# Weathering the Storm of Caregiving for Persons with Alzheimer's Disease

Alzheimer's disease (AD) is a progressive incurable disease affecting an individual's cognitive, behavioral, and physical systems. As individuals become more impaired, assistance is required and care may be provided by spouses, family members, or other close companions who serve as informal caregivers. To examine the perceptions and meaning of caring for a person with AD an interpretive descriptive study was used. Semistructured interviews were conducted with 13 informal caregivers. Data analysis revealed two themes: *Grappling with the Responsibilities of Invisible Care* and *Weathering the Storm of Visible Care*. Both themes relate to the stress and struggle of the visible and invisible roles of caregivers. The results of the study strengthen the need for home care clinicians to support caregivers who provide both visible and invisible care for persons with AD.

Alzheimer's disease (AD) is a progressive incurable disease affecting an individual's cognition, behavior, and physical wellness. As the disease progresses, assistance of caregivers is required. Spouses, other family members, or close friends may serve as informal caregivers. Many caregivers choose to care for a person with AD at home due to the high cost as well as concerns about trusting others to provide quality care. Caring for a person with AD can be physically, emotionally, and financially overwhelming.

Hartmann et al. (2016) examined caregiving duties and categorized them as visible and invisible care. Visible care was described as the responsibilities of keeping a clean house, providing personal hygiene and clean clothes, shopping, stocking a refrigerator, and helping with daily routines. These caregiver duties were more visible and recognized by others. There is a lot written about visible care in the literature, both positive and negative. The positive experiences included feelings of devotion to the care recipient, sense of competence, self-satisfaction, social support, and religious/spiritual coping mechanisms. The negative experiences described by caregivers included financial strain, negative physiological and psychological symptoms, social isolation, grief and loss, anger, loneliness, and lack of support (Dupuis, 2002; Lindauer & Harvath, 2014; López et al., 2015; Mayo et al., 2020; Wang et al., 2018).

Invisible care has been described as managing schedules, coordinating appointments, giving advice, acting as the go-between, and protecting loved ones (Hartmann et al., 2016). Invisible caregivers also experienced psychological distress and social pressures related to their role and felt they should be doing more for the care recipient. An additional pressure invisible caregivers experience is not being acknowledged for their contributions to the care of the person with AD (Hartmann et al., 2016; White et al., 2018).

The purpose of this study was to describe responsibilities of care by informal caregivers within the context of invisible and visible care. The research questions for this study were: 1. How do informal caregivers of persons with AD describe invisible and visible care? 2. How does providing each type of care affect the lives of the informal caregivers?

## Methods

### Research Design

Thorne's (2016) interpretive descriptive qualitative methodology was used to explain and under-

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stand the experiences of informal caregivers for persons with AD. The use of interpretive descriptive methodology in the phenomenon of caregiving may inform clinicians working in home care about the responsibilities of caregivers and how to tailor interventions directed to improving their well-being (Thorne, 2016).

Following approval by the author's university institutional review board, snowball sampling was used via colleagues and key informants who shared an informational flyer about the study. Potential participants contacted the researcher. Inclusion criteria included individuals 18 years and older who cared for a person with AD for more than 1 year. Ultimately, 13 participants were selected and agreed to be interviewed. Caregivers were asked to participate in semistructured interviews and describe a typical day caring for the person with AD.

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## Data Collection

Participants were asked to complete a demographic questionnaire and informed consent prior to the interview. Semistructured interviews lasting 60–90 minutes were conducted in person and digitally recorded. Participants were asked open-ended questions to describe experiences in depth. All were given the choice to discontinue participation or refuse to answer questions at any time if the questions or topics were upsetting. Confidentiality was maintained by coding with pseudonyms.

## Data Analysis

Interviews were transcribed verbatim using a transcription service after completion of each interview. The transcripts were reviewed then compared to digital recordings to ensure accuracy. Open coding was used to organize and deconstruct data into categories. Through this process, themes and patterns were identified to describe the phenomenon of caregiving.

Trustworthiness and credibility were accomplished through an extensive literature search and review to identify gaps in the literature regarding invisible and visible care. After each interview, the data were compared to the literature to gain an understanding of the phenomena of invisible and visible care. Themes were developed to document the inductive reasoning process. The researcher reviewed the data and notes taken during the interviews and compared the transcribed data to the audio recordings to check for accuracy. In addition, an experienced qualitative researcher confirmed the findings after listening to the recordings and reviewing the transcriptions.

