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Experience of the healthcare system for caregivers of persons with dementia

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Abstract

Background: Persons with dementia are generally older and often have multiple other chronic conditions, necessitating several healthcare visits each year. Most live in the community supported by unpaid family caregivers who often assist with healthcare management. Little is known about caregiver and person with dementia experience engaging with the healthcare system, which may be more complicated in the context of cognitive changes such as memory loss.

Methods: This is a targeted subanalysis of a major code, *experience of the healthcare system*, which emerged from a qualitative study investigating perspectives of family caregivers ($N = 24$) of community-dwelling persons with dementia about telemedicine.

Results: Caregivers were asked to describe their experiences taking persons with dementia to medical visits. Caregivers' detailed descriptions of the process resulted in three categories related to their experience of the healthcare system: Preparing for Visits, Visit-Related Time and Travel, and In-Visit Experience. Categories revealed the complexity of dyads' participation in healthcare both in and around actual clinic visits. Findings also highlighted the often-negative impact of person with dementia cognitive symptoms on various stages of the process, which was partly offset by perceived benefits related to social participation and interactions with care teams.

Conclusions: This study improves our understanding of the experience of engaging with the healthcare system for caregivers and persons with dementia. By explicating the complex factors involved with participating in healthcare visits outside the bounds of clinic walls, this study offers insights for clinicians and systems supporting persons with dementia and caregivers.

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Declaration of Competing Interest

None

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Keywords

Dementia; Caregivers; Access to health care

1. Introduction

Persons with dementia (PWD) rely on more than 16 million Americans for unpaid assistance with day-to-day needs [1]. Several factors make caring for PWD distinct from being a family caregiver in general. First, due to progressive declines in physical, cognitive, and emotional functioning, PWD require ever-increasing caregiver supervision, assistance with instrumental activities, such as money management or driving, and self-care tasks such as bathing and dressing [2]. In later stages, PWD behavioral changes and communication difficulties may increase caregiving needs and caregiver stress, resulting in declines in caregivers' own mental and physical health [3,4].

Since age is the primary risk factor for dementia, PWD often simultaneously contend with multiple chronic conditions and age-related changes, such as declining vision and hearing [1,5]. This complex network of functional deficits necessitates ongoing, comprehensive, and coordinated care by an interdisciplinary team [6,7]. Given PWD's increasing challenges with memory and insight, caregivers are vital advocates of PWD healthcare both in and out of actual clinic visits. Limited extant data elucidates the tasks that caregivers perform related to healthcare management of PWD, including coordinating visits, taking PWD to visits, providing history to clinicians, and implementing care team recommendations [8,9]. PWD may not, for example, remember to take a medication or implement home safety modifications, placing the responsibility on caregivers.

As the bridge between PWD and the health care system, caregivers are also more likely to communicate directly with care teams as compared to caregivers of people without dementia [10]. Caregivers, thus, are instrumental in providing all-encompassing care to PWD, and understanding the impact of these responsibilities is essential for healthcare teams. In our work enrolling families in-home video telemedicine dementia management follow-up visits, caregivers were asked to provide reasons for choosing telehealth. Caregivers cited convenience regarding travel and preservation of PWD's daily routine as their top reasons [11]. While the specific impact of dementia-related symptoms on caregivers' experience engaging the healthcare system has not previously been detailed in the literature, this ranking suggests that visits are challenging for not just logistical reasons, but that dementia-specific factors are potential stressors for these families. For example, changes to PWD's routine during hospitalization and when in-home supports are not available increase negative behaviors [12,13]. This also suggests there is an exigent nature of engaging with the healthcare system for PWD which may affect caregivers as well. This is corroborated by informal guidance posted on several websites (including AgingCare and National Institute on Aging), which provide tips for attending hospital and doctor visits with PWD, including scheduling visits for the PWD's best time of day and bringing a friend to the visit, all with an eye towards minimizing stress [14,15].

