


# Managing Alzheimer's Dementia with Homecare in an African American Family During the COVID Pandemic

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## Abstract

In the US, over 95 million people have been infected with COVID and over 1 million have died. 10% of Californians are infected with COVID with higher rates reported among Latinx, Pacific Islanders, and low-income people. Higher death rates have been reported among African Americans. People living with Alzheimer's Disease (AD) are also more likely to be infected with COVID. African Americans with AD have three times the COVID rate of Whites. Homecare workers who care for moderate to severe AD in home and community settings are frontline essential workers who manage complex AD-related problems like incontinence. Little is known about communication and problem-solving processes between homecare workers and families of people with AD to manage continence at home. This report describes the challenges facing homecare workers illustrated by an African American family caring for a relative with advanced AD during pandemic.

## Keywords

caregivers, home health, domestic workers, structural family therapy, clinical case studies

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## Introduction

COVID has placed additional burdens on AD patients and their families. Homecare workers face a wide range of occupational risks, including injury from lifting, turning, and moving disabled clients. This report describes the challenges faced by an African American family caring for a relative with advanced AD using homecare. About 90% of homecare workers are women, and approximately 28% are of African descent, 33% Latinx, and 38% White (Bureau of Labor Statistics [BLS], 2022). The median age is 45, 30% of homecare workers are immigrants, most have high school education and the median income \$30,000 (BLS, 2022).

The Stress Process Model (Pearlin et al., 1990) has been the predominant organizing framework for over 30 years in family caregiver research. The Stress Process Model was developed to examine stress among AD family members. The Stress Process includes socioeconomic characteristics and resources of family caregivers in the model. Primary stressors include the AD diagnosis and symptoms. Secondary stressors include the caregiver employment demands, social life constriction, and

family conflict. Pearlin hypothesized that high levels of caregiver distress lead to depression and adverse physical outcomes.

The family is the most proximal and influential interpersonal context throughout the life span and plays a role in AD caregiver stress and coping (Mitrani et al., 2006). Caring for a family member with dementia is a stressful experience associated with negative outcomes such as depression, anxiety, and diminished physical health (Mitrani et al., 2006; Schulz et al., 1990).

Very little is known about the stress toll on homecare workers or formal caregivers. When homecare is introduced, the family system is enlarged and modified to include the new caregiver–patient relationship, modified by homecare giver resources, homecare giver

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values, and client disability (Eisdorfer et al., 2003). Little has been published regarding communication between homecare workers, family members, and clients that allows for effective care of people with AD. Muramatsu and Yin (2019), however, have explored the dyadic nature of the caregiver relationship for health promotion and physical activity interventions.

Organization, scheduling, time management, assessment, and care planning skills are necessary. Flexibility, cleanliness, competence with cleaning products, cooking, and shopping are also necessary. An ability to comprehend individual and family psychopathology is very helpful. Homecare workers with family or life experience may possess these attributes.

For the past 20 years, AD caregiver research has documented risks and hazards to AD family caregiver health from the stressors and strains of caregiving (Schulz & Eden, 2016). Home and Community Based Services (HCBS) have been developed as a part of the Affordable Care Act to make homecare more affordable for elderly and disabled individuals and their families.

After the COVID pandemic, few nursing homes are admitting short-term Medicare beneficiaries (Grabowski, 2019; Grabowski & Mor, 2020). Hospitals are not performing elective procedures like joint replacements, so patients who would ordinarily require post-acute care are not being referred to nursing homes. An increasing number of hospitalized patients are recovering from COVID and are medically stable enough for post-acute rehabilitative care, but most nursing homes are not admitting these patients because of an inability to care for them safely. Some nursing homes are facing bankruptcy due to decreased Medicare revenue and the increased costs of managing patients with COVID. More than 300 nursing homes have closed during the COVID pandemic and another 400 could go out of business this year, according to a new analysis (Brown, 2022).

## COVID and AD

A large proportion of elderly live with symptoms of AD including difficulty remembering recent events, problems with language, disorientation, and mood swings. Given the progressive nature of AD, which is a chronic neurodegenerative disease, symptoms usually start slowly and gradually worsen over time (Alzheimer's Association, 2022). As AD advances, symptoms can affect judgment, motivation, decreased self-care, and behavioral issues (Alzheimer's Association, 2022). As AD progresses, clients often withdraw from family and society. Gradually, bodily functions are lost, ultimately leading to death. Although the speed of progression can vary, the typical life expectancy following diagnosis is 3–9 years (Alzheimer's Association, 2022).

AD typically progresses slowly in three stages with mild symptom profiles indicating early stage, a moderate profile indicating middle stage, and a severe profile indicating late stage (Gallagher-Thompson et al., 2020).

All caregivers of people with AD undertake a range of tasks that vary across the disease trajectory (Gallagher-Thompson et al., 2020). For the past 20 years, AD caregiver research has documented risks and hazards to AD family caregiver health from the stressors and strains of caregiving (Schulz & Eden, 2016).

