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"I Didn't Sign Up for This": Perspectives from Persons Living with Dementia and Care Partners on Challenges, Supports, and Opportunities to Add Geriatric Neuropalliative Care to Dementia Specialty Care.

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## “I didn’t sign up for this”: perspectives from persons living with dementia and care partners on challenges, supports, and opportunities to add geriatric neuropalliative care to dementia specialty care

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### Abstract

**BACKGROUND:** In the United States, dementia specialty centers affiliated with centers of excellence for research hold promise as locations to develop innovative, holistic care in care systems otherwise siloed by discipline or payer.

**OBJECTIVE:** We conducted foundational research to inform development of patient-and family-centered palliative care interventions for dementia specialty centers.

**METHODS:** We interviewed persons living with dementia (PLWD), current, and former care partners (CP) recruited from a specialty dementia clinic and purposively selected for variation

across disease syndrome and stage. A framework method of thematic analysis included coding, analytic matrices, and pattern mapping.

**RESULTS:** 40 participants included 9 PLWD, 16 current CPs, and 15 former CPs of decedents; 48% impacted by Alzheimer’s dementia. While help from family, support groups and adult day centers, paid caregiving, and sensitive clinical care were invaluable to PLWD, CPs, or both, these supports were insufficient to navigate the extensive challenges. Disease-oriented sources of distress included symptoms, functional impairment and falls, uncertainty and loss, and inaccessible care. Social and relational challenges for PLWD and/or CPs included constrained personal and professional opportunities. The obligation and toll of giving or receiving caregiving were challenging. Clinical care challenges for PLWD and/or CPs included care fragmentation, insufficient guidance to inform planning and need for expert interdisciplinary clinical care at home.

**CONCLUSION:** Findings highlight the breadth and gravity of gaps, which surpass the disciplinary focus of either behavioral neurology or palliative care alone. Results can inform the development of novel interventions to add principles of geriatrics and neuropalliative care to dementia care.

### Keywords

Dementia; palliative care; neuropalliative care; geriatrics; hospice care; caregivers; quality of life

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### Introduction

In the United States, more than 1 in 9 people over the age of 65 are living with dementia syndromes and more than 11 million family and friends serve as care partners [1]. By 2050 over 12.7 million Americans will be living with dementia. While researchers work towards treatments and cures, given the increasing prevalence of people living with dementia (PLWD), we need to simultaneously develop evidence-based approaches to ameliorate suffering and support the specific needs of PLWD and their care partners (CPs).

PLWD are often shuttled between clinical silos: they may raise concerns to primary care clinicians, who may refer them to neurologists for diagnosis, to palliative care for help with advance care planning, to geriatrics or housecalls practices once homebound, and to hospice for end-of-life care. Dementia specialty centers, especially those affiliated with centers of excellence for research, hold promise as locations to develop innovative, holistic care in a care system otherwise siloed by discipline or payer. In the United States, there are 33 Alzheimer’s Disease Research Centers (ADRCs) funded by the National Institute on Aging that set standards for dementia care in the context of conducting research that advances understanding of prevention, diagnosis, and treatment [2]. Though ADRCs vary substantially in structure, disciplinary leadership, and goals based on their local clinical context, they participate in the collection of standardized data for a subset of patients and therefore share some similarities in assessment methods. The 2017 NIH Alzheimer’s Disease Centers Panel Recommendations newly recommended they engage PLWD and CPs with the goal of “improving services to patients and caregivers across the spectrum of disease” [3] to facilitate achieving the goals of the National Plan to Address Alzheimer’s

Disease [4]. This makes specialty dementia centers affiliated with ADRCs crucial locations for developing evidence-based dementia care services tailored to the needs of PLWD and CPs that can be further adapted and disseminated to other sites in the future.

One promising path towards these goals is developing and implementing a robust model of dementia palliative care. Palliative care focuses on reducing suffering and improving quality of life by attending to multi-dimensional sources of distress for seriously ill individuals and families [5–7]. There is international consensus around the importance of integrating palliative approaches into the care of persons with dementia syndromes[8] and into the full scope of neurologic practice, often via the emerging subspecialty of neuropalliative care [9–18]. There are multiple potential avenues for integrating neuropalliative care principles into dementia care, including training dementia clinicians in practices like serious illness communication [12] or embedding a specialty palliative care outpatient clinic within a dementia clinic [19]. Yet to date, the majority of the evidence for dementia palliative care interventions come from facility settings or end-of-life care [20]. To build effective neuropalliative care interventions for dementia, we need to understand setting-specific sources of support, ongoing challenges that need to be addressed, and other opportunities to improve quality of life for PLWD and CPs.

We conducted a qualitative study to comprehensively explore challenges and supports experienced by PLWD and CPs associated with a specialty dementia center to understand strengths to build from and gaps to be filled. Prior qualitative research on the lived experiences of PLWD, current or former CPs worldwide detail the stigma and impact of a diagnosis on the PLWD, desire for additional support after diagnosis, lack of knowledge and support from primary care providers regarding how to find additional services and supports, appreciation when health care providers displayed sensitivity and validated feelings, and need for organizational structures that ensure PLWD are cared for in a dementia-friendly environment by a dementia-trained workforce [21–23]. A recent scoping review of evidence for community-based dementia palliative care services found the integration of dementia and palliative care services have been found to improve care for PLWD and CPs, but that research is needed to identify key components of dementia palliative care [20]. The design was informed by the National Consensus Project Clinical Practice Guidelines for Quality Palliative Care, which defines processes and practices for any clinician to attend to palliative care needs of seriously ill people and care partners using a biopsychosocial framework detailing biological and physical, psychological, social, spiritual, and cultural aspects of care [24,25]. Our findings provide foundational data to develop novel palliative care-informed interventions to improve care within ADRCs.

## Methods

### Design:

We carried out a descriptive qualitative study [26] using in-depth interviews [27] with PLWD and CPs associated with a specialty dementia center to conduct foundational research to inform developing palliative care interventions within the ADRC-affiliated center. The study was approved by the University of California San Francisco (UCSF) Institutional

Review Board and adheres to Consolidated Criteria For Reporting Qualitative Studies (COREQ; Appendix 1) [28].

**Site:**

The specialty dementia center is located within a quaternary medical center and offers diagnostic and longitudinal care for persons with cognitive and behavioral symptoms and their families. Patients and families can choose to enroll in research through the affiliated ADRD or other research programs or can receive insurance-reimbursed clinical care. Most insurance carriers are accepted using Medicare; rarely, patients and families may pay out-of-pocket for consultative and clinical care, such as when they travel from abroad and have no insurance in the United States. Neurologists typically provide longitudinal clinical care, with additional evaluation and care available from specialists with expertise in neuropsychology, nursing, social work, genetics, geriatrics, geriatric psychiatry, physical therapy, occupational therapy, and speech therapy, depending on the needs of the patient. Patients are referred to the specialty dementia center by regional primary care physicians, general neurologists, or other specialists, or can self-refer if insurance carriers do not require provider referral. Patients have a median of 2 appointments at the specialty dementia center (range 1-30); approximately 20% of patients have only a single consultative visit [29].

**Participants:**

We purposively sampled three perspectives among PLWD and CPs associated with the specialty dementia center: (1) PLWD with mild-to-moderate disease who could self-report; (2) current CPs of community-dwelling PLWD with mild-to-moderate disease; or (3) former CPs of a PLWD who had died 3-12 months earlier who could reflect on the entire disease journey. We aimed to recruit at least 50% with experience with Alzheimer's dementia and the rest with less common syndromes. We identified potential participants through chart review and approached clinicians for referral and approval. The study coordinator contacted the associated clinic provider to request permission to approach and to review eligibility (including diagnosis and severity). Once approved, the study coordinator called the candidate up to three times. With all participants, we used a teach-to-goal informed consent process that assesses decisional capacity by asking the prospective participant to answer questions about or explain the main study elements [30].