All who have experience with dementia care recognize caregivers' key role as advocates and care coordinators. Yet caregivers' experience navigating the healthcare system as it relates to complex care management of dementia and general needs is not well-understood. Given the lack of formal investigations of caregivers of PWD's experience of bringing a PWD to medical visits, we were eager to explore this topic through analysis of dementia caregiver interview data.

2. Methods

2.1. Objectives

The objective of this study is to examine the experience of caregivers of PWD engaging with the healthcare system to better understand potential barriers and facilitators to accessing care. This work derived from a primary study which gathered perspectives of caregivers of persons with dementia about telemedicine (specifically, in-home videoconferencing) for dementia management [16]. Below is a summary of procedures for the primary study and for this subanalysis.

2.2. Summary of primary study procedures

The objective of the primary study was to examine barriers and facilitators to in-home video telehealth for dementia management. A convenience sample of caregivers of Veterans (ages 60–100) with a scheduled appointment at one of our VA hospital's Behavioral Neurology led interdisciplinary outpatient dementia management clinics (including our telemedicine clinics) were eligible to participate. The only inclusion criteria were caregiver age of at least 18 years old and ability to speak and understand conversational English. A total of twenty-four interviews were conducted between August and November 2019. Interviews averaged 23.3 min (SD 13.3). Questions included discussion of caregivers' experiences with videoconferencing technology such as Skype or Facetime for personal, professional, and medical purposes, including what they liked or disliked about it and whether similar technology could be utilized for dementia care. During discussions, caregivers were asked to describe their experiences bringing PWD to in-person medical visits, to lay the foundation for whether and how that experience might differ from visits using telemedicine.

All interviews were audio-recorded and professionally transcribed. Data were imported into NVivo QSR, ver. 12 [17] for analysis. To answer the primary research question related to barriers to dementia telemedicine, the first author, along with L.M. and J.E.M., analyzed interview data using directed content analysis [18], utilizing a theoretically derived codebook of factors identified as influencing older adults' adoption of technology. The team also employed open coding, an inductive approach used to capture salient ideas identified during interviews [19]. During open coding, a single additional code not captured by the theoretical framework, *experience of the healthcare system*, was identified. Complete details of the primary study are reported elsewhere [16]. All analyses are within the scope of the study protocol approved by the VA Bedford Health Care System Institutional Review Board (IRB).

2.3. Subanalysis of ‘Experience of the healthcare system’ code

During directed analysis using the theoretically derived codebook, the coding team noted that caregivers’ descriptions of bringing PWD to medical visits were very detailed. They went far beyond just providing context for whether and how telemedicine might be different. Given caregivers’ rich descriptions, the coding team decided to code responses to this question as *experience of the healthcare system* and further investigate this code through a targeted subanalysis. The subanalysis of the *experience of the healthcare system* code was conducted three months after analysis of the primary study data by two members of the initial coding team, M.G. and J.E.M., and an additional coder not involved in the primary study (S.E.M.).

All 24 interviews were included in the analysis of the *experience of the healthcare system* code which was analyzed using conventional content analysis, an inductive approach which aims to describe a phenomenon or experience [18]. Analysis involved repeatedly reading interviews to elucidate categories related to caregivers’ *experience of the healthcare system*. To increase reliability, the first author maintained an audit trail of the coding process, and the coding team met weekly to address discrepancies in coding and resolve challenges, in an iterative, interactive process designed to ensure coding consistency [20]. Analysis resulted in the identification of three categories related to *experience of the healthcare system*.

3. Results

Twenty-four caregivers (65% response rate) participated in interviews—see Table 1 for demographics. Caregivers were mostly female spouses of Veterans who were evaluated at our outpatient VA dementia management clinic within the year prior to interviews. Veterans with dementia were all male, with cognitive status based on most recent Mini-Mental Status Examination (MMSE) or Montreal Cognitive Assessment (MoCA) score [21,22]. All participants were white. One caregiver had prior experience with in-home video telehealth for dementia management, and all caregivers had experience with videoconferencing for personal or professional reasons. One Veteran lived alone; all others lived with a caregiver.

