

Original Research

Experiences and Support Needs of Informal Caregivers in Managing Behavioral Symptom of Dementia

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Abstract

About 90% of people living with Alzheimer's disease and related dementias experience behavioral and psychological symptoms during the course of the disorder. Although extensive research exists on the roles of informal caregivers in dementia care, their abilities to manage behavioral symptoms and the resources they turn to for support remain understudied. This phenomenological study explored informal caregivers' experience, knowledge sources, and self-initiated strategies for managing behavioral symptoms of dementia. Through in-depth interviews with 15 informal caregivers, three key themes were identified. The findings revealed the challenges faced by informal caregivers in managing the behaviors, as well as the lack of real-time personalized support and guidance accessible to them. Dementia care training, conferences, webinars, and support group meetings were associated with the need to memorize and recall information. The findings highlight the need to empower informal caregivers with 24/7 real-time, personalized, evidence-based interventions for behavioral symptom management to enable them to provide quality care to their loved ones living with Alzheimer's disease and related dementias.



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Keywords

Alzheimer's disease and related dementias; Informal caregivers; family; behavioral symptoms; management; prevention; non-pharmacological interventions; home settings; qualitative; thematic analysis

1. Introduction

The prevalence of Alzheimer's disease, the most common type of dementia, is projected to double from 6.5 million to approximately 13.8 million in individuals aged 65 and above in the United States by 2050, indicating an increase of about 4.7% [1]. It is estimated that up to 90% of people with Alzheimer's disease and related dementias (Pw-ADRD) exhibit behavioral and psychological symptoms of dementia (BPSD) throughout the course of the disorder [1]. These symptoms include aggression, wandering, refusal to eat, refusal of care, and agitation, which intensify as the disorders advance [2, 3]. Although BPSD might be viewed as disruptive rather than a significant expression of a need or goal, thus overlooking chances for intervention and prevention [3-5], they could also signify attempts by Pw-ADRD to express unmet needs when they cannot effectively communicate or satisfy these needs on their own [6-8]. Research indicates that BPSD is strongly associated with functional and cognitive decline, leading to earlier nursing home placement, increased emergency service usage, and a higher demand for caregiving support [1, 9] contributing to ADRD becoming the costliest chronic condition in the U.S., with expenses totaling \$321 billion in 2023 [1].

Approximately 80% of Pw-ADRD reside at home, receiving care from family and friends (informal caregivers) [1]. In 2023, approximately 11.5 million informal caregivers provided an estimated 18.4 billion hours of unpaid care, valued at around 347 billion U.S. dollars for Pw-ADRD [1, 9]. The reliance on informal caregivers is expected to increase due to the expansion of Medicaid's home and community-based services, as well as the COVID-19 pandemic, which has reinforced preferences for home care over institutional settings [10, 11]. This highlights the need for informal caregivers to acquire knowledge and skills to prevent and manage BPSD in their care receivers effectively. Research indicates that using non-pharmacological interventions effectively manages many BPSDs in individuals with ADRD, both in clinical and home settings [12-14].

1.1 Study Purpose

The present study's purpose was to explore informal caregivers' experience, knowledge sources, and self-initiated strategies for managing behavioral symptoms of dementia in their care receivers.

2. Methods

2.1 Study Design

This was a qualitative descriptive study that was part of a larger study that focuses on developing an assistant voice app for dementia informal caregivers. Qualitative descriptive research involves exploring and understanding the lived experiences of individuals [15]. This approach was

appropriate for the study as it focuses on gaining insights into how people perceive and make sense of their everyday reality [15].

2.2 Study Sample and Sampling Method

We utilized a purposive sampling approach to recruit informal caregivers who satisfied the following criteria: (1) caregivers aged 18 and above who identified themselves as the primary, unpaid caregiver for an individual with clinically diagnosed dementia exhibiting behavioral symptoms like care refusal and wandering, and (2) caregivers who confirmed they had access to virtual meeting platforms or a telephone to engage in a 60-90 minutes semi-structured one-on-one interview. This study's sample size was determined based on the principles of data adequacy and saturation, which ensure that the data is rich and comprehensive for thorough analysis. We followed an iterative process of data collection, which continued until we reached saturation—at which point no new themes, patterns, or insights emerged from the additional data. This indicated that the sample size was adequate to meaningfully address the research questions.