**Study setting:**

Between November 2018 and September 2019, a PhD sociologist (SBG) interviewed 9 PLWD, 16 current CPs, 15 former CPs of decedents. Three current CPs and PLWD were dyads. Interviews were conducted by phone or in-person based on participant preference.

**Interview topics:**

Questions focused on key experiences along the PLWD's disease trajectory, challenges and sources of distress, and supports that did or could have helped (Appendix 2). Probes related to domains of the guiding palliative care biopsychosocial framework [24]: challenges or supports related to physical, behavioral, psychological, social, cultural, spiritual/religious, legal, financial, ethical aspects of their experience, as well as memory care services

or preparation for end-of-life. Interviews ended with a demographic survey to fulfill funder reporting needs and to facilitate descriptions of diversity in lived experience. An interdisciplinary team of social scientists and physicians in behavioral neurology, geriatrics, and palliative medicine developed the interview framework, which we piloted and refined before use.

### **Analyses:**

All interviews were recorded, transcribed, and identifying information removed. Our framework method [31] for thematic analysis included immersion in the data, coding to label units of meaning, examining patterns, writing memos, diagramming, and interpreting data [32,33]. Methods to maintain transparency and rigor are detailed in Appendix 1. Four authors (KLH, CSR, SBG, MH) iteratively developed and refined codes. We first coded all explicit statements of challenges, things that helped (empirical supports), or things participants thought might help or recommended for others (hypothetical supports). We then identified and coded the source of the challenges or supports. One author (MH) applied the final codebook (Appendix 3) to all data using ATLAS.ti [34]. We used coded data to extract quotations for analysis and to map patterns across cases [35]. Throughout this process, we used analytic matrices [31] and memos [32] to reflexively summarize and analyze data and to consider disconfirming evidence [36,37].

## **Results**

### **Participants:**

The 40 participants were predominantly white (75%), well-educated (55% with master's degrees or more), and well-resourced (50% with annual incomes over \$100,000); this is comparable to the demographics of the population of patients seen at the specialty dementia center [29]. The sample did, however, include 3 participants who self-identified as Black (one further specified Creole), 4 as Asian, 1 as Arab American, 1 as Italian; 3 who referred to a spouse or domestic partner of the same gender; 7 who self-identified as having less education than a college diploma; and 8 participants categorized as very low income based on their self-reported income category compared to the U.S. Department of Housing and Urban Development Income Limits for the San Francisco Metro Region (in 2019, \$56,400 for a household of 1 and 64,500 for a household of 2)[38]. In accordance with our purposive sampling, 48% participants had experience (as PLWD or CP) with a primary diagnosis of Alzheimer's disease (AD); the remainder had experience with less common syndromes: Lewy body disease (LBD); behavioral variant frontotemporal dementia (bvFTD), vascular dementia (VD), corticobasal syndrome (CBS), logopenic variant or nonfluent variant primary progressive aphasia (lvPPA or nfvPPA), progressive supranuclear palsy (PSP), posterior cortical atrophy (PCA); 10 participants had actual or hypothesized copathologies (Table 1). CPs were comprised of spouses (n=23), a domestic partner, and 7 adult children.

Below we summarize themes within the four categories of challenges and supports shared by participants: the disease itself, relational or social changes, caregiving, or clinical care (Figure 1). We provide a summary inventory and illustrative quotes in Tables 2 and

3; additional quotes are available in Appendix 4. Quotes are cited by participant type (p=PLWD, ccp=current care partner, fcp= former care partner) and participant number.

## Challenges

Every participant reported at least one type of challenge; over half the sample reported challenges from all four categories (Table 2, Appendix 4). CPs identified more challenges than PLWD, and former CPs focused on challenges relevant to late-stage caregiving and caregiving burden.

*Disease-oriented challenges* were discussed by nearly all of the participants. Challenges related to disease manifestations such as symptoms, functional impairments (especially falls) and behaviors were common and distressing: “*Last night, in the middle of the night, he was hitting me and kind of screaming in his sleep, and I tried to wake him up. It seemed, in his dream, only to provoke him more and he really became physically violent*” (ccp25). PLWD and current CPs shared their fears about disease progression, including loss of independence, dependence in activities of daily living (ADLs), and distressing behaviors. Occasionally, participants talked about how other illnesses (e.g., cancer) interacted with and complicated living with dementia: “*On top of it all, he can’t see*” (ccp19).

Participants were frustrated by the uncertainty of the speed of decline, duration, symptoms, and intensity of the disease: many felt anxious not knowing. As a bereaved husband of a wife with CBS/PCA said, “*I’m on call 24 hours a day. I’m dealing with something I am clueless about and I don’t know where it’s going and how fast it’s going and my wife is disappearing. It’s not an easy thing to navigate*” (fcp05). The prognostic uncertainty made it difficult for participants to plan for retirement, job leave, or paid caregiving. Losses for PLWD included loss of control and privacy (e.g., help with bathing) and especially independence; loss of ability to drive was often lamented. Some PLWD expressed awareness, frustration, and shame at how the disease changes their mental and physical function: “*it’s a big downer to know that I have Alzheimer’s. It’s embarrassing*” (p04). CPs also expressed distress at the losses caused by the disease.

Many participants described a lack of accessible or affordable resources for navigating the disease. Participants often mentioned concerns about the cost of paid caregiving at home or in a facility, such as this husband of a wife with PSP: “*my concern is if we had to send my wife to the nursing home...the financial... that would be a big burden*” (ccp28). Navigating clinical settings became taxing as impairments grew, sometimes resulting in patient falls, distress, and missed appointments. Support groups and clinical appointments that occurred during work hours created challenges for employed participants such as PLWD with early-onset syndromes or adult children CPs. Many support or activity programs for PLWD could not accommodate later-stage disease.

*Social and relational challenges* were described by nearly all CP, and by multiple PLWD. Participants were particularly distressed about how the diagnosis and disease changed their relationships: “*People, since they know that he has Alzheimer disease, they treat him differently. Like, you know, they think that he’s not capable of fellowship [at church]... and then they don’t want to get involved*” (ccp02). A few participants indicated the

stigma of dementia prevented them from telling friends; one person with AD perceived an acquaintance *“thinking of me... in a way I don’t think of myself”* (p08). As the PLWD lost communication and functional skills, CPs described the challenge of role changes and loss of their vision for the future. Spousal CPs grieved losing their prior relationship with the PLWD. Former CP experienced deep distress of grief after the PLWD died: *“I’m grieving what I had. The way we were... the way he was... There’s times when I just, I literally hurt inside. I actually feel pain. I feel hurt and I can’t always make it go away and I’m trying to recreate my life. And how do you recreate your life when you’re 73?”* (fcp06).

For most participants, the disease or caregiving constrained social and professional opportunities. For example, a wife CP of a person living with bvFTD said, *“the social issues are what are the worst, because [my husband], he says inappropriate things in front of people, and he makes sometimes inappropriate remarks, especially when it comes to young women, and so we don’t do a lot of social things because of that reason”* (ccp29). Some CP described friends and family becoming unwilling to engage the PLWD or adapt activities. PLWD or CP who were employed communicated distress about losing professional opportunities amid disease progression or mounting caregiving responsibilities: one bereaved husband CP of a man with AD/VD noted: *“You have to make your choices. Do you get your report at work in on time? Or do you run home at the end of your day to make sure your husband is okay?”* (fcp04). Many of those who lost or reduced their employment expressed sadness about associated losses of meaning, travel, and income.