Three categories related to *experience of the healthcare system* were identified: Preparing for the Visit, with sub-categories, PWD Cognitive and Behavioral Limitations; Visit-Related Time and Travel, with sub-categories PWD and Caregiver Physical Limitations, PWD Cognitive and Behavioral Limitations, and Perceived Benefits to PWD and Caregivers; and, In-Visit Experience, with the sub-categories PWD Cognitive and Behavioral Limitations, and Interaction with Healthcare Team. Also see Fig. 1. Each category is described below, including illustrative quotes from interview transcripts.

3.1. Preparing for Visit

Preparing for Visit refers to the process of physically and emotionally preparing PWD for a healthcare visit. Caregiver statements in this category all reflected barriers, which were categorized into the sub-category, PWD cognitive and behavioral limitations. There was no identified facilitator sub-category. Below are caregiver statements explicating perceived challenges, including facilitative strategies to address barriers, when mentioned.

3.1.1. PWD cognitive and behavioral limitations—Caregivers described the process of physically getting PWD ready (e.g., bathing and dressing) as generally challenging. The process was described as “a lot,” and “a big production.” PWD advanced age and comorbidities complicated the process, requiring changes to the morning routine on the day of the visit. One caregiver described, “He is 95 and getting going early in the morning I got to get him up 8ish, 9ish and give him his blood pressure and take his pills and then hit the road.” Perceived challenges were exacerbated by cognitive and behavioral symptoms such as confusion, anxiety, and memory loss, particularly with activities of daily living (ADLs). “I always thought he was being a pain in the ass to be honest” one caregiver noted about his father’s refusal to shower, until “a nurse pointed it out this phenomenon where Alzheimer’s patients, the feeling of water is disconcerting to them for some reason.” Caregivers needed to repetitively cue about the purpose of the visit, to compensate for memory loss: “Even though he doesn’t retain it, we would start in the morning and I had say, you have a doctor’s visit today and he’d say, yeah. And then we’d go through the ADLs and stuff.” While cuing aided the process, “the constant reinforcement, the constant repetition, the constant re-answering of things” was difficult. As one caregiver noted, “when their memory is short-term, it’s truly short-term.”

Caregivers also described cognitive symptoms such as anxiety and memory loss as negatively affecting emotionally preparing PWD for visits, that is, the process of discussing the purpose of the appointment with the person with dementia before the visit. Informing the PWD about the visit ahead of time resulted in the PWD “not sleep[-ing] the night before” due to agitation. On the other hand, not telling PWD out of a desire for them “to sleep and... not worry” often resulted in PWD showing resistance the period before the visit. Caregivers were reportedly “very frustrated when he doesn’t want to have to move or get ready to go.” Facilitative strategies to emotionally prepare PWD for visits included adhering to routines, i.e., not interrupting the “compulsive things” which were part of the typical routine. Incorporating family members more effective at convincing PWD of the need for the visit was another facilitator. One caregiver noted, “He [PWD] was like I’m not going back again and my son goes if the doctor says you are then you are. He goes okay.” The negative emotional impact on caregivers for this process was made clear through interviews.

3.2. Visit-related time and travel

Visit-Related Time and Travel refers to the caregiver and/or PWD experience arranging travel, traveling to and from the visit, and experience at the healthcare facility. This includes all aspects other than the actual healthcare visit itself (e.g., experience of the waiting room), which was captured in In-Visit Experience (see below). Caregiver statements about Visit-Related Time and Travel reflected a balance of challenges and facilitators.

3.2.1. PWD and caregiver physical limitations—Physical disability and decreased mobility were barriers to visit-related time and travel for PWD and caregivers, of whom fourteen were spouses over 65. Caregivers described assisting PWD with walkers and wheelchairs, and that, “trying to get him into the offices, that’s what makes it harder.” Sometimes this was because of PWD fatigue which made traveling even short distances difficult. For caregivers with their own physical limitations, “it’s a project to get us both

there at the same time.” One caregiver said because of her disability, “I cannot accompany him to any appointments.” In these instances, assistance by other family members (often adult children) taking PWD to the visit was facilitative, with one adult child caregiver noting, “My mother could never take him on her own.”

