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Living alone with dementia: Supportive care for dementia, a replicable model for support and lessons learned

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Abstract

Introduction: Current support programs for individuals with dementia focus primarily on patients living with caregivers. Research on individuals with dementia living alone is sparse, with small sample sizes. This report describes data collected from the Supportive Care for Dementia program. The program's goals are to provide support services that allow the person to remain in their residence, increase involvement and decrease the stress experienced by family members, reduce neurobehavioral disturbances, reduce hospitalizations and emergency room visits and related costs, and facilitate placement or caregiving support when appropriate.

Methods: The data were collected from 300 patients enrolled in the Supportive Care for Dementia program. Measurements included patient behaviors, distant caregiver stress, hospitalizations and emergency room visits, and provided services.

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Results: Program participation was associated with positive outcomes, including decreased emergency room visits, decreased distant caregiver stress, and increased supportive services and familial engagement. Demographic data including racial and ethnic differences are discussed.
Discussion: The Supportive Care for Dementia program is a replicable program with demonstrated positive outcomes for individuals with dementia living alone.

Keywords
living alone with dementia, caregiver burden, dementia, supportive home care, ethnicity and living alone

Background

The incidence of Alzheimer's disease and related dementias is rapidly rising in the United States, with estimates of over 6.7 million individuals currently affected (Rajan et al., 2021). About 65% of individuals with Alzheimer's Disease and related dementias reside in the community, and approximately 26% of them live alone at home (Alzheimer's Association, 2024). With the aging population expanding and dementia prevalence on the rise, the number of individuals living alone with dementia is expected to increase drastically (Clare et al., 2020). Those living with dementia encounter cognitive changes that significantly impact their daily functioning (McKhann et al., 2011). Instrumental activities of daily living such as managing finances and medications, and activities of daily living such as grooming and feeding, are particularly affected by cognitive decline in dementia and often require caregiver assistance (Alzheimer's Association, 2024; Dubbelman et al., 2020). Persons with dementia living alone lack live-in caregivers and assistance in completing instrumental activities of daily living and activities of daily living, which are crucial for daily functioning. Consequently, these individuals have comprehensive and diverse support needs (Crance & Yu, 2025; de Medeiros et al., 2022).

Current studies on supportive services for individuals with dementia recommend meal delivery services, community activities, medication management, and housekeeping services (Eichler et al., 2016; Miranda-Castillo et al., 2010; Odzakovic et al., 2021; Soto et al., 2015). Although individuals living alone with dementia utilize these services more often than those living with a caregiver, they still have more unmet needs (Eichler et al., 2016; Miranda-Castillo et al., 2010; Soto et al., 2015). There is sparse research on support programs designed to assist individuals living alone with dementia (Crance & Yu, 2025). Recognizing the unique needs of these individuals is crucial for designing impactful community-based programs that provide readily accessible support and services (Crance & Yu, 2025). This article presents the findings of a supportive care program for individuals living with dementia in the southwestern United States. The Supportive Care for Dementia program was developed in 2013 and expanded in 2020 with a grant from the U.S. Administration for Community Living, Department of Health and Human Services. The program includes three interlocking components: (1) monthly home visits by a Dementia Educator; (2) phone consultations with a physician or nurse practitioner with expertise in dementia care; and (3) a 24/7 phone triage service provided by nurses trained in dementia care. The impact of this program on those living with caregivers is included in a separate article (Hamilton et al., 2023). This study examined the impact of the Supportive Care for Dementia program on persons living with dementia who are living alone.

This research, which analyzes retrospective data collected during the program, qualifies for exemption from IRB review under 45 CFR 46.104(d) (4) for secondary research that does not require consent. This determination was made by the Hospice of the Valley Institutional Review Board on May 19, 2023.