2.3 Recruitment

Potential participants were recruited by posting flyers about the study at community sites, such as community halls and grocery stores, as well as on the websites of caregiver organizations. Additionally, public health and community organizations helped circulate information about the study within their networks. We also employed a snowball sampling approach, where individuals familiar with the study shared the information with their friends, family, and contacts.

Those interested in participating were asked to contact the research team directly via email. A member of our research team responded to those who expressed interest, providing them with further details about the study and inviting them to ask any additional questions. Recruitment continued until data saturation was reached when no new themes emerged from the analysis.

2.4 Data Collection

Data collection occurred between December 2023 and June 2024 using a semi-structured qualitative interview guide with open-ended questions and prompts. This data collection method was chosen because it offered a comfortable private approach, encouraging candid responses and enabling caregivers to share their thoughts and reflections with the interviewer freely. The interview occurred via the researchers' University's subscribed virtual platform and secured telephone line. A consent cover letter and the virtual platform invitation link were sent to the recruited participants before the interview session. On the interview day, the facilitator reviewed it and clarified any inquiries from the participants, who then verbalized whether they consented to participate. The participants who consented were then requested to complete a brief online socio-demographic questionnaire to obtain information about their age, gender, race, and ethnicity. Once demographic data were obtained, the participants were interviewed by a qualitative interviewer using the interview guide developed by our research team to lead the interview sessions. During the interview, a team member takes notes on vocal intonations, physical expressions, gestures, and other details not captured in the recorded interview. The interviews began with a general question: "What is your relationship with the person you are providing care for?" Initial answers were then probed until the

experience was fully described. During the interviews, open-ended, clarifying questions were asked. Based on the caregivers' responses, the sequencing of probing questions was changed during the study. Examples of guiding questions include: Home Care: *"Please, share your thoughts why you continue to provide care to your loved one living with dementia at home"*, Behavioral changes: *"Please describe the behavioral symptoms or changes in behavior you have observed in your care receiver?"*, *"Please describe the most challenging behavior you observed. Share with us how these behavioral symptoms impact the daily life of your care receiver and you as well as your caregiving responsibilities."* Preventive strategies: *"Please describe the strategies or interventions you have found effective in preventing or reducing these behavioral symptoms."* Support: *"Describe how you get information and support on preventing and managing these behavior symptoms."*

Each interview session lasted approximately 60-90 minutes and was digitally audio-recorded and transcribed verbatim to ensure the accuracy of the captured discussions. We recruited and interviewed participants until saturation was reached, which took about three months. By consensus within our research team, saturation was considered as the point when no new information or emerging themes were obtained from the participants with subsequent interviews. Data saturation was reached after interviewing 15 participants. The participants were given a \$50 Amazon e-gift card as a token of appreciation for their participation in the study.

2.5 Data Management

To ensure that the collected data were secured, we implemented measures such as storing electronic copies in secure electronic systems or hard copies in locked physical storage, using password-protected devices, and only allowing authorized research personnel to access them. For the online socio-demographic questionnaire, we enabled secure sockets layer encryption in the Qualtrics® system to protect data as it moves between the participant's computer and the Qualtrics servers. We used a cooperative approach, prolonged engagement with the data, and consensus by the research team on all aspects of the study to establish trustworthiness in our qualitative methodology [16].

2.6 Data Analyses

The collected socio-demographic data were analyzed using SPSS software (version 27) to compute descriptive statistics. Each recorded interview session was auto-transcribed. Two members of our research team cross-checked the transcriptions with the audiovisual recordings to correct any missed and incorrect spellings/wordings. Thereafter, the transcripts were sent to the participants to verify the accuracy of their responses, ensuring that their perspectives were accurately represented in the narrative data. All personal identifiers were replaced by unique numeric identifiers and pseudonyms and all identifying information related to persons and/or places were redacted within the transcript before the thematic analysis.

We (name placeholder) applied Braun and Clarke's [17] six-phase thematic analysis (Table 1) to analyze the data. The analysis was iterative, moving between phases to reach consensus. In the first phase, we immersed ourselves in the transcripts, recording our initial impressions. Subsequently, in phase two, we organized the data and embarked on a theoretical thematic analysis, coding relevant segments and employing open coding to evolve and refine these codes. In the third phase, we discerned general themes by scrutinizing the codes and arranging them into broader themes

pertinent to our research purpose. We then reviewed and honed these themes, assigning names and definitions, and pinpointing subthemes. Ultimately, we synthesized themes and subthemes into comprehensive descriptions, crafting a cohesive thematic framework. During this entire process, we engaged in discussions about the data, codes, and themes to achieve consensus and settle disagreements. Table 2 displays the codes, categories, and themes overview. Also, Figure 1 depicts a thematic map of the relationship between the codes, categories, and themes.