3.2.2. PWD cognitive and behavioral limitations—PWD cognitive and behavioral symptoms were also barriers to visit-related time and travel. It was, “the anxiety of getting there. He doesn’t really like the car.” Another caregiver observed that if her husband “had to wait a long period of time [in the waiting room] he’d get agitated and want to leave.” In addition, the need to juggle multiple appointments was a challenge, with caregivers trying to get “everything done in one day, his blood work done and everything,” since repeated visits were a challenge. In a similar vein, not having to attend healthcare visits “if it’s not a critical or crucial need” was a potential “morale booster” to PWD. One caregiver noted that involving PWD in visits to track dementia progress demoralizes PWD by bringing attention to cognitive decline. Less frequent visits, she suggested, may be “uplifting” for her father, who might think “oh, I’m not that bad, I don’t have to go there all the time.”

3.2.3. Perceived benefits to PWD and caregivers—On the positive side, for some caregivers, attending healthcare visits offered an opportunity for social participation. Because dyads “don’t get out much at all,” attending a visit was “an outing and maybe we’d stop for lunch on the way home.” For some PWD, traveling to the visit was “a nice trip for us because we got to drive by his old house.” One caregiver described how his father “chit-chats with whoever’s sitting on the bench,” enjoying the chance to see his father “happy and being healthy” through this opportunity to engage.

3.3. In-visit experience

In-Visit Experience refers to PWD and caregivers’ experience during visits, e.g., communicating with care teams, test-taking, providing history. Caregiver statements about In-Visit Experience reflected a mix of barriers and facilitators. Below are sub-categories.

3.3.1. PWD cognitive and behavioral limitations—Caregivers reported PWD difficulty engaging in healthcare visits due to cognitive symptoms such as confusion, poor memory, and lack of awareness of deficits. Some PWD, according to caregivers, struggled to “comprehend or listen to what people are saying.” PWD have problems with short-term memory, and thus “two minutes later he will ask me the same question.” Similarly, if PWD retain awareness, they may get “a little uncomfortable” during cognitive assessment. One caregiver noted, “he knows what they’re asking and – and looking for” but can’t answer questions. Just being in the clinic may present a challenge. One spousal caregiver described, “They’re already confused in their own environment, then you bring them to a strange environment and I think that increases their fear and paranoia.” Taking PWD out of their normal context, coupled with challenges of being tested and interviewed by clinicians, were problematic.

For some, making PWD aware of their deficits during visits had negative emotional consequences for both members of the dyad. According to one caregiver, because the PWD

lacked insight into limitations, “he gets frustrated and he thinks he’s okay but he’s not.” Consequently, some caregivers “try to say as little as possible” during the visit in part to protect PWD from being made aware of what they are “failing in.” Similarly, having an opportunity to speak to care teams without PWD present was beneficial, with caregivers “not in a position of potentially being inhibited by him sitting there while I’m talking” but instead being able to speak openly.

3.3.2. Interaction with healthcare team—Caregiver participation in visits, along with positive perceptions of care teams, facilitated in-visit experience. Caregivers noted that members of the care team “want my input as much as they want his.” Similarly, when questions are directed at them, PWD may “look at me and go, what do I say, because he doesn’t remember.” Knowing this, caregivers often had “questions beforehand and written out” to be able to anticipate and answer questions and provide a history of recent events. Caregivers were also instrumental in making plans for next steps and following through on care team recommendations: “That’s the whole point of my being there [because] if he’s supposed to take some memory medicines or follow up with another appointment,” caregivers were ultimately responsible.