Method

Participants

The 300 individuals included in the study were all those admitted to the Supportive Care for Dementia program between January 2021 and July 2023 who lived alone. Individuals demonstrated cognitive impairment ranging from mild cognitive impairment to advanced dementia, as assessed by their physician or on the first home visit. The most common program referrals (37%) were from physicians (primary care, neurologist, or psychiatrist). The second most common source of referrals (16%) was Senior Adult Independent Living, a program of the Area Agency on Aging that provided case management twice a year. Other program referrals came from individuals familiar with the sponsoring agency, Hospice of the Valley (15%), word-of-mouth or media (15%), community agencies (8%), health care insurers (5%), hospitals (1%), and others including fire departments (3%). Only two patients were self-referred.

Program description

The overall goal of the Supportive Care for Dementia program is to stabilize the patient's situation, which may include a number of interventions. The primary program component consists of monthly home visits by a Dementia Educator ("Educator"), usually a social worker, although may be a person with a graduate degree in a health care field. New Educators complete a one-month onboarding process. This onboarding begins with the completion of program dementia educational modules and two half-day sessions with a Nurse Practitioner with advanced expertise in dementia (Doctor of Nursing Practice). Onboarding then involves home visits with an Educator initially shadowing, then completing documentation, and finally completing two visits independently with observation and mentoring.

The standard program length is five monthly visits over the course of six months. During the first visit, the Educator collects patient information and a list of medications and identifies any urgent issues. They administer the cognitive Mini-Mental Status Exam (MMSE). If the Mini-Mental Status Exam score is high (indicating minimal cognitive deficits), at their discretion, they may also administer the Montreal Cognitive Assessment (MoCA) which is more sensitive in detecting mild cognitive deficits. During or after the visit, the Educator attempts to identify a caregiver who may live locally or out of state. If a caregiver is successfully contacted, the Educator assesses the caregiver's perceived burden by administering the Zarit Burden Interview (ZBI).

During the second visit, the Educator engages the patient in discussions related to health care decisions, including completing a medical and mental health care power of attorney and whether the person wishes to be resuscitated if they stop breathing or their heart stops beating. If they do not want cardiopulmonary resuscitation (CPR), pre-hospital directives are completed and posted for paramedic calls.

On the initial and subsequent visits, the Educator provides interventions that are designed to help the person living with dementia remain safely in their own home if that is their desire. These interventions may include fall prevention (e.g., rearranging furniture and rugs, suggesting grab-bars, ramps, or railings, improved footwear), obtaining an emergency call button or tracker, discussing how to request help when needed, and discussing methods to obtain food, medical assistance, and socialization. The Educator provides information about available supportive resources and services, such as Meals on Wheels, Area Agency on Aging or paid caregiver, Long Term Care System/ Medicaid for services, and alternative placement. If the person living with dementia is considered to be at high risk of health decline due to fall risk, not taking medications or taking too many, wandering away from home, or other risks, placement becomes a goal. Assisting with eligibility for long-term care coverage through Medicaid is provided through documentation to decline and advocacy. During the fifth visit, the Educator re-administers the Zarit Burden Interview to the family caregiver. If the person living with dementia is considered in danger of rapid decline and remains living alone, monthly visits by the Educator continue. Emergency room visits and hospitalizations for the six months before and during the program are tracked through the state-wide shared hospital database.

The Educators are each assigned 55-60 patients, including those living alone (11%) and those living with caregivers (89%). They attend weekly conferences with the team's Medical Director and Nurse Practitioner. If behaviors are challenging (e.g. physical or verbal aggression, severe agitation, delusions, hallucinations, dangerous wandering or driving) the team's Medical Director or Nurse Practitioner may call the person living with dementia, identified caregiver, and/or primary care physician or neurologist to discuss possible adjustments to medications and other interventions, including writing to the Motor Vehicle Bureau to retest or remove license. A nurse is available to make home visits to assess medication compliance, provide adapted medication organizers, simplify medications, and talk with prescribers. In addition, a 24/7 triage phone line staffed by trained nurses is available, providing the patients and families with a consistent source of information and advice.

