyce, James, Xie, & Karlawish, 2005; Menne & Whitlatch, 2007; Whitlatch, 2008). Much of this literature focuses upon decision-making about daily care activities, but does not address joint decision-making in the face of hazard events, such as hurricanes. Furthermore, there is only scant research that explores risk assessment in e.g., people with “mild Alzheimer’s disease” (Sinz, Zamarian, Benke, Wenning, & Delazer, 2008).

CAREGIVING AND RELATIONSHIP TO PERSON WITH ADRD

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, p. 130)

The cognitive and behavioral changes associated with ADRD can affect the relationship between caregiver and person diagnosed with the disorder (Gaugler, Zarit, & Pearlin, 2003; LoboPrabhu, 2006; Zarit, 2006). These changes also impact decisions about treatment and daily care, and they can shift social roles that may influence disaster response. In the early stages of the disease, the caregiver may still perform his primary social role or maintain her identity as a spouse or adult child (LoboPrabhu, 2006). Once cognitive decline is formally diagnosed, these roles begin to shift
During the early stages, especially if a professional has not legitimized the cognitive deficits and resulting behaviors (forgetfulness, safety, and judgment problems) by labeling the disease, family members may have more difficulty taking on a decision-making role, including and especially during disasters (Christensen, 2012; Hahn & Kleinman, 1983; Helman, 2001; Kleinman, 1973, 1980; Womack, 2010).

As the disease is diagnosed and begins to progress, the caregiver transitions from his or her role as spouse or adult child to that of caregiver, which holds a different set of social responsibilities and power differentials (LoboPrabhu, 2006). As the ADRD progresses, the assistive caregiver role once again shifts to a more involved care manager role, which requires caregivers to provide major decisions about risk and safety (Hasan, Ukkusuri, Gladwin, & Murray-Tuite, 2011; Mahoney, 2003; Ostwald, 2006).

METHODS

The research was part of a larger, mixed-methods study conducted in southeast Florida between October 2010 and December 2011. To answer the research questions—(a) How do people caring for someone with ADRD plan for hurricanes? and (b) What unique needs do families affected by ADRD have when preparing and responding to hurricanes?—the first author conducted 9 months of participant observation, semistructured interviews \((n = 20)\) with informal caregivers, professional caregivers \((n = 8)\), a baseline \((n = 290)\) and follow-up \((n = 259)\) disaster plan review, and a quantitative survey \((n = 253; \text{Christensen, 2012})\). These data were collected with the assistance of the staff from a partnering organization, Alzheimer’s Community Care (ACC), which serves approximately 1,000 families per year in South Florida. ACC is a 501 (c) (3) that provides community-based services, such as specialized adult day care and case management, for families affected by ADRD. It serves families in an area that was impacted by multiple hurricanes during the 2004–2005 hurricane season.

Sample

The demographic profile of the families using ACC services was determined from the baseline disaster plan review \((n = 290)\), which also listed basic demographic information such as age, gender, self-identified race, ethnicity, and the relationship between the caregiver and the person with dementia. The first author purposely selected a subsample of caregivers who would reflect the general distribution of these groups in the larger population, choosing participants by gender, relationship to the caregiver (adult...
TABLE 1 Sample by Caregiver Gender

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<tbody>
<tr>
<td>Men surveyed</td>
<td>83</td>
<td>28.6</td>
<td>Men interviewed</td>
<td>4</td>
<td>20</td>
</tr>
<tr>
<td>Women surveyed</td>
<td>207</td>
<td>71.4</td>
<td>Women interviewed</td>
<td>16</td>
<td>80</td>
</tr>
<tr>
<td>Total</td>
<td>290</td>
<td>100</td>
<td>Total</td>
<td>20</td>
<td>100</td>
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TABLE 2 Sample by Caregiver Relationship to Person With ADRD