*Challenges of caregiving* were described by all CPs; these related to caregiving activities and the CP role. A common theme was the CP’s overriding sense of obligation: *“Caregiving was not my big, not my strong suit, <laughs> and I really hated it, and I hated it and then I felt guilty about it and I was back and forth and then I would just-- I would even cry, because I think I’m a terrible woman”* (fcp06). A daughter CP of a mother spoke of cultural norms influencing her sense of obligation, *“When Black people raise their children, they teach their children always take care of their mother. That’s a lot. It’s a lot. It’s a lot, and that means do whatever is necessary, and, you know, I don’t know if you know this, but a lot of Black people will not put their parents in nursing homes and leave them there”* (ccp03). Participants described taking on a myriad of responsibilities as CP, including catching mistakes from clinicians with inadequate dementia expertise. Many faced steep learning curves at home, becoming solely responsible for decision-making, navigating legal issues, learning ADL support skills, and household and financial management. CPs additionally described the challenges of family disagreements about care and decisions: a current CP of a wife with LBD said, *“The one place I wanted to move her to, it was in a house, in a home, right near the park...and she got it into her head those were the woods. “I don’t want to be near the woods,” and I couldn’t get through to her that it was the park...I could’ve practically walked to that place, and that’s what I really wanted. It would’ve been the right thing for me in terms of convenience. But I acquiesced to that, you know”* (cc10).

For most, caregiving exacted a substantial toll. CPs spoke of losing their freedom and identity: *“I actually thought about suicide at that time. ... I was pretty sure where [Spouse] was going... and then having lost my job... I really kind of lost my identity”* (fcp06). Many CPs became emotional describing physical (providing ADL help), mental (sleep disruption,



managing behaviors), emotional (distress, grief, burnout, guilt) and financial (loss of work, exorbitant cost of paid care) challenges. One a daughter CP of a father said, “*it was definitely a challenge. Moreso as he could give less back. You know, going over there and, like <chokes up> sitting and not feeling like you’re doing much or helping the situation or helping him.... Like, I wondered, like, sometimes he would yell at me and, you know, yell me out of the house, and it’s like I knew he didn’t mean it and I knew it was the disease, but did he, you know, maybe I should just not go, because I clearly agitate him, and yet if I don’t go, nobody goes*” (fc08). The uncertainty of caring for a PLWD intensified these challenges.

*Clinical care and care system-oriented challenges* were described by most participants, whose experiences illustrated the challenges of navigating a fragmented care system: “*we would see a social worker, or a therapist, and they were wonderful. We’d sit there and talk and everything. And they said they would follow up with us, and they never did. We never heard from anybody*” (fc06). PLWD and CP described the assessments and diagnosis at the specialty dementia clinic as difficult for the PLWD: “*it was distressing to see my loss, say, remembering words and repeating them back*” (p08). Most said that receiving a diagnosis was surprising and concerning; two PLWD considered suicide in reaction to the diagnosis.

Many participants reported that specialty dementia clinicians supplied less guidance than they wanted about disease progression or stage: “*I would like to ask [his doctor], you know, ‘What’s the end game? What’s going to happen?’ and nobody’s able to tell me, and maybe they can’t*” (ccp10). Some participants also described frustration with clinicians whom they felt had inadequate dementia expertise. Many CPs reported problems with prescribed medications or side effects. A few participants worried that they received lower-quality care in hospitals because of the dementia diagnosis and/or their signed do-not-resuscitate order.

## Supports

All participants discussed empirical or hypothetical sources of support across at least 3 challenge areas; most (30 of 40) discussed supports across all 4 (Table 3, Appendix 4). We report hypothetical supports only if they are not already represented among empirical supports.

**Disease-oriented supports.**—Many participants discussed their appreciation for information, programs, and resources (especially websites and support groups) that enabled them to learn about the disease and symptom management strategies. These were offered by the Alzheimer’s Association, local organizations focused on aging or caregiving, and the specialty dementia clinic. One CP of her mother said, “*what I appreciated was being able to read and see what kinds of symptoms and science, hearing other people’s stories. Granted you might learn that going to a group, but the last thing I want is another appointment. I’m going to be home holding her hand*” (fc14). Participants affected by rarer syndromes appreciated disease-specific support groups; for example, one CP of a person with LBD said the center, “*had an early-onset group, and I’m very grateful for that. That was what I was in. We have some different needs because our partners are younger, and often generationally interested in different things*” (cc09). Participants recommended these types of resources for other CPs.

Most participants described activities and strategies that they felt helped to manage symptoms (particularly exercise and social opportunities for PLWD), and to maintain wellness as their or their loved one's disease progressed. PLWD described benefits of writing things down (e.g., in an appointment book) and having a routine: *"I belong to [local running group], it's a social organization, too. Afterward, we always meet for coffee and talk. And solve all the problems of the world"* (p07). CPs described myriad practical techniques to manage caring for PLWD and to manage negative emotions.

**Social and relational supports.**—Support groups were one of the most common sources of both disease-oriented and social help: *"That group was very helpful because everybody had different solutions and different things that they had gone through where they could be helpful with what you do and what you don't do"* (ccp27). In addition to helping participants feel less alone, groups provided recommendations for services, planning advice, and new social opportunities. Several participants continued to meet informally with group members even after groups concluded.

Many participants benefited from engaging the PLWD in social activities, including those that were meaningful prior to the diagnosis, adapting as needed as the disease progressed: *"we had priests coming by regularly to see my dad, since he couldn't go to mass anymore-- it became harder. ... Hospice brought people to talk to him...the caregivers would play the mass for him, every day, from Rome"* (fc08). Others discussed the benefits of new social activities such as an adult day center.

Former CPs shared strategies for managing and honoring grief for the deceased PLWD: *"I'd say for the last three months of his life, he was never without [stuffed animal name]. So now I sleep with [stuffed animal name] and it's kind of comforting"* (fcp15). Many appreciated support from family and friends. Multiple CP reported that hospice had offered bereavement services but few had engaged it.

Supports for caregiving included those for CP and for PLWD seeking help with everyday life. As dementia progressed, both PLWD and CPs described appreciating household services for activities that the PLWD used to do or to enable time and energy for caregiving activities: *"I now have a housekeeper. He [PLWD] used to do all the housekeeping. I now have a gardener. He used to do most of the heavy gardening, still does light gardening. I have ordered a food service...so I rarely go to the grocery store anymore"* (ccp19).

Participants received tangible help with caregiving and basic ADL support, such as bathing the PLWD, through friends, family, paid caregivers, or facilities. One current CP of a person with LBD expressed appreciation that a local LGBTQ+ organization had received funding to partner with area nursing facilities *"doing active education for the providers, you know, just about our needs and our culture... We've always lived in a straight world, but it's wonderful to just have that little tiny fishbowl for [Spouse] that I don't have to explain what my being her partner is and all of that every time"* (cc09). Participants also appreciated help navigating programs and paperwork such as disability benefits, Medicaid, and advance directives: *"Well, legally I started out by trying to find out what was Medi-Cal, could I qualify for Medi-Cal and that was a labyrinthian procedure ... There is no way to navigate it"*

*without a very, very smart lawyer*" (fcp05). Several CPs expressed gratitude they had taken care of financial, legal, and advance care planning prior to the diagnosis, or that they had long-term care insurance for paid caregiving.

Some supports made caregiving easier or more sustainable for the CP. They sustained their resilience through mindset (e.g., living in the present), strong religious faith, counselors and therapists, meditation, exercise, journaling, re-engaging in professional work, and flexible working arrangements. Some CPs benefited from day programs and respite care. Many CPs wished for caregiving supports they did not have, such as a person to stay with the PLWD while the partner traveled, someone to help with activities of daily living, and more (affordable, trustworthy) paid caregiving. As a current CP said, *"I'd like to have extra help. For instance, like one or two days, you know, someone could take him out and then I be able to rest, and I know that in realistic, in real life, you cannot keep giving and giving all the time and then not take care of yourself"* (ccp02). CPs appreciated resources that facilitated access to needed services, such as prior training in health or dementia care or social connections to healthcare leadership. For example, a person living with nvPPA/PSP said, *"I speak Chinese, and the Chinese community have a lot of help"* (p10).