Results

Data was analyzed for 300 person with dementia living alone who received at least one program visit from January 2021-June 2023. In the cohort, 71% were female, and 29% were male. The median number of monthly visits across the cohort was 5 visits: 46% of patients had less than five visits, 37% had five visits, and 17% had more than five visits. Patients had fewer visits if their needs were met before the fifth meeting (70% of early discharges), they could not be contacted (19% of early discharges), or they refused further visits (13% of early discharges). Reasons for refusal, when given, were due to families not wanting outside agencies concerned they were providing inadequate care, or patients not wanting their current situation to be changed. Patients had more than five visits if their situation was not yet stabilized.

For the patients who completed the Mini-Mental Status Exam ($N = 262$), the mean score was 21 (range: 5–29). Although the Educators made concerted efforts to identify a caregiver, none could be identified for 60 patients (20%). For the 240 patients with an identified distant caregiver living locally (92%) or out of state (8%), 72% of their caregivers were female. The relationships of distant caregivers to patients were: 70% children of the patient, 29% non-familial relations (e.g., neighbors, friends, ex-spouses), and 1% spouses living elsewhere.

Some caregivers visited or called daily, bringing or ordering food and helping to organize the home. Some caregivers visited or called weekly, and others visited or called only every few months. One of the goals of the Educators was to encourage families to become more involved by educating them about the person's decline, and this was often successful.

The ethnic distribution of the cohort living alone was: 87% White/Caucasian, 6% Hispanic, 5% Black/African American, 1% Asian/Asian American, and 0.3% Native American. African Americans make up 5%, and Hispanics make up 18% of the Arizona Maricopa County population over 60 years (Arizona Department of Health Services, 2022). This distribution was similar to the one observed in the patients living with caregivers, with the exception of a higher proportion of Hispanics living with caregivers (13% living with caregivers vs. 6% living alone) (Hamilton et al., 2024).

This finding suggests that Hispanic individuals with dementia were more likely to be placed in a family home setting instead of living alone.

Medical power of attorney

In the cohort, 55% of individuals stated they had a Medical Power of Attorney at the start of the program. Through the program, 30% of individuals completed Medical Power of Attorneys by the time they left the program, resulting in 85% of the cohort having established Medical Power of Attorneys. The remaining 15% refused to appoint a decision-maker.

Care services and placement

Through the efforts of the Educators, 8% of individuals were able to obtain caregivers (family or agency) visiting them weekly to provide food, cleaning, medication checks, and other support. The program Educators arranged for placement for another 30% of patients. The most common placement was moving to an assisted living facility (88% of placements), but also included moving in with family members (7% of placements) or family members moving in with the patient (5% of placements). Finally, 9% of patients went to hospice care, which provided support in the home several times a week.

Additional support services

The Educators arranged for Meals on Wheels for 22% of patients. Educators arranged for home-visit medical providers for 3% of patients, and nurse visits to support the individual's medication protocol (e.g., reviewing medication compliance, simplifying medications, arranging for a medication organizer) for 2% of individuals.

Hospitalizations and emergency room visits

One program goal was to reduce hospitalizations and emergency room visits. For the 162 individuals who completed at least five visits over six months, the mean hospitalization rates for the six months prior to the program versus during the program were 0.18 hospitalizations per adult and 0.17 hospitalizations per adult, respectively. The reasons for the hospitalizations included falls (46%), urinary tract infections (14%), change in mental status without clear cause (9%), dyspnea/pneumonia (6%), hypertension (5%), headaches (3%), and other miscellaneous causes (17%). The mean rates of emergency room visits without hospitalization for the six months prior to the program versus during the program reflected a slight decrease: 0.29 emergency room visits per patient and 0.19 emergency room visits per patient, respectively.