## Ethnicity and AD

Ethnic minority status and AD is associated with delaying treatment, avoiding institutionalization, and extended family members being involved in care (Mukadam et al., 2011; Nápoles et al., 2010). African American families may believe that memory impairment comes with normal aging.

Mayeda et al. (2017) identified inequalities in dementia incidence between six racial and ethnic groups with people over 65 ( $N=59,555$ ). Dementia incidence was highest for African Americans and Native Americans, intermediate for Latinx, Pacific Islanders, and Whites and lowest among Asian-Americans.

Wang et al. (2021) conducted a retrospective analysis of patient electronic health records of 61.9 million adult and senior patients in the United States up to August 21, 2020. Patients with dementia were at twice the risk for COVID as compared to patients without dementia. Patients with vascular dementia were three times as likely to be COVID infected. Those with presenile dementia (Alzheimer's diseases, senile dementia, and post-traumatic dementia) were also three times as likely to be COVID infected. Black patients with dementia had three times the risk of COVID as compared to Whites. The 6-month mortality and hospitalization risks in patients with dementia and COVID were 20.99% and 59.26%.

## Annie Jackson

Annie is a 78-year-old African American woman who is a homecare client. She was born and raised in Alabama and has lived in northern California for 45 years. Her husband, who is deceased, worked for AMTRAK. Annie was diagnosed with AD by a physician at a county public health clinic 10 years ago. The clinic visit was initiated when she began to show signs of memory problems to her daughter. Currently, Annie has difficulty with basic ADLs including bathing, toileting, grooming, cooking, and mobility. Annie also has comorbid kidney disease, hypertension, and asthma.

Annie's primary family caretaker is her daughter. Her daughter lives in nearby city and is a social worker. Annie lives with her granddaughter, age 27, who is a graduate student in education and works full-time. Annie worked as a cook for a public school system for 35 years. She is a high school graduate. She is a homeowner, receives a pension and her husband's pension. Annie relies on her daughter to handle her bills and other administrative tasks.

Annie spends days in a wheelchair, chair, or sofa watching television. TV shows that have fighting or violence can provoke Annie to become agitated and shout at the show. She likes to watch game shows which calm her down, but often has difficulty finding calming shows and requires the assistance of the homecare worker. Annie also has poor memory and erratic behavior. She was taken by her daughter to get COVID vaccinated at a public health clinic. Prior to COVID, Annie attended an adult day health center which closed without notice in the beginning of the COVID pandemic.

Annie has two homecare workers. Martha, who is 56 and Latina, takes care of Annie 5 days a week from 6 am to 5 pm. She is off on weekends and holidays. Martha lives three blocks away from Annie. Annie and Martha communicate well. Martha is aware of Annie's trigger points and tries to keep her day calm and relaxed and adheres to her schedule.

Alane is an African American woman, age 60, who lives in a distant county and works for Annie for 3 hours on Saturdays. Alane has known Annie for more than 7 years and, prior to moving, was her full-time caregiver. Alane and Annie communicate well, and Annie has a special bond with her. She takes Annie out for a ride or walk. They often go to the store, to Annie's daughter's home, or walk to the park.

## Schedule

**6:00–7:00 am:** Annie is usually soiled with urine. All soiled clothes are placed in a black bag and left on the back porch. Annie needs some assistance out of bed.

**7:00 am:** With homecare assistance, Annie bathes, grooms, and gets dressed.

**7:30–8:00 am:** With homecare assistance, Annie has breakfast. She is lactose intolerant and prefers rice milk. She cannot tolerate any TV shows with violent content. "Roxanne," "I Love Lucy," "Mary Tyler Moore," and Judge shows are preferred.

**9:00 am:** Annie likes to watch "Let's Make a Deal" and "Family Feud." During this time, the homecare worker launders soiled clothing.

**10:00–10:30 am:** Annie needs a bathroom break, the homecare worker takes her to urinate.

**12:00 pm:** Another bathroom break, the homecare worker must take her to urinate.

**12:00–1:30 pm:** Annie enjoys a walk outside in the neighborhood accompanied by her homecare worker.

**1:30 pm:** Annie is served lunch prepared by her family and heated by the homecare worker.

**1:30–2:30 pm:** Annie reads a book or magazine. She also enjoys board games with the homecare worker.

**3:00–4:00 pm:** Annie is generally assisted to the bathroom for usually a bowel movement.

**4:00–5:00 pm:** Annie will take a nap.

**5:00 pm:** Annie needs to be woken and helped out of bed or she will be up all night.

**5:00–6:00 pm:** Annie is served dinner and eats with the homecare worker or sometimes with family.

**7:00–8:00 pm:** Annie likes to go in her room and sleeps all night. "Wayne Brady" and "The Price is Right" are preferred shows.

**Sundays:** Annie is with her family and often attends church. Other family events or dinners are planned by Annie's daughter, generally on Sunday.