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<tbody>
<tr>
<td>Adult child caregivers surveyed</td>
<td>151</td>
<td>52.1</td>
<td>Adult child caregivers interviewed</td>
<td>15</td>
<td>75</td>
</tr>
<tr>
<td>Spouses surveyed</td>
<td>95</td>
<td>32.8</td>
<td>Spouses interviewed</td>
<td>4</td>
<td>20</td>
</tr>
<tr>
<td>Other relationship surveyed</td>
<td>34</td>
<td>3.4</td>
<td>Other relationship interviewed</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>Total</td>
<td>290</td>
<td>100</td>
<td>Total</td>
<td>20</td>
<td>100</td>
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</table>

child, spouse or, other family member), ethnicity (Hispanic, non-Hispanic or Caribbean Islander), and reported race. See Tables 1 and 2 for caregiver demographics. For example, the larger population was 28.6% men (n = 83/290) and 71.4% women (n = 207/290). To mirror this distribution, 20% (n = 4/20) of the 20 caregivers interviewed were men and 80% (n = 16/20) were women.

The same sampling strategy was used for the relationship between caregivers and the person with ADRD: there were four spouses interviewed (two wives, two husbands) and one other family member (a sister). The remaining familial relationships between caregivers and people with ADRD were adult children (two sons and 13 daughters). In terms of race, six interviewed caregivers were Black and 14 were White. With ethnicity, two of the caregivers who identified as Black were Afro-Caribbean, rather than African American. Authors identified 6 caregivers as Hispanic or Caribbean Islander and 14 who were non-Hispanic.

An attempt was made to sample from all socio-economic status backgrounds, however, many caregivers were reluctant to share their income (Christensen, 2012). There were three caregivers in the interview sample who were living in HUD housing and on public assistance.

All 20 caregiver interviews reflect the demographics of the larger population served by the partner organization (ACC); however, this article’s findings center on the experiences of the 12 who were living with, and providing care for, someone with ADRD during the 2004–2005 hurricanes season. It was only through the inductive coding (described in the following) that the researchers discovered that within this sample of 20 caregivers, 12 reported having caregiving experience during a hurricane.
Procedure

Most of the interviewed caregivers (18 of 20) had family members in one of the three adult day-care centers at which the first author conducted 9 months of participant observation. The remaining two caregivers were recruited through their involvement in ACC outreach activities.

A sample interview was piloted with three caregivers to refine the questions. In the next stage, the first author interviewed a purposeful sample of 20 caregivers (described previously), reflecting the general distribution of these groups in the larger population of those receiving services through ACC. Monetary compensation of $20 was offered to each caregiver. Each caregiver signed an informed consent form approved by The University of South Florida Institutional Review Board before participating in the interview, which explained how their personal information would be protected. The interviews were recorded by hand, and transcribed by the first author immediately after the interview.

Analysis

Qualitative responses were coded with the goal of exploring how caregivers plan for and respond to hurricanes. Initial categories for analysis were based on interview questions about caregivers’ past experiences and what they planned to do in the event of a future hurricane and, therefore, deductively split between past experiences and future plans. The remainder of the coding process employed an inductive approach informed by grounded theory.

During the inductive open coding phase of the analysis, the texts were initially analyzed for reoccurring themes, patterns, and structures (Creswell, 1998). Inductive coding requires multiple readings of the interview texts to identify topics that are either highly common (mentioned several times, as in text analysis), or present unusual circumstances. The authors used a modified grounded theory for the inductive phase, which means that codes were not created before reading the texts for themes. Codes were used to summarize statements within individual interviews and matched with similar statements in other interviews. During this phase, it became clear that the caregivers had different experiences: (a) if they evacuated or (b) if they sheltered at home during the hurricane seasons.

The second step of this analysis included the axial coding stage, in which the researcher looks for patterns, central phenomena or causal conditions across the codes (Creswell, 1998). Across all these subcodes, an overarching theme became apparent—multiple responses suggested that challenges experienced during previous hurricanes would not be observed during future hurricanes because the stage of the ADRD patient’s disease had changed. This theme, coded as change over time, gave a description of changing needs for people with ADRD at different stages of the disease.
process. This observation led the researcher to identify change over time as the central phenomenon or pattern that tied all the other categories (within the provided care during 2004–2005 hurricane season category) together (Creswell, 1998).