Mortality. Seven patients (2%) died during the program unexpectedly. Two adults died in their homes, with the cause of death not determined. One individual, who had a history of depression and anxiety, committed suicide. Four patients died in the hospital of pneumonia or stroke.

Distant caregiver stress

The potential effect on distant caregiver perceived burden levels was examined using the Zarit Burden Interview (ZBI) scores obtained at the first visit and after six months ($N = 72$). The mean

Zarit Burden Interview score of distant caregivers was significantly higher at the first visit (22.1, SD = 9.5) compared to their score after six months (17.9, SD = 8.3, $p < .001$). (Note: Higher scores reflect higher perceived burden or stress.) Thus, the distant caregivers reported significantly lower stress levels after participating in the program. In comparison to a previous study of dementia patients with in-home caregivers, the mean Zarit Burden Interview scores of in-home caregivers (N = 400) were slightly lower initially and after six months (19.82 and 16.18, respectively) (Hamilton et al., 2023). Of note, for the 6 patients with caregivers living out of state, the mean Zarit Burden Interview score was 26.5 at the start of the program and 18.5 after six months. This sample is too small for quantitative analysis but does suggest that caregivers living far away may experience more stress than those living nearby.

Discussion

There is sparse research support for individuals with dementia who live without an in-home caregiver. The expanding incidence of Alzheimer's disease and related dementias in the older population will be associated with an increase in the number of individuals with dementia living alone. Effective programs that facilitate access to, and implementation of, supportive services will be critical for this vulnerable population. The Supportive Care for Dementia program utilizes a structured approach that includes in-person visits with trained Dementia Educators, phone consultations with clinicians with expertise in dementia care, and a dedicated triage phone service provided by nurses. This study examined the impact of the program on a cohort of 300 individuals with varying severities of dementia who lived alone.

Overall, the program was associated with many positive outcomes. The percentage of individuals with an established Medical Power of Attorney increased from 55% to 85% of the cohort. This is important because if (when) their cognitive status declines further through hospitalization or other medical events, having a decision-maker who knows their wishes will be critical for their future care. The Educators provided intervention options, including home safety interventions, education about resources, and food and medication support, to allow patients to remain safely in their own homes, which for many was their goal. In addition, Educators helped 8% of the cohort to obtain in-home caregivers, 30% to find placement, and 9% to receive hospice support. Thus, the program facilitated direct assistance to almost all patients and changes related to their living situation for 47% of the individuals living alone.

Hospitalization rates before and throughout the program were relatively stable, and emergency room visits showed a downward trend. Any reduction could reflect thousands of US dollars in hospital-related expenses and reduced patient distress. Emergency room and hospital visits often lead to cognitive decline, so preventing these visits is important to keeping patients safely at home.

In addition to the increased support services, there was evidence that the Supportive Care for Dementia program significantly decreased distant caregiver-perceived burden levels. It is noteworthy that the initial caregiver stress was slightly higher for the distant caregivers (22.1) than for the in-home caregivers (19.82), suggesting that geographic distance may not necessarily mitigate caregiver stress. For the caregivers living out of state ($n = 6$), the initial perceived stress level (26.5) was even higher. These findings highlight an interesting dynamic between caregiving proximity and stress levels. On the surface, one might think that caregivers who live farther away would experience less stress since they are not directly involved in caregiving tasks. However, the study suggests that distance can increase perceived stress. This could be due to factors like guilt, concern for the well-being of the person living with dementia, or the emotional burden of not being able to provide hands-on support. On the other hand, those living with the person they are caring for may experience stress in different ways, but having direct control over the care can provide reassurance and potentially reduce feelings of guilt. This underlines how caregiving stress is not only related to physical demands but also to emotional and psychological factors like worry, guilt, and the feeling of responsibility.