Caregivers also described positive perceptions of the care team. One caregiver noted, “His-physician and his nurse is a sweetheart and it’s been great,” and that the PWD “built a relationship with them he trusts them.” In a related vein, the way clinicians communicated may optimize PWD engagement. One caregiver described how the clinician would, “Look at him in the face, have his attention, looking at them, and go through everything slowly with constant repeating because he doesn’t hear very well.” Hearing loss was an age-related factor that may, in addition to PWD cognitive symptoms, necessitate caregiver involvement to support PWD participation in healthcare visits.

4. Discussion

To our knowledge, this is the first study to examine caregivers’ perspectives of the process of attending healthcare visits for persons with dementia (PWD). By elucidating the continuum of a healthcare visit, i.e., the period before and during the visit, and related barriers and facilitators, these findings reveal engaging with the healthcare system as a microcosm of the dementia experience overall. Underscoring caregivers’ vital role as intermediary between PWD and the healthcare system, findings delineate caregivers’ complex responsibilities while suggesting considerations for clinicians and healthcare organizations serving PWD and caregivers. Below are cross-cutting themes and related implications.

Our findings suggest that PWD (and to a lesser degree, caregiver) physical limitations negatively affect healthcare visits, influencing preparing for visits and visit-related time and travel more so than in-visit experience. This makes sense given that these aspects involve physical tasks like dressing, driving, and walking to the visit, which necessitate caregiver assistance. While this aligns with caregiving research, it illustrates caregivers’ high-degree of physical involvement and responsibility within what may be a stressful and time-pressured context of attending a healthcare visit.

Caregivers' physical challenges were also barriers to preparing for visit and visit-related time and travel. Given the known negative impact of caregiving on caregivers' physical and emotional well-being, and potential reciprocal negative impact on PWD [4], it is important to consider that caregivers may have their own age-related impairments and disabilities, particularly older caregivers. Caregiving may also affect caregivers differently, depending on their relationship and the type of dementia [23,24]. Relatedly, the importance of the caregiving network [25] (i.e., adult children assisting an older spousal caregiver) may be facilitative, raising important considerations for caregivers who lack such familial support.

Cognitive symptoms such as PWD memory loss and difficulty comprehending negatively affected preparing for visits and in-visit experience, exacerbating caregiver stress. Findings revealed caregivers' need to cue PWD to compensate for PWD either not remembering or recognizing the need for the visit. This stress may compound the physical demands of getting PWD ready. Often PWD were anxious and agitated about the visit and even resisted attending, raising the difficult question of whether and when caregivers should inform PWD that they have a healthcare visit. While caregivers did not discuss overtly lying to PWD about visits (with caregivers instead describing using repetitive cuing), concepts of disclosure and use of lies or 'therapeutic fiblets' is a thorny issue for both clinicians and caregivers [26,27]. Caregiver stress about decision-making around communicating with PWD around healthcare visits warrants further study.

Findings also illuminated the impact of PWD cognitive challenges before and during healthcare visits. In addition to PWD general resistance to attending visits, caregiver statements suggest that increased waiting room times may cause PWD frustration and agitation. PWD may also have difficulty during visits, including problems providing a history of recent events, difficulty during cognitive assessment, and problems communicating with the care team due to poor memory and language skills [28]. Caregivers described PWD often deferring to caregivers when questioned or being unable to answer questions. PWD inability to answer questions or to answer them 'correctly' may cause PWD frustration which in turn may increase caregiver stress and cause them to limit what they say, for fear of further upsetting or shaming the PWD. In addition, PWD may resist care team recommendations due to low insight about their limitations, which may also increase caregiver stress.

Taken together, perceived limitations of PWD engagement in healthcare visits has potential ramifications on visit logistics. Given that PWD may have difficulty waiting, teams can try to ensure shorter wait times before the visit. Caregivers discussed consolidating PWD healthcare visits into one day to avoid the repetitive disruption of bringing PWD to healthcare visits, so accommodating such requests may be helpful. Caregivers also discussed the issue of whether PWD need to attend visits as frequently, citing the negative impact on PWD. Consequently, care teams may consider increasing the period between clinic visits if feasible. Remote care options, such as telemedicine, may maintain connection between the care team and the dyad, thereby obviating potential stress and strain of preparing for and attending in-person healthcare visits [11,29]. Though virtual care options for dementia management have expanded since COVID-19 [30–32], options may be limited, particularly for PWD who lack broadband access such as those in rural communities [33].