**Supports from clinical care or care systems.**—All participants expressed appreciation for information and guidance from their clinicians: *"[Clinician] was really clear about how, "Oh, this is happening neurologically and she can't perceive the distances right or can't perceive stepping right or she shuffles stepping instead of stepping normally and so she's likely to trip on rugs and stuff like that"* (fcp26). Many wanted more guidance than they received. Some participants described receiving a diagnosis as helpful for enabling planning: *"it's helpful to know, to not just be in this gray zone... Also so we could begin to plan, think about the future"* (ccp01). Participants particularly appreciated clear and timely interactions with the clinical team. Many additionally wished that clinicians gave more, earlier, or more frequent advice about planning ahead, advance care planning, and CP support.

Clinical services that participants found helpful included the specialty dementia clinic (especially a behavioral symptom clinic), home-based care, hospice, and, occasionally, specialty palliative care. For example, one former CP of a wife with CBS/PCA said, *"the medical group had a geriatric doctor come and visit [[Wife]] once a month, very nice guy and that was helpful. I felt like I needed somebody to be helping observe [[Wife's]] condition because it went up and down"* (fc05). Participants wished for more home-based services, having care co-located with other services, care provided to both PWLD and CPs simultaneously, and/or local satellite offices for the dementia specialty center. One current CP said *"I would recommend [palliative care]. I think that a chronic illness involves the family. And the quality of the interactions in the home life effect the person. And I think [clinicians] have to deal with the whole system. They have to address the whole system"* (ccp25)

## Discussion

This qualitative study illuminates the breadth and gravity of the needs reported by PLWDs and CPs associated with a specialty dementia center (summarized in Figure 1). While support from family and friends, social programs like support groups and adult day centers, paid caregiving, and sensitive, timely, interdisciplinary clinical care were invaluable, these supports were insufficient for navigating the extensive challenges participants faced, which multiplied with disease progression. Sources of distress stemmed from 4 main sources: the disease, social/relational changes, caregiving, and clinical care/systems. Patients shared distress at the uncertainty of the progression and symptoms of the disease, constrained professional or social opportunities and relationship with spouse, and inaccessible care or support groups (especially if they still worked). Care partners also found these challenging, and additionally shared distress at the obligation and toll of caregiving, desire for clinician guidance to inform planning. Former caregivers articulated appreciation and/or desire for expert interdisciplinary clinical care at home, hospice care to help with imminent death, and distress at incremental anticipatory grief while the PLWD was alive and grief after they died. Both sources of distress and support provide data to inform the development of interventions to reduce suffering and improve quality of life within specialty dementia centers.

Every year, the Alzheimer's Association publishes a "Facts and Figures" updated aggregation of data on the public health impact of dementia in the United States [1]. Many of our findings among participants associated with a specialty dementia center mirror those in nationally representative data or systematic reviews of qualitative research, such as the distressing symptoms of dementia, challenges with the stigma and impact of diagnosis [21,22], the desire for prognostic estimates and anticipatory guidance [21,39–41], the gaps in advance care planning [20,42], the intensifying demands of caregiving – including negative impacts on CP mental, physical, and financial wellbeing [1,43–46] – and challenges accessing paid help [47]. Our work also aligns with scoping reviews of qualitative research on dementia end-of-life care, including challenges of caregiving that include loss of relationship with the PLWD and social isolation and impact of caregiving on CP sense of self and wellbeing [48].

Our findings add to the body of qualitative research across the dementia disease course [20,23,48,49]. Using a palliative care lens for study design and analysis, we provide more specific findings and offer concrete, practical guidance for developing interventions in dementia specialty centers. Our work augments prior research by demonstrating both the persistence of common challenges like stigma, falls, progressive functional impairment, desire for prognostic information, and insufficient attention to caregiver wellbeing even among the well-resourced population able to access care within a specialty dementia center and associated services; yet we also highlight how supports and services can reduce these challenges. Notably, system gaps and care fragmentation were ubiquitous. Even when PLWD and CPs attempted to find the best quality care through an ADRC-affiliated specialty dementia center, they experienced further care fragmentation.

Moreover, many participants expressed an unmet desire for home-based care and services. Nationally representative data indicate over 50% of completely or homebound older adults

in the United States have dementia, and only 12% of homebound older adults receive home-based services annually, with access being even more tenuous in rural settings [50–54]. Recognition of the importance of including CPs as well as PLWD in the provision of home-based care (either in parallel or sequentially may have increased during the COVID pandemic. For example, home-based health care clinicians vaccinated both homebound patients and CP during the same visit in recognition that the health of the household is essential to the health of the PLWD, and that CPs are limited in their ability to leave the home to obtain their own healthcare[55]. A recent systematic review indicates few studies investigate the impact of home healthcare on outcomes for PLWD[49]. Gaps in access to care could be addressed through targeted outreach to PLWD/CPs, care augmentation in the community or home setting [56–58], depending on risk and management needs, and training and support for home healthcare providers in decision-making and initiating palliative and hospice care [49].

### **Clinical implications:**

Though clinical care is often divided into disciplinary silos, the needs of PLWD and CPs are not. This insight appears throughout the interviews with PLWD and CPs here, as well as in a constellation of related quantitative and qualitative studies designed to inform the development of interventions in specialty dementia clinics [29,40,59–62]. Many sources of distress expressed by CPs and PLWD in this study involved lack of symptom management and guidance around care decisions—gaps that palliative care is well-suited to fill. Yet participants described needs that require expertise traditionally found in clinical disciplines such as behavioral neurology and geriatrics. Participants in our study appreciated the expertise of behavioral neurologists and their interdisciplinary colleagues in the specialty dementia clinic (e.g., geriatric psychiatry, neuropsychology, nursing, social work) in explaining the source of behaviors and management strategies, dementia-appropriate medication, diagnosis of rare diseases, and referring to syndrome-specific support groups. A 2022 position paper on neuropalliative care from the American Academy of Neurology [16], and a 2021 position paper on ethical considerations in dementia [63] highlight the importance of serious illness communication, advance care planning, decision-making in light of changing capacity, and support for hospice transitions. Participants in our study also commonly mentioned challenges from loss of independence, falls, functional impairment (including incontinence), multimorbidity, and polypharmacy/medication issues, problems that are often addressed in geriatric care. Importantly, no single discipline encompasses all domains of needs expressed by participants, even in a well-resourced study population able to obtain care from a top medical center. As such, future interventions in specialty dementia centers must draw on *all* of these disciplines. Integrating a geriatric neuropalliative care approach to specialty dementia care may provide care that is most aligned with the needs described by PLWD and CP in this study [64,65].