Table 1 Braun and Clarke’s (2006) six-phase for thematic analysis.

Phase 1	Become familiar with the data
Phase 2	Generate initial codes
Phase 3	Search for themes
Phase 4	Review themes
Phase 5	Define themes
Phase 6	Write-up

Table 2 Codes, categories, and themes overview.

Code	Category	Theme
Desire for Home Care Fear of Mistreatment Vulnerability of Care Recipients Formal Caregiver Response Quality of Life Concerns Preference for Familiarity	(1) Home Care Preferences (2) Home Care Concerns	Preference for Home Settings
Refusal to Eat Refusal to Bathe Impact on Caregiver Stress Frequency of Behaviors Emotional Reactions Strategies for Management Communication Barriers	(1) Caregiver Struggles (2) Behavioral Management	Most Challenging Behaviors
Self-Initiated Strategies Preventive Measures Learning Resources Practical Skills Development Prioritized Needs Adaptation and Flexibility Support Network Utilization Trials and Errors Emotional Resilience Feedback Mechanisms	(1) Proactive Management (2) Support Strategies	Management of Behavioral Symptoms Subthemes: (i) Self-initiated Interventions, (ii) Learning Resources for managing the behavioral symptoms, (iii) Caregivers Needs.

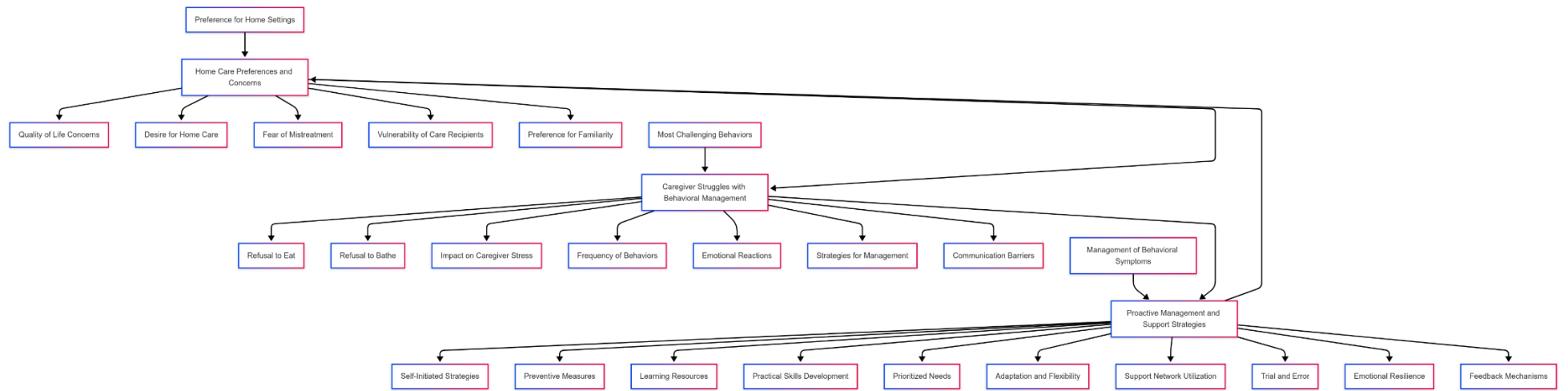


Figure 1 Thematic map.

The inclusion of participants' quotes enhanced the trustworthiness and confirmability of our analysis.

To minimize the impact of our pre-existing beliefs about dementia care on this study, we took time to reflect on our personal experiences and assumptions before beginning data collection. As a team, we openly discussed our understanding of dementia caregiving and any potential biases we might have. This process resulted in a shared document summarizing our reflections, which served as an ongoing reminder throughout the study.

During data analysis, we revisited these reflections to ensure our focus remained on identifying themes grounded solely in the participants' narratives. We provided feedback to each other, rechecking any potential biases during the analysis. By consistently referring to our reflections and engaging in open discussions, we ensured our conclusions were driven by the data, rather than influenced by our preconceptions.