Findings also raise ethical considerations about the extent to which care should integrate and perhaps even be directed towards caregivers, particularly if PWD are at a stage at which they lack insight or the ability to comprehend the impact of dementia. Disclosing a dementia diagnosis is fraught; the stigma and terminal nature of the disease often trigger an emotional conversation [34]. It is not surprising, therefore, that dementia is underdiagnosed [35,36]. Since caregivers interviewed cared for PWD who were already receiving dementia care, the issue is more about the extent to which PWD need to be directly involved with dementia care teams as the disease progresses and cognitive challenges worsen, given caregivers' reported negative impact of attending the visit for PWD. Evidence supports care that maximizes the greatest good for PWD and their social network, and enables, where possible, shared decision-making with PWD [37,38]. However, reimbursement and the need for PWD to be physically present during the visit for billing purposes [39] often force PWD to attend visits that may no longer be beneficial. Clinicians may consider the cost-benefit analysis of having PWD present versus the negative impact on PWD and caregivers in terms of stress and not feeling able to speak openly. Family-centered care, which prioritizes relationships with family members, is less understood in dementia than with other populations such as pediatrics, and warrants further study [40].

Although describing many barriers to bringing their PWD to healthcare visits, caregivers also perceived a benefit to being able to meet with the care team. Caregivers recognized when care teams positively engaged with PWD and appreciated the opportunity to speak to the care team without PWD present. This underscores the need for dementia-capable care. Principles of dementia-capable health care include integrating information about dementia diagnosis and management across settings (particularly primary care), so that all providers can recognize and respond to dementia signs and symptoms [41,42]. Effective communication tailored to changing dementia symptoms and collaboration with caregivers are also key. There is a concurrent need for training initiatives to build a workforce able to provide comprehensive support to the dyad throughout the disease course [43]. The visit itself was also an opportunity for social participation for PWD and caregivers, highlighting social isolation and loneliness for this population which has been exacerbated during COVID-19 [12,44,45]. Some caregivers also perceived a benefit of coming to visits for the PWD, particularly if care teams utilize dementia-capable communication. There are several limitations to this study. As a subanalysis, the objective of the primary study was not to explicate caregivers' experience of the healthcare system. Future studies should formally measure dyad experiences of dementia healthcare visits, as clearly this process is multi-faceted. This study was conducted prior to COVID, which increased the availability of telemedicine for this population. Future work may include comparing challenges to in-person and telemedicine visits, given emergent barriers, e.g., communication through masks and the need to involve family members for technological support. We also did not include perspectives of PWD or clinicians. Therefore, we lack a complete picture of this phenomenon. Participants in our study were from a racially homogenous, affluent, and suburban sample which may not be generalizable. Moreover, perspectives of those interviewed may have been unique to this setting and differ from those receiving specialty dementia care elsewhere, dementia care in a primary care setting, or not at all. For example,

there may be factors unique to Veterans Affairs that do not translate to private sector healthcare.

5. Conclusion

There is a growing need to develop dementia-capable care that considers the complexity of the dementia experience for persons with dementia (PWD) and caregivers. This study identified three aspects of engaging with the healthcare system, both inside and outside the visit itself, from the perspective of family caregivers of PWD, delineating potential barriers and facilitators. Although there were barriers related to PWD physical and cognitive limitations, findings reveal potential strategies to optimize care to meet dyad needs. There were also benefits related to attending healthcare visits. This study also raises reimbursement considerations and implications for family-centered dementia care.