## Results

Interviews were conducted with 13 caregivers; 9 were female and 4 were male. The average age was 59 years old. Seven participants worked full-time while providing care in the home for an average of 12 hours a day. These participants used formal caregivers during the day to keep their loved one in a community setting, however they assumed care once at home. Three worked part-time and three were retired. In terms of relationship to the patient, three were sons, eight were daughters, and two were spouses.

Each participant was asked to describe a typical day caring for their loved one. Two themes emerged: *Grappling with the Responsibility of Invisible Care* and *Weathering the Storm of Visible Care.*

### Grappling with the Responsibility of Invisible Care

The caregivers described invisible care responsibilities as paying bills, making doctor appointments, arranging transportation, providing medical supplies, coordinating care, spending time with the person with AD, and using their strengths (personality traits or previous job experiences) to assist with care. Giving up the visible role and finding other ways to assist with care was an emotional struggle.

The participants who provided invisible care also described the important responsibility of supporting the visible caregiver. For example, two caregivers were providing invisible care, but also supporting a parent who cared for a spouse with AD. A daughter described the role she played in the care of her mother. Her father was a retired professor in his late 70s who provided visible care for his wife along with the assistance of two paid LPNs. She was content in helping stating:

*“I have been contacting hospice and trying to set things up. I do not mind because my dad gets more frazzled talking to people, possibly from his hearing issues. I am fine with that part of the care. I need to provide more support to my father, because I have a bigger network than he does.”*

The father stated how much he appreciated his daughter helping him. His wife had previously been combative but was sleeping more, although he preferred when she was more active and said, “*My wife is going to a dark place and I just want to be there to hold her hand*.” By managing the care of her mother, the daughter enabled her father to spend the remaining time with his wife.

Another caregiver supported his father with AD by allocating resources for care through the Veterans Administration to subsidize medications, nursing care, and insurance plans. He was able to assist with these responsibilities because of his previous experience in the medical profession. He stated, “*I have been talking to my mom about how dad is becoming more confused and may eventually need to be placed into a nursing home. I am doing what I can to maintain him and thankfully my mom is younger and healthier*.” For this participant, the greatest part of the role was supporting his mother, knowing his father’s health was deteriorating. A short while after the interview his mother died of stroke complications, and he was forced to place his father in a nursing home after he had wandered off during the night.

One participant discussed the challenges of managing the care of her father who lived in another state and her mother’s acting out against the father. Once a month the participant traveled to the family farm to visit and assist with care in addition to paying bills and coordinating care from a distance. She described a lack of familial support as well as nursing care.

*“My father and mother had five children, two who live close and do not assist with care. The children who assist with care for my dad are a brother in Florida, another brother in New York, and myself in Pennsylvania. … My mother who lived with my father began physically attacking him and my father and had to be relocated to an apartment in another town with a restraining order. Since we did not live close, we had to find caregivers in upstate New York who charged $4000 a week for nine weeks until approval from Medicaid.”*

Another caregiver described current health issues which changed the role she played in the care of her mother. She began as a visible caregiver but developed health problems. Her husband had a hip replacement and she had to help care for a grandchild with autism. She transferred care to a sister who began providing the visible care. As a nurse, she became the invisible caregiver and used her nursing knowledge to assist with decision making while finding medical supplies and offering financial support. She also sat with her mother and listened to music. She described the management of care as overwhelming at times.

These descriptions demonstrate the importance of invisible care. The emotions and intentions shared in the interviews suggested the invisible caregiver gave as much support as those providing visible care, but it often went unnoticed.