2.7 Ethics Statement

This study [Placeholder] was reviewed and approved by [Placeholder] Institutional Review Board prior to its implementation. We followed ethical guidelines for human subject research as reflected in the procedures explained above.

3. Findings

3.1 Sample Characteristics

Table 3 depicts the characteristics of the 15 participants. Most of the participants were African Americans, female, and aged between 25-34 years old. Many of the participants (n = 9) identified the specific diagnosis as Alzheimer's while few (n = 6) could only say that their loved ones were medically diagnosed with dementia, not knowing the specific type.

Table 3 Socio-demographic Characteristics of Participants.

Variable	Category	n (%)
Age	18-24	2 (13.3)
	25-34	7 (46)
	55-64	3 (20)
	65 and older	3 (20)
Gender	Male	7 (46)
	Female	8 (54)
Education	Masters	3 (20)
	Associate degree	4 (26.7)
	Bachelor's degree	4 (26.7)
	Vocational Training	2 (13.3)
	Secondary	2 (13.3)
Ethnicity	Africa-American/Black	13 (86.7)
	Caucasian/White	2 (13.3)
Relationship to the care receiver	Child	12 (80)

	Spouse	2 (13.3)
	Friend	1 (6.7)
Years of being the primary dementia caregiver	Less 1 year	1 (6.7)
	1-2 years	1 (6.7)
	3-4 years	9 (60)
	5-6 years	4 (26.7)

3.2 Themes

Three themes were revealed from the analysis: (1) Preference for Home Settings, (2) Challenging Behaviors, and (3), Management of Behavioral Symptoms. Three subthemes emerged from the last theme: (i) Self-initiated Interventions, (ii) Learning Resources for managing behavioral symptoms, and (iii) Caregivers Needs. To illustrate the identified themes and subthemes, we choose representative quotations from the interview transcripts:

3.2.1 Theme 1: Preference for Home Settings

This theme encompasses the families' desires to keep their loved ones at home despite the progressive behavior symptoms. The participants expressed a strong preference for their loved ones to continue to be cared for in their homes, expressing the belief that if behavioral symptoms became too severe, the care recipient might be vulnerable to mistreatment or staff might not respond to even greater cognitive decline. For example, participant #1 stated, "I definitely didn't want to see my mom going to a nursing home. I didn't want nobody to mistreat her, especially when the behavior got really bad." Similarly, participant #6 said. "I feel that it's very safe for him to be at home." A more elaborated explanation was given by participant #2. "He hadn't got to the point where he didn't know us. I think at one time they gave him some medicine and they were evaluating him. And they gave him this medicine, and he said, who are you? My mother took him out of, she hurry up and got him out the facility. And when she got him back to the house and got him on regular medicine. Then, you know, you came by and he started saying your name. He knew (who) you were."

Other participants expressed their preference for providing care in a home setting, as they viewed this as an important responsibility for the child of the care recipient, to reciprocate the care their parent provided to them as children. Participant # 12 stated: "It's very important for us and we also feel like it's important for her. You see, home is a familiar place for her. She knows it very well. If we were to take her somewhere else, I don't know. We would feel like bad kids. It's our mom. She took care of us."

While there is a strong desire to keep their loved one at home and be the caretaker for as long as possible, some participants expressed financial motivations for providing care in home settings. Participant #13's statement highlighted this concern: "How long can I continue to work so there's all these big life decisions rolled into that, but I'm simultaneously looking at what it would take to have someone come to our home and then also what are the local care facilities like and what are their care units like? What can we afford? We don't have long term care insurance, you know, these things are pretty hideously expensive."

3.2.2 Theme #2: Most Challenging Behaviors

This theme captures the various struggles faced by caregivers in managing behavioral symptoms in their care recipients. The participants described what they considered to be their care recipient's most challenging behaviors. Refusal behaviors such as refusal to eat or to take a bath were frequently reported as particularly challenging. Participant #14 mentions "We have issues with not being willing to eat and especially in the morning he's so reluctant to eat that has been the main challenge for him." Participant #11 illustrated the challenge with the care recipient's refusal of a bath. "Uh, the bath was always the hardest. And in the evening time, when she didn't want to go to bed like that was another big thing too, like when it was time to go to bed. Why do I need to take a shower? Well, you need one at least every other day. Mom, just for hygiene. Umm. So that was the biggest struggle." Refusal behavior related to medication taking was illustrated in participant #9 statement, "I usually find her in the closet. She'll be on the floor in the closet and you know. There were times when she wouldn't take her medicine, because she just didn't want to." Likewise, participant #4 stated, "Oh sometimes when I'm giving her the medicine, she doesn't want to take. Yeah, sometimes she can be quite resistant."