Families who had been caring for someone with ADRD during the 2004–2005 hurricane season had a greater number of factors influencing their decisions to shelter in place or to evacuate than caregivers who did not have experience providing care during hurricanes. Of the 20 caregivers interviewed, 12 reported a family member having an ADRD diagnosis at the time of the 2004–2005 hurricane season in Florida. These 12 narratives were unique from those obtained from caregivers who had not been in the caregiver role during previous hurricanes and who, therefore, received a separate subcategory code. Twelve interviews are considered to be an appropriate amount of to reach a saturation of meta-themes (Guest, Bunce, & Johnson, 2006). The quotes that referred to (a) cared for person with ADRD diagnosis during 2004–2005 hurricane season or (b) currently a caregiver but not during 2004–2005 hurricane season were separated into two different documents in a modified pile-sorting technique.

Findings from the interviews were also triangulated with data from the larger project, including (a) a review of family disaster plans on file with the organization for those families using specialized adult day services (baseline \( n = 290 \); follow-up \( n = 259 \)) and (b) surveys with caregivers who used any of the services offered at the organization (\( n = 253 \)) about their potential vulnerability to hurricanes (based on proximity to evacuation zones, bodies of water, housing structure, and socio-economic status). The specific results of these complementary data sources are described elsewhere (see Christensen 2012; Christensen et al., 2013). This article focuses on the analysis of past experiences during hurricanes and describes results from the 12 caregivers who had experienced hurricanes while caring for a person diagnosed with ADRD. As several themes and topics were repeated, especially the prediction that past troubles during evacuation would not be repeated as the disease progressed, it is believed that a meaningful degree of saturation was achieved.

## RESULTS

### Caregiver Interview Demographics

Of the 12 people who were caring for someone with ADRD during a hurricane, the majority (\( n = 10, 83\% \)) of the caregivers who had hurricane experience while caring for someone with an ADRD diagnosis were women. Eighty-three percent (\( n = 10 \)) were adult children of the person with ADRD; 17% (\( n = 2 \)) were spouses. The majority (\( n = 10, 83\% \)) identified as White; the remainder (\( n = 2, 17\% \)) identified as Black. The self-identified
ethnicity of the sample was 67% non-Hispanic \( (n = 8) \) and 33% \( (n = 4) \) Hispanic/Caribbean Islander. The majority of the 12 families \( (n = 9, 25\%) \) sheltered at home during the storms. Three of the 12 \( (25\%) \) caregivers chose to evacuate for the storm.

Caregiver Hurricane Experiences

All 20 caregivers reported that they had experienced a hurricane; however, only 12 had had the person with ADRD living with them during those experiences. For the purpose of this article, analytical emphasis is placed on this group of caretakers. Two themes emerged from the caregiver interview analysis that will be discussion in the following sections: (a) neutral hurricane experiences and (b) hurricane-related problems for the person with ADRD.

The most prominent theme across caregiver experiences was the progressive nature of ADRD, which altered the patients’ interpersonal relationships, decision-making, and, ultimately, their experiences in a disaster-preparedness situation.

Theme 1: Neutral Hurricane Experiences

Eight caregivers made statements about those with ADRD faring well or having a neutral response during past hurricanes. Three mentioned that, although their family members had already been diagnosed with dementia prior to the hurricane season discussed in interviews, they were still well enough to assist with preparations and recovery because the level of dementia had been less pronounced at that time. This section is divided into three major themes: (a) those affected with ADRD but who assisted with hurricane preparation or recovery, (b) activities and distractions during the hurricane, and (c) those affected with ADRD who did not notice the hurricane.

Affected by ADRD but assisted with preparation or recovery. Three caregivers specifically mentioned that their family members with an ADRD diagnosis helped prepare for the hurricane or clean up after the hurricane. For example, one caregiver, June (a pseudonym), 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.” Another caregiver, Ken, was more specific about how his wife assisted him in moving furniture and objects from the patio:

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. (Ken, spouse caring for his wife with early stage ADRD during the 2004–2005 hurricane season)
Ken’s 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. Because Ken’s wife was in the early 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, Ken’s wife was no longer weight-bearing and was primarily nonverbal, although she smiled when spoken to or touched. Although it went unsaid, it was clear Ken’s wife would not be able to help prepare for any future hurricanes. This example demonstrates how, over time, the disease process changes a person’s ability to participate in disaster preparation process. In the past, she was able to assist her husband with the yard work, but is no longer able.