### ***Weathering the Storm of Visible Care***

The participants who provided direct care described visible care as performing activities of daily living, shopping, and comfort care. Many of the participants described the challenge of balancing the demands of family, work, and providing care to the person with AD. Ten participants who provided either part- or full-time care, managed care for the person with AD, and worked through the emotional strain of the role. These caregivers lived in a constant storm of responsibilities with little or no time for respite because the person with AD resided in the same home. In many instances, family or social support was not available or offered, so caregivers were unable to step away from the role. One participant, who provided visible care for his father with AD and lived in the same home, described caring for his father this way:

*"My father's health has declined requiring more prompts with getting dressed and eating meals. I call my brother while at work to make sure our dad eats because it has become more difficult. It is difficult to see this change in my dad because he was a totally different person and I always looked up to him. Now he is like my kid, a total role reversal."*

Another participant reminisced about the times he had spent with his mother. He had struggled to balance a job, care of his mother, and demands of the father as well:

*"In the beginning I got a little emotional because my mom and I were really close. My dad worked late Friday nights so me and my mom would sit outside, drink wine, listen to music, and talk. It is hard to see her progressively getting worse. A few weeks ago, I got a bottle of wine and had music playing. It got me very emotional because it is what she used to do, we did it together."*

Although the care seemed challenging, it was more difficult when the care recipient became agitated or their behavior escalated. Some of these behaviors described by the participants were spitting out food, difficulty taking medications, or roaming the house at night. One participant discussed the behavior with her mother in the evening.

*"We do dinner and then things start to go downhill. Later in the day she gets very agitated, anxious, not so nice, and she is no longer my mom. I try to get her ready for bed at 10 pm and she says she is ready for bed, but then I find her… making sure that everything is on her desk. It is almost like it is anything else but going to bed."* In these situations, adverse behaviors were a concern because many of the caregivers felt beaten down by the storm of responsibilities, but managed to find the beauty in their role and dedication to the person with AD.

> The positive experiences included feelings of devotion to the care recipient, sense of competence, self-satisfaction, social support, and religious/spiritual coping mechanisms.

## Discussion

This study adds to the literature about the visible and invisible roles of caregivers for persons with AD. The umbrella term "caregiving" encompasses responsibilities that are visible to the family or outside community. This type of care was described as physical care such as activities of daily living, medication administration, and meal preparation (Hartmann et al., 2016). The participants providing visible care experienced periods of being overwhelmed by the physical care, psychological strain, social isolation, and the financial burdens of care. Long hours were expended to provide care in addition to the caregiver's own work and family obligations. The stressors identified are familiar to caregivers and similar to previous research (Araujo et al., 2017; Carpenter et al., 2020; Gehrman et al., 2018).

Hartmann et al. (2016) described another concept which was invisible care. Invisible care in the current study was identified as a more difficult role because it involved tasks not typically seen by others and were thought to be unappreciated. Participants identified their strengths as having communication, organizational, or previous career skills to assist with care. An important aspect was to be an emotional support for the person with AD and for those providing visible care. This role can also be draining and there were times when the stress of planning, coordinating, or managing finances was overwhelming.

In many situations, as described by White et al. (2018) caregiving was something family members perceived as their obligation. The responsibilities of care were not even clearly defined by the caregivers themselves and sometimes just assumed because of being a family member or friend. In addition, caregivers may have experienced a shift in their role with the person's progression of AD, changes in family or social support, and at times with their own health concerns. Many times, caregivers expressed frustrations with lack of social support from other family members which increased stress as well as being self-critical of their abilities to provide care (Carpenter et al., 2020; Goncalves et al., 2020; Mayo et al., 2020; Wang et al., 2018).Because of these circumstances, caregivers experienced variability in the role from providing visible to invisible care because of their own declining health or other responsibilities. Uncertainty in navigating one's role accompanied by changing responsibilities become additional stressors that accompanied the caregiver until the end of life for the care recipient. The fluidity of these roles can contrast with the literature that does not discuss shifts or a division of the responsibilities; they are only described as "caregiving"(Carpenter et al., 2020; Goncalves et al., 2020; Mayo et al., 2020; Wang et al., 2018).

Participants in the current study offered an understanding and distinction to the characteristics of caregiving. Defining invisible care and the variability of the visible and invisible caregiver's role offers additional insight into the stress that accompanies the caregiver of the person living with AD. White et al. (2018) suggested raising awareness of the role within the community so caregivers would be acknowledged for their work which would also allow more access to social support or outside resources.

## Limitations

This research was conducted in a single metropolitan area in Northeastern United States and may not be generalizable to other areas of the country.

## Implications for Home Care Clinicians

Home care clinicians should identify caregivers who provide both invisible and visible care, assess their needs, and provide emotional support, information on stress reduction measures, and resources such as Alzheimer's support groups, adult daycare, and education about AD. If warranted, information about palliative and hospice care should also be provided.

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