Along with refusal behaviors, aggressiveness was also reported to be one of the most challenging behaviors. Participant #2 stated, "He would get aggressive sometimes. Especially in the evening. I guess they call it sundowners. That's when he would talk about leaving or going home." Similarly, Participant #7 said, "The aggressiveness at the most, the most challenging one was controlling him and it has been very hard. He's starting to be aggressive, throwing things that are around him." The outburst of anger is explained by participant #14: "OK, the frustration is that he's so like out of nowhere, he gets angry. Like when we are playing chess or cards and he loses, he gets angry."

The need for the care recipient to engage in frequent repetitive activities or activities with which they are familiar was found to be challenging to manage by some participants. For example, participant #13 commented, "He can't learn new things anymore. Learning new things is very, very hard, but things that he's very accustomed to doing that he repeats frequently, he's able to keep those up. He has to stay busy constantly. That's a little challenging actually, because he has to stay busy constantly, which means it requires a lot of prep and oversight on my part, and I also still work."

3.2.3 Theme #3: Management of Behavioral Symptoms

This theme encompasses the diverse self-initiated strategies caregivers employ to prevent and manage behavioral symptoms, the learning resources they utilize, and the needs they prioritize.

The participants described their strategies for managing behavior symptoms, the resources they use to learn about the symptoms and how to manage them, and their needs as informal caregivers. The three subthemes that were identified from this theme are presented below.

Theme I: Self-Initiated Interventions. Participants discussed the interventions that they came up with to manage the behaviors manifested by their care recipient. These strategies often involved music or singing. Participant #1 stated, "She would love to listen to music. So someone told me to get a radio. So I brought her this radio and I would put it on and play music for... and that seems to like calm her down. One time I had to change the locks on the door, because my mom always thinks, like I said, she always thought she was in New Jersey." Participant #7 stated "Sometimes there are some specific songs he likes to listen to. Really very happy because of the songs." Another self-

initiated intervention focused on the need to modify the home environment to promote the care recipients' safety, as illustrated by Participant #4, "So you know, I've tried to, like, make the living environment around her safe and consider potential dangers." Participant #11 commented "She actually left the property and I had to call the Sheriff's Department cause for me to go after her and get her back. It's I put bells on the doors now to know when she was going out the door."

Finally, caregivers were creative in combining an activity the care recipient enjoys with an activity that is frequently refused to achieve a particular caregiving goal. For example, Participant #14 stated, "With taking medication, sometimes it can be challenging because especially the days when he doesn't want to eat, he also doesn't want to take medication. So what do I do? I prepare porridge and he takes the medicine together with the porridge. And, you know, Porridge has that capability of making someone hungry. I really try to incorporate his preferences. Like, what do you feel like you want to eat today and it's something that I noted recently that when I asked him what he wants to eat and I could put, he wants to eat he eats better compared to when I choose what I want to cook. So we just play as he's eating. So with that, he's more concentrating on chess than eating. So as he eats, I tell him as we are playing, I tell him it's time to eat. And by the end of the game, we find out that he has finished all the food."

Theme II: Learning Resources on Managing the Behavioral Symptoms. Participants provided details on how they access information to improve their abilities to manage behavioral symptoms. The main source reported by participants was a web search for information. For example, Participant #1 said, "Well, a lot of times I will go to the computer and I looked it up".

In addition to searching the internet for resources, participants reported visiting trusted websites with ".org" and ".gov" domains, as well as the Alzheimer's Association website, to find information on managing behaviors and recent pharmacological discoveries. This approach is highlighted in the comment from participant #13: "Well, I go to the Alzheimer's Association. Spent a lot of time on PubMed just looking. So when the new generation of Alzheimer's drugs came out, I spent a lot of time researching efficacy and drawbacks." Similarly, Participant #9 said "I've been using the CDC and the Alzheimer's Association. A podcast that I was listening to for a while too. Honor Society podcast dementia care partner talk show." A smartphone application was mentioned by participant #12: "We've been using an app that helps educate you on planning and trying to help you schedule, it's called Dementia Caregiver Solutions. That's what I've been using. It helps me arrange how the schedule is supposed to be. The nutrition part always plays a role, it has really been helpful. It helps with giving you practical ways to deal with different behaviors. Like taking long walks, engaging in conversation, or playing music."