Drawing on our findings, we recommend an integrated, biopsychosocial geriatric neuropalliative care approach to improve care within specialty dementia centers associated with ADRCs (Figure 2). Clinical geriatric neuropalliative care interventions tailored to the needs of PLWD and CPs would include the following biopsychosocial elements. (1) Biologic and physical components: calibrated assessments of, and interactions with, CP/

PLWD to minimize strain; thoughtful diagnostic disclosure and anticipatory guidance [40], education about and optimal management of disease-related distressing symptoms; advice on adapting to functional changes over time; and provision of accessible home-based services to both CP and PLWD. (2) Psychologic components: regular provision of support groups, including options for CPs caring for severe or advanced-stage disease; encouraging CP attention to their own well-being [66] through self-care and respite, while acknowledging the associated challenges; providing dyadic and individual behavioral health support; and grief support [67]. (3) Social components: ensuring social resources for CP/PLWD are tailored to needs and made accessible; providing help obtaining ADL and IADL assistance; facilitation of meaningful activities for PLWD; and provision of care navigation and help with paperwork. Ideally these trainings and services would be provided in multiple venues (including the home) and formats (in-person, online, in-print, etc.). New functional roles within the dementia specialty care infrastructure will need to be developed within ADRCs that can iteratively identify and address needs, assemble tailored care teams of clinicians, coordinate care across settings, and smooth the dysfunctions of the healthcare delivery system. One such example might be the Care Ecosystem, a telephone and web-enabled intervention to enable health systems and clinics to provide dementia-competent care [68–71].

In concert with the development and refinement of clinical geriatric neuropalliative care interventions for PLWD/CP affiliated with specialty dementia centers, clinical teams will need supplementary trainings. For example, clinicians in specialty dementia care centers will need training in basic principles of geriatrics and neuropalliative care tailored for dementia [59] and guidelines for referring patients to specialty palliative care and hospice services. Similarly, primary care, palliative care, geriatrics and hospice [72–74] clinicians will need training in how to effectively address specific needs of people with dementia (such as distressing behavioral symptoms) and guidelines for making referrals to specialty dementia centers [75]. All clinicians may need training in grief support. Community outreach groups associated with health care organizations or specialty dementia centers can provide training in normal brain aging and reduce stigma of dementia. Development, implementation, and refinement of these clinical and training interventions in specialty dementia centers, in the context of research, could allow for the development of financial models, business cases, and recommended policies that could enable the spread of geriatric neuropalliative dementia care in community organizations.

### **Limitations:**

Our study sample from this single academic medical center lacked nationally representative racial/ethnic and socioeconomic diversity; participants were largely advantaged and well-resourced so their experiences likely do not represent the full breadth of issues PLWD and CPs face. Our participants were heterogenous in other ways, representing different dementia syndromes, disease stages, and roles. The sample size was not sufficiently large to analyze challenges or supports related to family structure, community, or culture. Relatedly, PLWD were under-represented in our study due to recruitment difficulties; several could not complete teach-to-goal consent processes. The COVID pandemic disrupted our ability to engage in member checking to validate findings with participants or other PLWD or CP; we

did not return transcripts to participants because of the burden of correcting transcripts amid ongoing decline of the PLWD, caregiving challenges, or grieving. Finally, the study setting (in the United States, associated with an ADRC funded by the US National Institutes of Health) means findings may be less transferable to an international audience with different structures for health care systems.

### Conclusions:

In this comprehensive qualitative interview study of PLWD and CPs receiving care at a specialty dementia clinic, we describe the value of resourcefulness and assistance from family and friends as well as profound challenges and needs for greater support. Integration of geriatric neuropalliative care-informed services into specialty dementia care has the potential to vastly improve quality of life for PLWD and their care partners, and enhance the robust services already provided.

### Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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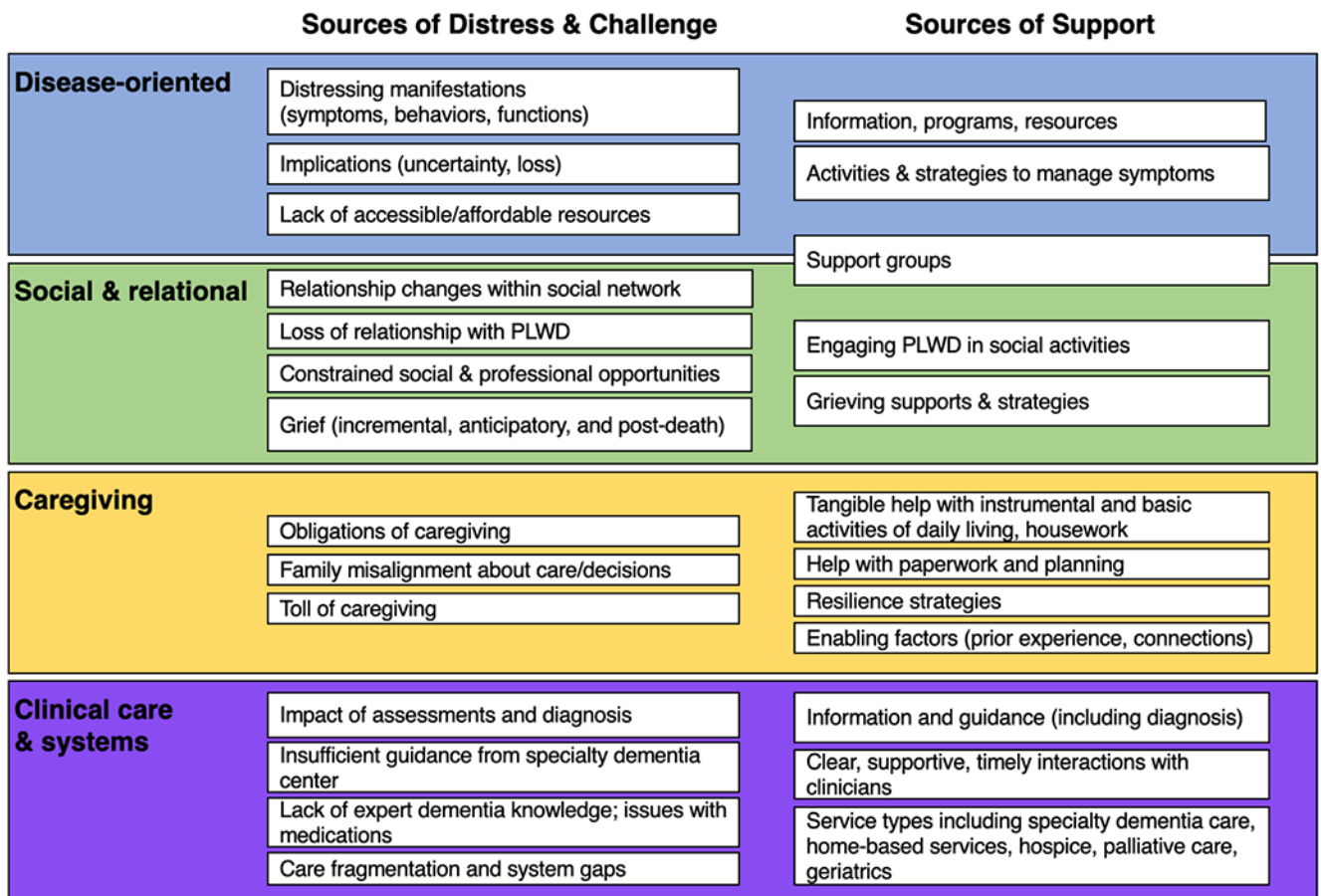