**Activities and distractions during the hurricane.** Some caregivers said they provided different activities during the hurricane to try to keep the people with ADRD 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. (Juanita, adult daughter caring for her mother with early to mid-stage ADRD during the 2004–2005 hurricane seasons)

Activities such as these can distract a person with ADRD from anxiety-induced behaviors. The unfamiliar sounds of the wind, in this case, were drowned out by a competing noise.

**Unaware of 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 caring for her mother who had early to mid-stage ADRD during the 2004–2005 hurricane seasons). 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” (Jorge, adult son caring for his mother with middle to late stage ADRD during the 2004–2005 hurricane seasons).

Theme 2: Hurricane-Related Problems for the Person With ADRD

A second theme of the hurricane experience includes more negative experiences for both the person with ADRD and for the caregiver. Of the 12 caregivers caring for a person with an active ADRD diagnosis during a hurricane, seven reported difficulties during at least one of the five storms in the 2004–2005 seasons. Their challenges include: (a) the progression of the disease, rendering the person with ADRD less able to assist
in preparations; (b) the person with ADRD resisting evacuation, and (c) difficulty with recovery.

*Progression of disease renders a person unable to assist.* Of the three caregivers who were caring for a person with ADRD during the 2004–2005 hurricane seasons, two said that their family member was unable to assist with preparations for a due to ADRD. One caregiver, Betsy, mentioned difficulty in 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 2 days for me to get them up. My husband was unable to help by this time [he had had the disease for about 10 years by this point]. (Betsy, spouse caregiver, caring for her husband who had early to mid-stage ADRD during the 2004–2005 hurricane seasons)

This is somewhat related to Ken’s story, where although his wife assisted him in the past, she would no longer be able to help him prepare for an oncoming hurricane.

*The person with ADRD 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 person with ADRD when they tried to evacuate. The first, Luz, explained her experience with her sister, the person with dementia: “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” (Luz, sibling caregiver, caring for her sister with early to mid-stage ADRD during the 2004–2005 hurricane season). It is important to note that, in this case, there were not any negative consequences from Luz’s decision not to evacuate to her brother’s nearby home. However, had the family lived in an evacuation zone, this situation could have become problematic.

Another caregiver, Betsy, who did live in an evacuation zone, expressed more anxiety surrounding her husband’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, spouse caregiver, caring for her husband who had early to mid-stage ADRD 2004–2005 hurricane seasons)

Betsy’s husband was physically larger than she was, and she could not force him to leave. Eventually, she was able to get him into the car for
Caregiver Experiences and Social Roles During Hurricanes

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 10 miles from here. (Betsy, spouse, caring for her husband who had early to mid-stage ADRD 2004–2005 hurricane seasons)

This situation draws attention to the importance of early planning. If the person with ADRD is resistant, evacuation might be delayed and complicated. As a result, some caregivers might be convinced to stay, even if it is unsafe to do so.

**Difficulty with recovery.** Two caregivers reported that they had more resistance to disaster response and recovery when the person with ADRD was in the earlier stages of the disease. 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]. (Gloria, adult daughter caring for her mother who had early to mid-stage ADRD during the 2004–2005 hurricane seasons)

This statement reiterates an ongoing theme: that changes in the environment can be upsetting to the person with ADRD. 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 4 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. (Lisa, adult daughter caring for her mother with early stage ADRD during the 2004–2005 hurricane seasons)

Lisa waited until her mother went to bed and then threw out the spoiled food, because her mother was unable to understand the danger of eating
meats and dairy products that had been in an unrefrigerated environment for over 3 days. Lisa went on to state that, as her mother’s disease progresses, it might actually become easier for her 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, adult daughter caring for her mother with early stage ADRD during the 2004–2005 hurricane seasons)