All participants reported feeling overwhelmed by the sheer volume of information they encountered on the internet, lacking a dependable method to sift through search results for relevance and accuracy. Some participants expressed uncertainty about the trustworthiness of online sources, unsure of which sites were credible. This is highlighted in participant #13's comment: "You never know if the information will work or not." Also, participant # 6 stated, "You just try it. It is a tried and error thing."

Theme III: Caregivers Needs. All interviewed participants expressed a need for 24/7 available evidence-based reliable support/helpline as reflected in this statement by participant #4: "So I like to have a 24/7 support or helpline. if I can get maybe an AI or something that, I can tell them how

the patient is behaving and they can tell me what to do or what they should try or what's not true, what's not to do.”

The participants described caring for an individual with dementia as stressful and a need for a respite period. Many of the participants expressed a lack of time for them to rest and socialize with other people and feelings of isolation. Participant #12 described her situation as follows: “It's very stressful every day and I don't even have a social life. Now it's me and my mom everyday, so it's hard, very hard. Sure, I have friends, but most of the time, when it comes to people my age, I feel like most of my friends are always going to parties, meeting up for movies just to catch up. I can't do that. I can't afford to leave my mom and go to a friend. So it's always me and her all the time.”

The need for other forms of support beyond the support groups for caregivers was expressed. For example, participant #13 expressed the challenges associated with joining a support group:

“I don't really have a way like there are support groups, but because I work it's really hard to join support groups for me. I would welcome that kind of support. It's just harder to find it. None of my friends are dealing with dementia so I don't have that kind of network of people that you can just, you know, automatically understand what it is you're going through.”

In addition, Participant#13 described concerns about employment and the cost associated with future care needs:

“If I just, you know, if his health was such that I couldn't do it, there's the issue of my work. How long can I continue to work so there's all these big life decisions rolled into that, but I'm simultaneously looking at what it would take to have someone come home to our home and then also what are the local care facilities like and what are their care units like? What can we afford? We don't have long term care insurance, you know, these things are pretty hideously expensive.”

Regarding the need to help them provide quality care in managing the behaviors, the participants made many inputs. For example, Participant # 1 said,

“Everybody needs a little training as to how to handle it, because it's becoming so frequent. I can go to an online class or go to a class or something like that. The things that they provide for me will be okay, like I'm listening. But then, when you're at home and these things are happening, something you can have there that can help you too, that you can go to help you to like deal with this kind of stuff.”

For one participant, seeing a therapist helped her gain perspective when the caregiving was overwhelming: Participant #14 stated

“To be very honest, sometimes it's emotionally draining because you have to wake up every day looking strong because someone is relying on you, and so it's quite challenging. So I also go for therapy once in a while when I feel things are overwhelming, I go talk to someone.”

There also was frustration about the lack of accessible resources as highlighted in this statement: “I don't know what resources are out there. As going back, even at 16, when I went and took care of her mother, people don't understand what a dementia patient is going through.” (Participant #11)

4. Discussion

This study explored informal caregivers' experiences, sources of obtaining knowledge and skills, and self-initiated strategies for managing dementia behavioral symptoms in their care recipients. Our study's findings highlight the complex challenges faced by caregivers in managing the behavioral symptoms of their loved ones. Also, the findings show that while the caregivers were proactive in searching for information on the internet through web searches and other apps, they did not have a "real time" source of relevant evidence-based interventions for them to improve their knowledge and skills in managing those symptoms. Our findings on the preference to provide care to Pw-ADRD at home settings concur with the report published by Alzheimer's Association [1] showing that 65% caregivers' have a strong desire to keep their family member or friend at home while 38% of caregivers perceived an obligation to the person with dementia.

Also, our findings revealed behavioral symptoms, such as resistance to bathing, aggressiveness, and medication refusal posed significant difficulties for the caregivers in managing the care recipients' daily routines. These findings align with previous studies on the behavioral symptoms that are challenging for informal caregivers to manage [18-23]. Although the participants did not categorize their care receivers' behavioral symptoms by specific stages, their descriptions aligned with moderate to severe stages of dementia [4].