The demographics of the cohort and their caregivers reflected a strong trend. In the cohort, 71% of those living alone with dementia were female, which is higher than the proportion observed in the cohort of individuals living with caregivers (56% female) (Hamilton et al., 2023). Additionally, 72% of the identified distant caregivers were female. Overall, a higher proportion of females was observed for both individuals with dementia living alone and distant caregivers. In examining ethnic/racial groups, the percentage of Latino/Hispanic adults living alone (6%) was lower than the percentage of Latino/Hispanic adults living with caregivers (13%) (Hamilton et al., 2024). This may reflect engendered cultural attitudes related to familial caregiving (Martinez & Acosta Gonzalez, 2022).

A common barrier to implementing changes was the refusal of the person with dementia to change their living situation even when distant caregivers and/or team members explained that the current situation was unsafe. With their diminished mental status, these individuals may not have had the cognitive capacity to make reasonable decisions regarding their living situation. In these cases, Adult Protective Services (a state government program) seldom intervened, and families were often informed that hospitalization might be needed before a placement could be arranged.

Financial barriers were also frequently observed within the cohort. For example, a high-functioning individual (e.g., independent ambulation, continent) who was dependent on social security income would likely not qualify for Medicaid assistance for a place to live, which would provide a “nursing home level of care.” These individuals may be unsafe at home due to wandering or unsupervised driving but have insufficient funds to change their living situation, even if they are willing. No individuals in the program went to homeless shelters, but several were at risk of eviction until the program team intervened and advocated on the person’s behalf. Given that social security income would not be sufficient to cover local assisted living housing, the program team continues to work with community foundations to assist individuals living with dementia in finding affordable supportive housing.

The Supportive Care for Dementia program employs a multifaceted support approach for individuals with dementia and their caregivers. The current study demonstrates the effectiveness and positive impact of the program on individuals with dementia who live alone and those who support them. The cost of the program is relatively low (US$250/month including agency overhead) when compared to the potentially devastating emotional and financial costs that can result when an individual with dementia who cannot function independently is left alone without services or support. The Supportive Care for Dementia program was successfully administered to a large group of individuals with varying levels of cognitive impairment. Further, the program’s structure is amenable to replication in other communities with the flexibility to address local needs and tailor program aspects to incorporate local services and resources.

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Ethical statement

Ethical consideration

The Original Study was reviewed by HOV's Institutional Review Board and determined to be Exempt from IRB oversight (11.9.22). The original research describes quality improvement activities and involves the use of identifiable private information that was collected during normal healthcare operations as defined by 45 CFR 164.501. The principal investigator requested a review by HOV's Institutional Review Board for this secondary research and the proposal was determined to meet the OHRP Exemption from IRB review under 45 CFR 46.104(d) (4) for secondary research that does not require consent by the Hospice of the Valley Institutional Review Board, decision date 5.19.23. The HOV IRB is registered with OHPR (Registration #IORG 0011334).

Consent to participate

Informed consent waived as above.

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Data availability statement

De-identified data will be available upon request from the corresponding author.

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Kylee Volk, MPH, is the Associate Team Leader for the Supportive Care for Dementia Program at Hospice of the Valley. With a focus on enhancing quality of life for individuals with dementia, she implements evidence-based practices and fosters community support to address the unique challenges faced by patients and their families.

Ethan Best is a senior at Arizona State University, graduating with Honors and a Bachelor of Science in Medical Studies. Initially, he volunteered in the Supportive Care for Dementia program to learn more about the dementia population. After volunteering, he realized his passion for the dementia community and started researching with Hospice of the Valley. He plans to attend medical school to serve the geriatric population further and improve the standard of care globally.

Sara Crance, MSN, MBA, RN, OCN is passionate about improving the lives of individuals living with dementia. She is a current DNP/PhD student at Arizona State University and Dementia Team RN at Hospice of the Valley. Her research interests include dementia-specific education for frontline healthcare workers and supportive care for individuals living alone with dementia. Through her education, research, and experience, she hopes to improve healthcare education and quality of life for individuals living alone with dementia.