DISCUSSION

Two primary themes emerged and are discussed in this article. First, progressive stages of the disease differentially challenged caregivers attempting to prepare and respond to hurricanes. Second, a caregiver’s relationship with a family member prior to the diagnosis of ADRD influenced disaster planning and response. A driving theme that connects the aforementioned experiences is the relationship between the progressive nature of ADRD, social roles within the family or household, and the ability to prepare sufficiently for a hurricane. Caregivers reported that cognitive and behavioral changes over the course of the disease can impact disaster planning from one season to the next. What worked one year may not work the next, as the disease progresses and the social roles and responsibilities of both the person with ADRD and the person who cares for him or her to shift. This article contributes to the scholarship on disaster preparedness by pointing out a perhaps counterintuitive issue for caregivers and social workers alike: namely, that caregivers are often taken by surprise by the difficulties in evacuating a person with ADRD in the earlier stages of the disease. This is contextualized by the fact that informal caregivers have preexisting relationships with the person with ADRD that might influence the household decisions to evacuate or not in the face of a hurricane, a phenomenon has not been well-documented in current research. The quality of such preexisting relationships that influence evacuation decisions is less likely to be an issue in institutional care.

Not all hurricane experiences were negative, and a great deal can be learned from the positive experiences; for example, caregivers reported using activities, such as making music to drown out the noise of the hurricane as they sheltered in their homes. In this way, they redirected attention from what could have been a stressful change in the environment (the sound of the wind, pressure changes, and darkness) and made the experience entertaining. This experience was described by a person caring for someone in
the middle-to-later stages of the disease, which may have allowed for this degree of distraction and redirection and might not have been possible for someone in the earlier stages. Music has been shown to be a positive, nonpharmacological stress reduction technique for people with ADRD. If the person with ADRD enjoys music, it is especially important to include a battery-powered music device (radio, mp3 player) to allow for environmental continuity and reduce the number of potential behavior triggers (Gallagher-Thompson et al., 2012; Gauthier et al., 2010; Kong, Evans, & Guevara, 2010; Lippa, 2010; Raglio et al., 2008). These lessons can be incorporated into caregiver disaster preparedness training materials.

In the earlier stages, the person with the diagnosis could sometimes assist with disaster planning preparations, as in the case of Ken and his wife, Barb. His past experience, which included Barb assisting with disaster preparations by clearing the porch of furniture, indicated that they were still operating as a partnership and Ken had not yet transitioned into a full-time-care provider role, because the disease had not yet made it necessary (LoboPrabhu, 2006). At the time of the interview in 2011, Barb was still living at home but required a wheelchair and assistance with her meals. She would have no longer been able to assist in hurricane preparations or disaster-related decisions, though Ken stated he would consider her needs when making plans (Christensen, 2012).

Betsy’s story best highlights potential challenges that caregivers might face during the early stages of the disease. Her husband, Joe, was still in the early-to-middle stages of the disease in 2005 and was highly resistant to evacuating. Betsy had not yet transitioned into a full-time-care provider role at this time, and her husband was unwilling to relinquish his autonomy in their partnership (LoboPrabhu, 2006). Betsy was aware, however, that her husband's ability to adequately assess the risk they faced from the impending hurricane was impaired. This desire for autonomy was carefully documented by Taylor (2007), himself diagnosed with early-onset Alzheimer's-type dementia, writing about his own desire for autonomy in his ever-changing relationship with his wife throughout the progression of the disease. He writes, for example, about being forced to relinquish the keys to the car because his wife and adult children had evaluated the risk of his driving as too great. Taylor describes his struggle to maintain autonomy by making decisions about risk and his need for medications (much to his caregiver's chagrin). Although Betsy's husband, Joe, was not interviewed in this study, his reluctance likely stemmed from both his desire to maintain his autonomy within the relationship and his concern in going to an unfamiliar place where he might become even more confused (Brown et al., 2012; Castle & Engberg, 2011).

Other caregivers resolved this dilemma by simply not evacuating, as Luz reported. When her mother refused to evacuate, Luz deferred to her sister's wishes, staying within her more traditional role as sister rather than taking on the role of a care manager making decisions about potential
risks (LoboPrabhu, 2006). This case illustrates well the findings from other research indicating that families with older relatives are less likely to evacuate for hurricanes (Cherry, 2009; Cherry et al., 2010; Christensen et al., 2013; Dash & Gladwin, 2007; Ge, Peacock, & Lindell, 2011; Solis et al., 2009).