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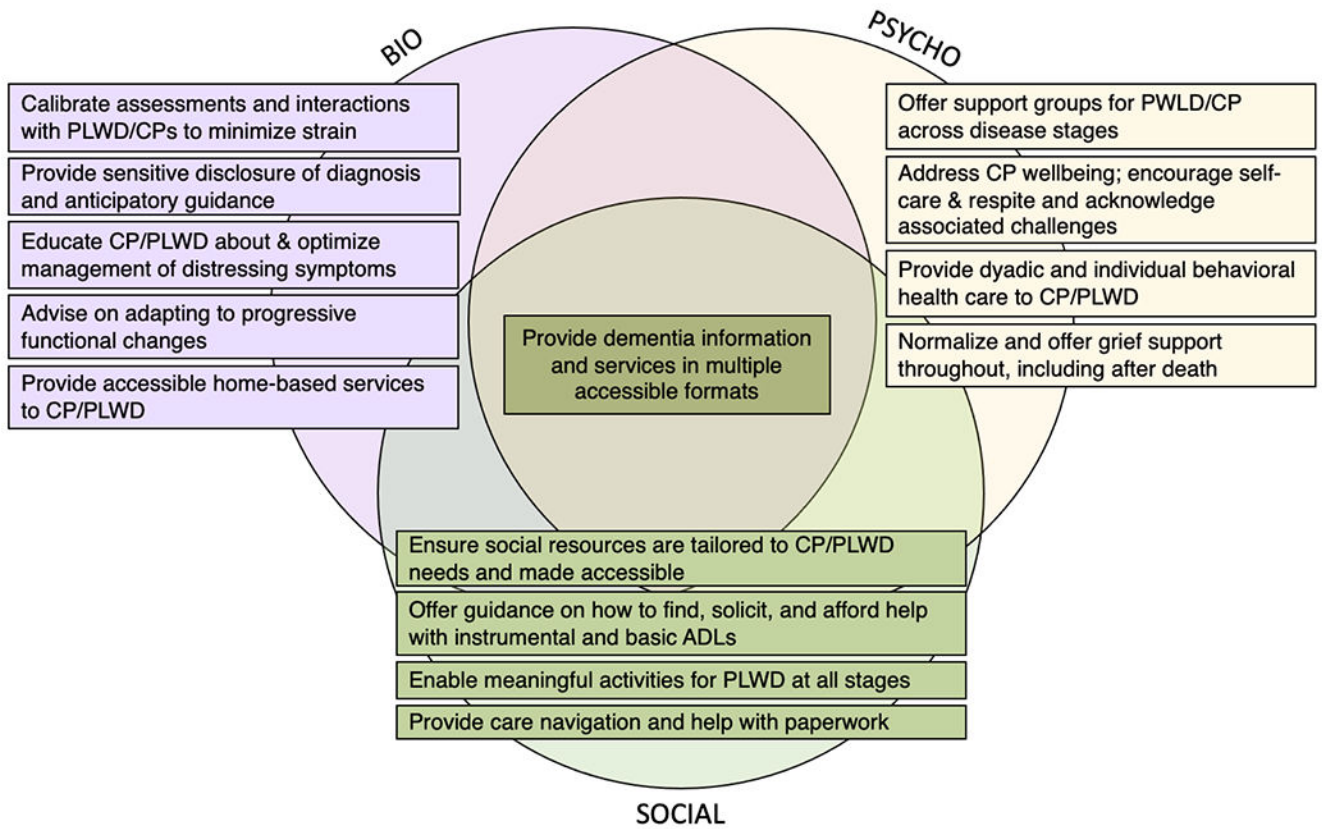
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**Figure 1:**  
 Visual summary of findings organized by theme  
 This figure summarizes qualitative findings from interviews with persons living with dementia, current care partners, or former care partners of people who died from dementia. We identified 4 major sources of challenge or support: related to the disease, social and relational changes, caregiving, and clinical care or care systems. Each box summarizes a subtheme within each category of challenges or supports.



**Figure 2:** Recommendations for an integrated, biopsychosocial, geriatric neuropalliative care approach to improve care within specialty dementia centers associated with Alzheimer’s Disease Research Centers  
 This figure summarizes empirically-based, person-and family-centered recommendations for improving care within specialty dementia centers and Alzheimer’s Disease Research Centers, organized around a biopsychosocial framework for geriatric neuropalliative care. Recommendations related to a biological or physical dimension are noted in purple, those related to a psychological dimension are noted in yellow, and those related to the social dimension are noted in green

**Table 1.**

Demographics of interview participants: persons living with dementia (PLWD), current care partners (CPs) of PLWD, and former CPs of decedents who died with severe or advanced disease

	PLWD (n=9)	Current CPs (n=16)	Former CPs (n=15)
	n (%)	n (%)	n (%)
<i>Self-reported demographics</i>			
Age in years (Mean [range])	75.3 [67-86]	65.8 [40-87]	68.9 [45-82]
Sex			
Female	3 (33%)	12 (75%)	9 (60%)
Male	6 (67%)	4 (25%)	6 (40%)
Marital Status			
Married/partnered/living together	6 (67%)	13 (81%)	2 (13%)
Widowed	-	-	11 (73%)
Divorced/separated/never married	3 (33%)	3 (19%)	2 (13%)
Race/Ethnicity <sup>1</sup> (multiple possible)			
White	7 (78%)	9 (56%)	14 (93%)
Black/African American	-	2 (13%)	1 (7%)
Asian	1 (11%)	3 (19%)	-
Other [text available] or missing	-	2 (13%)	-
Education (highest completed)			
HS graduate, some college, or vocational	1 (11%)	4 (25%)	2 (13%)
College graduate	1 (11%)	4 (25%)	6 (40%)
Masters/PhD/professional degree	7 (78%)	8 (50%)	7 (47%)
Income category (total household)			
<\$20,000	1 (11%)	-	1 (7%)
\$20,000-<\$40,000	-	1 (6%)	1 (7%)
\$40,000-<\$60,000	1 (11%)	2 (13%)	1 (7%)
\$60,000-<\$80,000	2 (22%)	3 (19%)	1 (7%)
\$80,000-<\$100,000	-	-	3 (20%)
\$100,000+	5 (56%)	9 (56%)	6 (40%)
Missing	-	1 (6%)	2 (13%)
Difficulty affording basics			
Not hard at all	7 (78%)	13 (81%)	12 (80%)
Somewhat hard	2 (22%)	3 (19%)	3 (20%)
<i>Self-reported during interview</i>			
PLWD used specialty palliative care	1 (11%)	3 (19%)	3 (20%)
PLWD used hospice care <sup>2</sup>	-	-	13 (87%)
Prior experience with dementia	4 (44%)	3 (19%)	3 (20%)
<i>Clinical data abstracted from chart for recruitment</i>			

	PLWD (n=9)	Current CPs (n=16)	Former CPs (n=15)
	n (%)	n (%)	n (%)
mean MMSE or MoCA (before recruitment) [range]	23.6 [15-29]	17.4 [15-29]	-
Dementia syndromes			
Alzheimer dementia	5 (56%)	9 (56%)	5 (33%)
Lewy body	-	2 (13%)	1 (7%)
Behavioral variant frontotemporal dementia	1 (11%)	1 (6%)	1 (7%)
Other syndromes <sup>2</sup>	1 (11%)	2 (13%)	2 (13%)
Mixed syndromes <sup>3</sup>	2 (22%)	2 (13%)	6 (40%)

<sup>1</sup>Race/ethnicity were collected to report per funder requirements and categorized based on NIH reporting categories.