Furthermore, our findings show that caregivers often implement self-initiated interventions to manage challenging behaviors, such as changing the home environment to ensure safety, and seeking creative solutions to prevent wandering. These self-initiated interventions concur with the findings reported in previous studies [24-26]

Also, we also found that caregivers lack the provision of adequate education about behavior symptoms that can affect people with dementia and that caregivers are often unaware of behavioral symptoms of dementia that their care receptors will develop as the disorder progresses. This finding highlights Ramirez et al. [27] report about the caregivers' frustration when they start to see those symptoms because they are unprepared to manage them. Our findings also support those of others [26, 28] that while caregivers are open to information sources, including internet resources, they are worried about the reliability and accuracy of the information provided. Also, our findings revealed that some caregivers rely on advice from friends with caregiving experience to understand and manage the symptoms. In situations in which the caregivers have had the opportunity to attend formal informative and training events, there is the problem of remembering learned information to translate to actions when their loved one experiences those symptoms. This finding does not support the sustainability of learned skills and knowledge via those traditional methods. Thus, there is a need for modes of support that do not require memorization and recall of information [27-29]. In addition, our findings show that one caregiver uses an application that is Chatbot based. Despite ChatGPT's strong ability to address non-clinical questions pertaining to dementia, when it comes to more advanced and clinical inquiries, its performance can often be lacking in accuracy, reliability, and relevance in clinical contextual inquiries, such as behavioral symptoms management [30-33].

4.1 Limitations

The main limitation of this study was that the data were collected cross-sectionally. Consequently, they represent a one-time snapshot of the participants' experiences which could change over time. Interviews were carried out through video calls or telephone, implying that

individuals lacking internet or telephone access would not have had equal opportunity to participate and might have encountered further difficulties. Also, we recruited only English-speaking caregivers, thus valuable data might have been missed from non-English-speaking family caregivers.

4.2 Implications

This study's results highlight the urgent need for substantial support and resources for caregivers who choose to look after their loved ones at home. The participants' marked preference for home care underscores the importance of providing caregivers with all-encompassing assistance. This includes offering training, guidance, and interventions that enable them to handle difficult behaviors and establish a safe environment for those they care for.

The detailed accounts of difficult behaviors, such as opposition to personal care, aggression, and refusal of medication, underline the importance of providing caregivers with the necessary information and support to tackle these challenges. Comprehending and managing these behaviors effectively is vital for improving the quality of care for both the caregiver and the recipient. Additionally, the study points out the ingenuity of caregivers in devising their own methods, like using music to calm the care recipient or enhancing safety in the home, which demonstrates their inventiveness in dealing with difficult behaviors. Promoting and aiding these self-devised strategies can significantly empower caregivers and improve the caregiving experience.

Also, this study's findings revealed that informal caregivers obtain information from government and non-profit organizations such as the CDC and the Alzheimer's Association to learn how to care for their loved ones [34, 35]. This finding highlights the critical need for publications from these organizations to be presented in an easily understandable format for caregivers who may not have a scientific background. The emphasis on readability will ensure that caregivers are able to understand and acquire the knowledge necessary to implement effective caregiving strategies.

One significant finding from this study focuses on the challenges linked to the knowledge gained from conventional events like webinars and support training sessions. It underscores the reliance on caregivers to recall the information learned during these sessions in high-stress situations. This situation points to the necessity for more immediate and practical support, as traditional training methods may not sufficiently equip caregivers for the unpredictable challenges they encounter daily. Thus, this study highlights the crucial need for round-the-clock, evidence-based support systems tailored to the unique challenges caregivers of individuals with Alzheimer's Disease and Related Dementias (ADRD) face. Access to such 24/7 resources enables caregivers to foster a supportive and secure environment for their loved ones and manage difficult behaviors more effectively.

5. Conclusion

Informal caregivers of dementia patients require 24/7 access to reliable, evidence-based resources for managing behavioral symptoms. Future research should prioritize the development of personalized, real-time interventions to support caregivers in preventing and mitigating these challenges. This will enhance the quality of life for both individuals with dementia and their caregivers.

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Author Contributions

Dr. Modupe Akintomide was the Principal Investigator (PI) and lead author. Dr. Xinyue Zhang was the Co-PI and second lead author. Ms. Lota contributed with literature review, recruitment, data collection and analysis. Dr. Mary Ramos contributed to the study of design writing.

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Competing Interests

The authors have no conflicts of interest to disclose.

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