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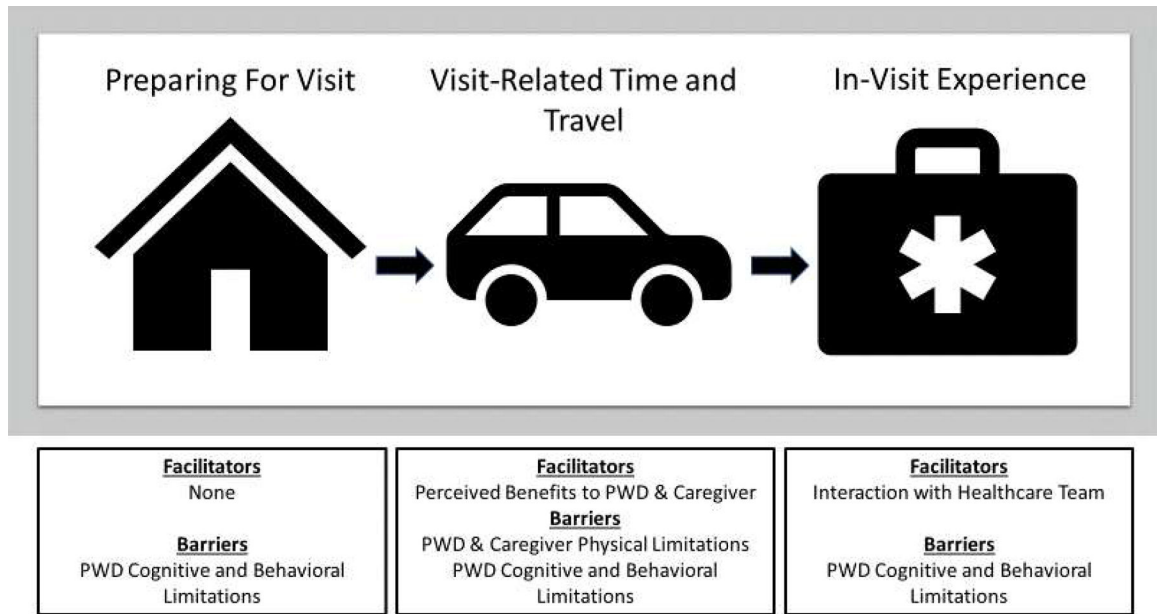


Figure 1. Caregivers’ identified barriers and facilitators to bringing people with dementia to healthcare visits.

Table 1

Participant characteristics.

Caregiver	Caregiver Age	Caregiver Gender	Caregiver Role	Veteran Age	Veteran Dementia Severity
1	75 or older	Female	Spouse	88	Moderate
2	75 or older	Female	Spouse	89	Moderate
3	75 or older	Female	Spouse	86	Moderate
4	65 to 74	Female	Spouse	77	Moderate
5	65 to 74	Female	Spouse	71	Severe
6	75 or older	Female	Spouse	98	Severe
7	75 or older	Female	Spouse	83	Moderate
8	55–64	Female	Child	84	Moderate
9	65 to 74	Female	Spouse	77	Severe
10	65 to 74	Female	Spouse	74	Severe
11	55–64	Female	Child	85	Severe
12	65 to 74	Female	Spouse	68	Mild
13	45–54	Male	Child	86	Moderate
14	65 to 74	Female	Spouse	74	Mild
15	45–54	Male	Child	90	Moderate
16	75 or older	Female	Spouse	86	Mild
17	55–64	Female	Friend	75	Mild
18	45 to 54	Female	Child	83	Moderate
19	45 to 54	Female	Child	84	Mild
20	55 to 64	Female	Spouse	69	Mild
21	55 to 64	Male	Child	94	Mild
22	65 to 74	Female	Spouse	70	Mild
23	55 to 64	Male	Child	91	Severe
24	65 to 74	Female	Spouse	75	Mild

Note: Dementia severity was based on Veteran's most recent score on the Mini-Mental Status Examination or Montreal Cognitive Assessment. Caregiver age was a categorical variable, with categories including: Under 25 years old; 25–34 years old; 35–44 years old; 45–54 years old; 55–64 years old; 65–74 years old; 75 years or older; and, Prefer not to answer. Caregivers were all White, and PWD were all male, White, and lived with a caregiver (except for one who lived alone).