<sup>2</sup>Represents all former caregivers

<sup>3</sup>Other syndromes: PLWD: 1 nvPPA/PSP (nonfluent variant primary progressive aphasia/progressive supranuclear palsy); care partners: 2 lvPPA (logopenic variant primary progressive aphasia), 2 PSP (progressive supranuclear palsy), 2 CBS (corticobasal syndrome - 1 mixed), 2 PCA (posterior cortical atrophy - 1 mixed);

<sup>3</sup>Mixed syndromes or copathologies: PLWD: 2 AD/VD (Alzheimer's Disease/vascular dementia); care partners: 1 CBS/PCA (corticobasal syndrome/ posterior cortical atrophy), 3 AD/LBD (Alzheimer's Disease/Lewy Body Disease), 1 AD/PCA (Alzheimer's Disease/posterior cortical atrophy), 1 lvPPA/AD (logopenic variant primary progressive aphasia/ Alzheimer's Disease

**Table 2:**

Challenges or sources of distress reported by PLWD or care partners

Challenge	Inventory of examples in data	Illustrative quote
<i>Disease-oriented challenges</i>		
Behavioral symptoms	Hallucination, panic, fear, swinging, fighting, pushing, sundowning, wandering, dream enactment, frustration, anger, cursing, delusions, refusing to take medication, lucidity, refusing to bathe, temper, resistiveness to care, sleep disturbances, making negative financial decisions, social disinhibition, refusing cleanliness	<i>“He started hallucinating during the day and he would go out outside... go into the street and he would tell people he was being held hostage and people were trying to rob the house” (fc06)</i>
Functional impairment	Fainting spells, urinary/bowel incontinence, falls, inability to stand, inability to walk, get things for themselves, inability to exercise, issues with transferece, inability to prepare food, loss of balance, inability to swallow	<i>“[she] got out of bed and lost her balance and hit ... just above her eyebrow on the bedside table, which you know, ended up in the ER getting a stitch or three” (fcp13)</i>
Multimorbidity	Cancer, knee pain, alcoholism, chronic high blood pressure, depression and anxiety, hip fracture, psychiatric issues, Parkinson’s disease, glaucoma, cardiovascular disease, macular degeneration	<i>“My PSP is not my sole disease, and physically I did 45 minutes of exercise, my own style. Because of my knee pain I no longer... ..do exercise. I skip that.” (p10)</i>
Uncertainty	Uncertainty of (physical, mental, verbal) decline, onset of aggressive behaviors, when to seek care, falls, end-of-life, loss in physical/functional abilities, when to consider more help with care, disease trajectory, cause of disease, if good or bad caregiving day	<i>“What’s the prognosis and the progression, and what should I be watching for?” (ccp09)</i>
Disease-related losses	Loss in memory, ability and/or interest to socialize, loss of friend group, ability to express self, energy, control and privacy, ability to drive, independence/freedom, ability to work, spousal relationship, ability to engage emotionally, good judgement, communication. “Disappearing” PLWD	<i>“You lose that person even though they’re there in front of you every day, and that really was the hardest thing for me. That was one of the things I couldn’t face, and I would like to say that’s one of the reasons I started drinking again, because it helped me hide the pain.” (ccp22)</i>
Lack of accessible or affordable resources	Difficulty finding groups, support groups during work hours, unable to accommodate those in later stage, expensive resources, turned down by social security/disability, difficulty getting referrals to resources, expensive resources, difficulty getting Medi-Cal, difficulty getting to groups, working person unable to access services, needing help from others to stay with PLWD to access services, facilities where people are more severe, facilities with little activities, PLWD too severe for support groups	<i>“we’ve gotten divorced so that he qualifies for care, because I can’t afford to pay what it costs” (ccp22)</i>
<i>Social and relational challenges</i>		
Distress about relationship changes	Loss of relationship with spouse, with parent, with friends; loss in contribution to relationship, loss in romance, change in responsibilities in relationship, loss in communication in relationship, resentment towards PLWD/partner, loss of needs being met, inability to share with PLWD, stigma preventing truth-telling about disease or asking for help	<i>I don’t want to talk about that with other folks....that’s personal information and it’s somewhat, to me, it’s almost a little bit like a stigma” (p07).</i>
Constrained social and professional opportunities	Loss of communication, inability to socialize, loss of community, inability to participate in social activities once enjoyed, loneliness, isolation, inability to keep up social life, people treating PLWD differently, people unwilling to socialize with PLWD, care partner unable to leave PLWD to participate socially, can’t join poke group, loss of relationships, working during medical appointments, missing work, missing meetings, leaving work early, inability to travel for work, impacted quality of work, rescheduling work for emergency care of PLWD, rescheduling meetings to make time to access resources, impacted concentration level at work, retiring early from work to care for PLWD, quitting job to find a more flexible job	<i>One PLWD said they tried “to avoid social gathering.... I stopped that because I get tired” (p10).  Speaking about when a PWLD had to stop working, her CP said, “That was just really heartbreaking to me. Less so to her. ... it was so much a part of her identity and feeling good about herself ...it was just sad” (ccp09).</i>
Grief	Making challenging end-of-life decisions, grieving loss, grieving post-death, watching PLWD slowly disappear at end-of-life, feeling the need to recreate life post-death, accepting	<i>“Well, I’m still grieving. I still think about her a lot. I dream about her. There are still times when I’m distracted, “Oh, I got to go see Mom today”... [and] I realize she’s not going to be there” (fcp11).</i>



Challenge	Inventory of examples in data	Illustrative quote
	PLWD decisions in end-of-life, telling PLWD they can let go when ready, adjusting to loss, family unable to make funeral	
<b>Challenges of caregiving</b>		
Obligations of caregiving	All responsibilities on CP, expectation that children take care of parents in older age, coordinating care and managing responsibilities, concern about finances, organizing paid caregiving, navigating ethical and legal issues, having to prepare for future, finding activities for PLWD	<i>I don't know how this happened, because I'm the youngest of six siblings. It seems as I was the one who step [sic] up to the plate and did everything, advocating for her, making sure she got whatever it was that she needed, while everybody else kind of like sat back" (fcp03).</i>
Family disagreement or misalignment about care and decisions	Disagreement on current care, care location (e.g. institutionalization vs in-home care), choice of facility, providers, end-of-life care, will/trust, medications	<i>"When two people have a difference of opinion and have to share the decision-making--it pretty much becomes 100/0" (fcp08).</i>
Toll of caregiving	Distress, struggling to meet own needs, managing behavior symptoms, labor of ADL/IADL help, grief, loss, loss of identity, guilt, negative impact on current and future financial state, changing of help available, burnout, toll of sleep disruption, impact on weight, depression, anxiety	<i>"I just, I cried about it. I cried a lot. In the middle of the night. When my daughter was sleep or whatever, when the house was quiet" (fcp03)</i>  <i>"I had a meltdown once. I just screamed and pounded on the bed and said, "I didn't sign up for this. It's not what I thought we were going to do." And, you know, [my spouse] wasn't in the room when I did it, but of course it wasn't a very big house. He obviously heard me. And he just when I was through he said, "I love you. I'm sorry." I said, "I love you, too. I'm sorry." I just needed that one big meltdown. And I was ashamed of myself for doing it" (fcp15).</i>
<b>Clinical care and care system-oriented challenges</b>		
Impact of assessments, diagnosis and treatments	Negative impact of clinical testing, clinical care causing UTI, becoming suicidal after diagnosis, fearful/anxious/sad reaction to diagnosis, more cognitive decline after taken off medication, clinician yelling PLWD, side effects to medication, negative reaction to change in medication, changing between medications	<i>"when she got off of those medicines, suddenly her brain went. It's like, it had been in this delicate balance and as soon as they took everything off to start fresh, she became agitated and aggressive" (fc14)</i>
Lack of guidance from specialty dementia clinic	Lack of guidance for PLWD and/or caregiver about diagnosis, disease trajectory, symptoms, treatment	<i>"First I was tested, of course, on my memory. You know, the standardized test, and then I saw [[Dr. L.]], and actually, I didn't learn much. I think he learned more ... I'm sure he printed out something. I honestly don't know where it is. But for myself, I came away with little information." (p08)</i>
Lack of expert dementia knowledge and issues with medications	Lack of knowledge about caregiver self-care or paid caregiving or respite, about disease trajectory & progression, how to best care for/interact with PWD, lack of clear diagnosis given to patient, lack of explaining diagnosis to CG, no clear diagnosis given to PLWD/CG, lack of feedback about progression from clinical team, lack of prognosis, clinician not checking possible drug interactions	<i>"I should not have listened to a primary care physician [about a medication that caused a bad interaction] without confirming it with a neurologist or a pharmacist" (fcp05).</i>
System gaps and care fragmentation	No one clinician/clinical site/system to continually see PLWD, medical team not present in end-of-life, parking garage inaccessible to PLWD, medical team not following through, office-based clinical care, not knowing where to go because too many options, difficult getting to services, difficulty scheduling appointments	<i>"I have to find out and make things happen instead of they, you know, contact[ing] me" (ccp02).</i>