Economic considerations may also affect willingness and ability to evacuate, because access to transportation and the ability to pay for a hotel is part of the calculation. In addition, shelters—even special-needs shelters—might not provide adequate services for people with ADRD, leaving families without appropriate evacuation options (Christensen, 2012). Finally, caregiver evacuation may be influenced by the strength of the oncoming storm and the caregiver’s assessment of risk against inconvenience (Christensen et al., 2013).

LIMITATIONS

These data were collected in 2011, or 5 to 6 years after the caregivers’ most recent hurricane experiences, which means data quality might have been affected by recall inaccuracies. It is well documented, however, that research on traumatic or emotional events are less vulnerable to recall inaccuracies than neutral events (Christianson, 1992; Faber et al., 2008). Research has shown that memories about disaster experiences are not as perishable as once thought and are still useful after a time lapse (Stallings, 2007).

This research did not include the input of people with an ADRD diagnosis, which could have enriched these data. For the later ADRD stages, interviewing might require creative questioning techniques to evaluate how a person with the diagnosis might respond to an impending disaster. Although attempts were made to purposely sample and interview caregivers who fit the demographic make-up of the of the larger population, women were oversampled by one caregiver, the ratios were not always a exact reflection.

Finally, as an exploratory study, we did not pursue interrater reliability during the coding phase of analysis. The experiences of caregivers who had provided care for someone with ADRD are important because they have implications for disaster-planning for vulnerable populations and can be considered an appropriate level of saturation for metathemes (Guest et al., 2006).

CONCLUSIONS

Appraising caregivers’ future plans for hurricane preparedness based on past experience is a difficult endeavor because of the central role played by the unpredictable, but inevitable, progression of the disease and the resulting shifts in social roles. Typically, participants reported more problems with
patients in the earlier stages of the disease, while those in later stages were associated with less resistance to evacuation.

Social workers and other professionals interacting with families impacted by ADRD should advise families to have a solid disaster plan and, if evacuation is necessary, to evacuate early. Although not all families will experience resistance to evacuation, they should be aware that it is a possibility, especially during the earlier stages of the disease. Steps can be taken to minimize stress experienced by people with ADRD before, during, and after a hurricane. Packing clothing and other preparations activities might cause anxiety about leaving their familiar environment. Thus, plans might be best minimally discussed until right before leaving.

Multiple sources cite music, for instance, as an effective activity for stress reduction and redirection (Gauthier et al., 2010; Hulme, Wright, Crocker, Oluboyede, & House, 2010; Raglio et al., 2008). Social workers and other professionals can encourage caregivers to include a battery-powered radio or other type of audio player in their disaster kits. Including songs enjoyable for the person with ADRD during car long rides and traffic associated with evacuation. During and after the storm, battery-powered music and light should also be made available. The stress caused by disasters could potentially elicit behaviors not previously seen or cause a shift in comprehension levels, so it can be helpful to include a wide range of activities that span the different stages of the disease in disaster kits: cards and word games for earlier stages; art supplies and tactile toys, such as stress balls, for later stages.

Further study of shifting caregiver roles is necessary, because even those who had positive or neutral experiences during previous hurricane seasons were well aware that their circumstances had since changed. Over time, they would have had to provide more care for their family members, who would have been less able to contribute to disaster preparations. Greater responsibility for disaster planning and recovery is placed on the caregiver over time, as the disease progresses.

This article focused on family experiences during hurricanes; however, there is also room for policy suggestions for disaster planning. Local government and nongovernmental organizations that assist with emergency shelters should train staff members on how to best assist individuals and families affected by ADRD during times of stress. The most vulnerable families, such as those who do not have access to transportation, should be tracked by local public health officials. In Palm Beach County, where many of these study participants were living, such tracking systems are in place, and local primary care physicians and organizations that provide assistance to families impacted by ADHD help who might be in need of assistance during disasters, providing transportation if needed. Furthermore, the Emergency Operations Center partners with local organizations to better provide services in the special needs shelters. These kinds of cooperative systems can serve as a
best practice for other local government organizations who seek to better provide for the growing number of families contending with ADHD.

REFERENCES