## Incontinence

Incontinence is experienced by about 42% of older adults, especially women (Dumoulin & Hay-Smith, 2008). Thirty to fifty percent of older women experience urinary incontinence (Ratini, 2020). Urinary incontinence is associated with lack of mobility, diabetes, and dementia (Northwood, 2021). A person with dementia is more likely to have accidents, incontinence, or difficulties using the toilet than a person of the same age who does not have dementia. Incontinence develops because messages between the brain and the bladder or bowel do not work properly. They may not recognize that they have a full bladder or bowel or be able to control them. Other reasons include not reacting quickly enough to the sensation of needing to use the toilet, not getting to the toilet in time, not being able to tell someone that they need to go to the toilet because of difficulty communicating, not understanding a prompt to use the toilet.

If someone becomes confused about their surroundings, they may urinate in an inappropriate place (such as a wastepaper basket) because they have mistaken it for a toilet (Ratini, 2020). They may neglect to undo clothing. They may be embarrassed after an accident, which the person unsuccessfully tries to manage. For example, they may try to hide wet or soiled clothes at the back of a drawer to deal with later, and then forget they have put them there. Many older people get up during the night to urinate. A person with dementia may wake up disoriented and be unable to find (or get to) the toilet in time. Installing motion sensors for lights or night lights in the bedroom, hallways and bathroom is helpful (Ratini, 2020). Plenty of sanitary wipes and bed protectors should be easily accessible.

People living with AD may have some urinary leakage in spite of best efforts to improve use of toilets. Overnight leakage can be especially hard to control. Incontinence supplies both disposable and washable are essential to stock. Bathing supplies such as bath and shower chairs and bath benches are also essential. Home modifications such as grab bars and lifts can be very useful. These proposals are the tenet of universal design.

Homecare workers often assist families and people living with AD to reduce shame and embarrassment. Sanitary products for incontinence are available at shops selling independent living aids and pharmacies. Families are generally responsible for supplying incontinence supplies such as disposable underwear, insertable

booster pads, and furniture protectors. Homecare workers may assist families to order or shop for supplies. Some families neglect to order or purchase incontinence supplies. This results in neglect of the AD family member and conflict with homecare providers who cannot work without supplies.

## Discussion

Homecare workers who care for moderate to severe AD in home and community settings are frontline essential workers. Homecare workers are predominantly low-income minority essential workers who are at high risk for COVID (BLS, 2022, Reitsma, 2021). People living with AD also have increased risk for COVID (Wang et al., 2021).

Shame and embarrassment at incontinence often become problematic for clients and their families coping with AD when accidents or chronic leakage occur. While some urinary incontinence is a normal part of aging, when AD is present it often initiates the search for homecare assistance or even institutionalization (Northwood, 2021). In the case of Annie, her strong family, her long-term relationships with her homecare providers, and her continued residency in her own home have helped her to preserve social functioning and daytime continence. Despite modest means, Annie's daughter has financial skills to maintain two homes. She also budgeted for and maintained an adequate stock of continence supplies.

One purpose of this report is to address policy implications such as funding allotments to state and federal agencies. A trained workforce is essential to timely COVID vaccination in the U.S. and California population. Homecare workers are uniquely positioned to locate isolated elders and offer accurate COVID vaccine information. For those lacking transportation, homecare workers can accompany clients to providers. Homecare workers lack venues, forums, meeting space, or access to expert speakers. Their voices are largely absent from public health discourse. Incontinence care, COVID prevention and care, hoarding, wandering, and risks for falls are possible education topics for homecare workers. Policy implications include health departments dedicating resources to improve pay, benefits, networking, and continuing education for homecare providers.

Research questions suggested by this report include, first, how do we develop valid quality measures for homecare worker competence like communication skills for clients and their families? Second, how can we educate homecare workers to develop skills to help family members coping with AD? Using evidence-based methods in homecare may enable clients living with AD to maintain or even improve function while living at home.

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The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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## Human Subjects

This fully anonymized single case study appears not to require IRB review. According to the University of Pittsburgh, IRB, a major site for Alzheimer's family caregiver research.

"A summary of clinical data, including medical history and other relevant information, that was collected initially for the purposes of analyzing and diagnosing the individual's condition and/or for instructional purposes, is considered by the IRB to be a 'case report' or 'case study'. Because this information was not collected with any intent to test hypotheses or otherwise produce 'generalizable' knowledge, the activity does not meet the criteria for 'research' (45 CFR 46.102(l)), and ordinarily does not require IRB oversight."

"Although publishing a case report may not require submission to the IRB, investigators should be aware of the use of individually identifiable health information in their publications. Under HIPAA, the disclosure of and individual's protected health information must be authorized by that individual. In other words, if a case report contains any identifiers as defined by the HIPAA regulations, authorization to disclose this information in a publication must be sought from the individual whose information is being disclosed."

Non IRB Activities, University of Pittsburgh, Human Research Protection Office, hrpo.pitt.edu retrieved June 6, 2022

## Add To Literature

1. Home and community-based services for dementia.
2. Home and community-based services during COVID
3. Cultural competence in dementia care

## Applications To Policy and Practice

1. Continence care is a teachable issue.
2. Need for home worker quality standards.
3. Need for homecare worker training.

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