**Table 3:**

Sources of empirical or hypothetical support reported by PLWD or CPs

Support	Inventory of examples in data	Illustrative quote
<i>Disease-oriented supports</i>		
Information, programs and resources	Information from professionals, learning of support groups from the Alzheimer's Association, learning of hospice team from specialty dementia clinic, educational program with Alzheimer's Association, clinics at MAC where NP helped with behaviors, Alzheimer's website, list of facilities from aging organizations, advice from MAC, book recommended by group, MAC seminar	<i>"The best thing that I had for guidance was the Alzheimer's website, which described the disease by stage, and there's about a half a dozen different stages that they describe with the symptoms associated with each of those stages, and that gave, for me, that was the best, although things don't always match up, but generally they did, and so I had an awareness that, you know, 8 to 10 years would probably be about right" (fc21)</i>
Activities and strategies to manage symptoms	Exercise, sleep, eating well, long walks, pets, writing, using appointment book, light treatment, using calendars, strategies navigating behaviors, reading books, using an ID bracelet to help identify a wandering PLWD, using a "club" to prevent a PLWD from driving	<i>"I've always been an active person and I play—I'm very happy to continue playing with an orchestra, community orchestra... It's also good exercise because as a percussionist, I stand up for three hours at a rehearsal or at a concert". (p11)</i>
Disease-related hypothetical supports	Information from other professionals, creating a community of those impacted by disease, a sponsor to check in on you, information from associations, clinical trials, exercise, pain relief, using devices like Echo, attachment to religious organization, books; treatments and cures	<i>"I do think it would be very useful for there to be ... people who had become caregivers who could help others, who could give advice, who could talk about their own personal experience... where people who had more experience could come in and there could be some discussion, I think, because caregivers really need so much support themselves" (fc16)</i>
<i>Social and relational supports</i>		
Support groups	Learning of possible future behaviors and loss of freedom, professional people in PLWD group to talk to, meeting other people with dementia, CP learning how to care for self while caregiving, lists of services for PLWD, learning about hospice, source of friends, helping with loneliness, learning ideas for management strategies	<i>"So Alzheimer's support group was amazing, and I don't know if you know how it works, but we would go every Thursday for an hour and a half, and the caregivers would meet in one room, and those with the illness met in another room and each with a social worker who sort of facilitated the meetings. And she found that group to be really something to look forward to because it was a group of people who in various ways-- not everyone had their unique kind of dementia as it turns out, but they walked into the room, and it was a community of people who were very open to everybody else's experiences, and likewise for me. I had very strong friendships with all these peoples. We still meet regularly" (fcp05)</i>
Engaging the PLWD in social activities	People to socialize with, looking at family albums, community help, playing games, church, arts and crafts, cooking with family, adult day health center, listening to music, classes, hiking, activities with nursing students	<i>"I think we're still in a good place where we're kind of doing everything we did before just a little slower or maybe a little less." (ccp27)</i>
Strategies for managing grief	Grief counseling, outreach from hospice, travelling, pets, faith, family support, connecting with others who have lost loved ones, enrolling in courses, bereavement groups	<i>"I've been fighting going to grieving or bereavement. I went to my first one on Tuesday, and it was helpful, I will tell you" (fcp06).</i>
Hypothetically helpful social & relational supports	Personal counseling, outreach meetings, discussion with spiritual leader, support system, connection with others, someone to read writings of PLWD, activities to keep PLWD socially engaged, travelling	<i>"My thought is that somebody who would read with him some of the writings that he has had before. Hopefully they would be able to ask questions." (ccp09)</i>
<i>Supports for caregiving in everyday life</i>		
Help with instrumental ADLs and household management	Help with household washing and cleaning, help with cooking, helping with PLWD outings, paying bills, driving to appointments or grocery shopping, cooking,	<i>"So she will bring her to her eye doctor appointments. She'll bring her to most of her [[Dr. #1]] appointments. She brings her to [[Dr. S]] and I use her expertise as an excuse for me getting a little time off. But she also gives me advice of how to handle the mental changes that are in [[Spouse]]. So I find her the best help" (ccp18)</i>
Tangible help with basic ADLs	Family, friends, paid help with: watching PLWD, bathing, feeding, dressing	<i>"I was very grateful to be able to... afford private care for [[Spouse]] because ... I didn't have to worry, is he sitting in wet diaper" (fcp16).</i>

Support	Inventory of examples in data	Illustrative quote
Help with documentation, paperwork and planning	Outreach for guidance when dealing with problems, prior end-of-life preparation, lawyer navigating Medi-Cal, having healthcare directives set up, financial advisor, help with paperwork, setting up legal power of attorney	<i>"I think also, [[Spouse]] and I had all our affairs taken care of, and this had all been done prior to [[Spouse]] getting ill, and then when DOMA was overturned, we were married. So, also, thank goodness. I don't even want to think about what it might have been like if that had not been the case" (fcp16).</i>
Enabling factors	Family members calling asking to help or being supportive; moral support, personal or professional connections; prior experience getting into clinic for care, prior skills to navigate systems gaps, being able to access resources, being able to access public transit, insight into dementia or caregiving from prior experience, being a donor to clinic, positive mindset, journaling, exercise, patience, guidance on self-care, spending time with friends/family, attending church, seeking help from therapist, reading religious book, Buddhist meditation, organized self-care, faith in God	<i>"[[spouse's]] son is married to a lovely woman who is a speech pathologist and she researched, through her friends, what would be the best place, because his son felt that he was not getting proper care" (fcp15).</i>  <i>"she's [psychologist] been a lifesaver for me. She really has. I mean, well, the most important thing she's done is to show me how to help myself, in a situation that was foreign to me, you know. I guess that's the best way I can use to describe it, and also just to vent and get my emotions out there." (cc10)</i>
<b>Supports from clinical care or care systems</b>		
Information and guidance	Finding out diagnosis, educational resources from clinic, guidance on symptoms, information on disease expectations, information on available resources and organizations	<i>"It was helpful to me to know that this was a disease, since I knew nothing about it, a disease that had a variety of causes, a variety of treatments, a variety of symptoms if they can call them symptoms, that it wasn't just one thing, that it was a whole cluster of different things and that's why people manifested such different behaviors. I think his behavior was pretty typical of one form, but I saw plenty of other people and heard plenty of other stories in caregiver groups that were very different." (fcp15)</i>
Interactions with clinicians	Relationship with clinical team, positive communication with clinical team, being heard by clinical team, support from multiple clinical members, clinical team being there for family, help filling out ACP forms & making plans for the future, finding a good neurologist, letters from clinical team for disability benefits, clinical team addressing whole system	<i>"[Clinician] was very attentive not only to the words of the question, but also to the emotional content behind it, and he responded to both, at both levels" (ccp25).</i>  <i>"It's not a real recognition that I am the caregiver if care is not provided to me"; they noted that when the PLWD had a transplant both CPs and patients were attended to (ccp25).</i>
Types of clinical service	Neurology, physical therapy, social workers, home-based medical care, geriatrics, hospice, palliative care	<i>"when we signed up for hospice... we got tons of resources from them, physical and emotional support and whatnot, and medical care and medical stuff, DME, whatever you call it. So we got a lot from hospice, and, I mean, I guess I feel like Alzheimer's is sort of a palliative diagnosis" (fc08)</i>

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