

# How do care partners overcome the challenges associated with falls of community-dwelling older people with dementia? A qualitative study

Dementia

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## Abstract

**Background and Objectives:** Previous studies have found that falls among community-dwelling older people with dementia negatively impact the health and well-being of their relative/friend care partners. Limited studies have explored the challenges care partners experience because of older people's falls (including fall incidents and fall risks). We sought to investigate care partners' experiences of these challenges and how care partners responded.

**Methods:** We conducted an inductive thematic analysis of 48 dementia care partner interviews (age range: 33–86, mean: 61, 70.8% women; 58.3% adult children; 29.2% spouse; 62.5% completed college; 25% people of color), conducted after a health crisis of older people with dementia from three local university-affiliated hospitals in the United States.

**Findings:** Care partners reported that falls in older people with dementia can intensify overall care demands and lead to self-sacrificing behaviors, dissatisfaction with healthcare providers, conflicts with care recipients, and intense emotions. Care partners described several adaptations to mitigate these impacts, including practicing acceptance, approaching falls as an opportunity for learning, facilitating collaborations within formal/informal care networks, collaborating with older people with dementia to balance autonomy and safety, and modifying the physical environment.

**Discussions and Implications:** Falls among older people with dementia are a significant stressor and an important activation stimulus for their care partners. Our findings suggest that care partners are “second clients” and “competent collaborators.” As they provide important insights about fall prevention, care partners should be engaged to co-design new multi-level interventions to facilitate collaborations among care networks, older people with dementia, and service providers.

## Keywords

aged, cognitive impairment, caregiving, fall prevention, lived experience

In 2016, nearly half of older adults with dementia in the United States (U.S.) experienced a fall (Okoye et al., 2023), often resulting in injury, functional decline, and fear of falling that may limit ambulation and further impair mobility (Feldman & Chaudhury, 2008). Older people with dementia have two to ten times more falls than age-matched peers without dementia (Allan et al., 2009), are more likely to be injured when they fall (Fernando et al., 2017), and have more adverse events during hospitalizations (e.g., delirium, falls in the hospital) (Ahmed et al., 2014; Watkin et al., 2012), resulting in higher costs and complicated recovery (Lin et al., 2013). However, research informing best practices for preventing and managing falls for this high-risk population remains limited (Racey et al., 2021; Wheatley et al., 2019). The experiences of relative/friend care partners who provide most of the care for older people with dementia at home could make an important contribution to developing such best practices (Bremer et al., 2015; Hebert et al., 2013; Xiao et al., 2014).

It is estimated that more than 7 million people aged 65 years and older were living with dementia in 2020 in the U.S., with more than 11 million care partners providing essential care that allows them to age in place (Alzheimer's Association, 2023). Previous studies have found that care partners often make extensive efforts to prevent falls for older people with dementia who live at home, such as providing functional mobility assistance, health management, and safety supervision, modifying the physical environment, and coordinating other caregivers and service providers (Zhou et al., 2022). They are often the first responders when older people fall and provide care and support for their recovery (Zhou et al., 2022).

Several studies discovered that falls among older people with dementia are associated with care partner burden (Faes et al., 2010; Kamiya et al., 2014; Reed et al., 2014) and care-related emotional

challenges (Leggett et al., 2018), and that fall events can increase concerns about the risk of future falls (Buri & Dawson, 2000; Gibson et al., 2014; McIntyre & Reynolds, 2012). Because of such concerns, care partners may struggle with balancing safety and autonomy for older people with dementia (Zhou, Strayer, et al., 2021). Another important finding is that many care partners report experiencing a lack of support from service providers (such as primary care providers and paid caregivers) while, at the same time, feeling distrust of others and preferring to take on all the responsibilities of managing fall risks (McIntyre & Reynolds, 2012; Owen et al., 2022). Very few rigorous studies posed clear research questions about care partners' experiences of challenges associated with falls among people living with dementia and explored how care partners cope with these challenges (Zhou, Strayer, et al., 2021). This understanding can help researchers and practitioners develop fall prevention programs by effectively engaging care partners without exacerbating the care burden.

Furthermore, the few existing qualitative studies were mostly conducted with a small sample of dementia care partners in European countries (i.e., the Netherlands, UK, and Sweden) (Buri & Dawson, 2000; Cedervall & Åberg, 2010; Faes et al., 2010; McIntyre & Reynolds, 2012; Owen et al., 2022). Little is known about dementia care partners' experiences of falls among people with dementia in the U.S. The disproportionality high risk of falls among people with dementia and the lack of evidence-based fall prevention programs is a significant gap in public health services. It is critical to examine how care partners are impacted and how they navigate these challenges in the U.S.; this study will provide insights into the growing awareness that providing proactive preventive care and caregiving support may reduce the likelihood of care recipients' hospitalizations (Ornstein et al., 2022). Using a convenience sample from healthcare organizations in Washington, U.S., this study aimed to examine: 1. What challenges are experienced by dementia care partners due to falls, including fall risk and fall incidents? 2. How do care partners address these challenges?

## Methods

### *Study design of the parent study*

This was a secondary (qualitative) analysis of interview data from a parent study conducted between November 2016 and July 2018. The parent study was a cross-sectional, mixed-method study, which recruited 100 care partners of community-dwelling older people with dementia who experienced a recent health crisis due to ambulatory care-sensitive conditions that resulted in an acute care encounter (hospitalization, emergency room visit, or observational status) for their care recipient. Older people with dementia were identified by the research team, in collaboration with information technology staff of three university-affiliated hospitals, using an electronic medical record (EMR) algorithm. Inclusion criteria included: (1) had a dementia diagnosis based on International Classification of Diseases (ICD-9 or ICD-10) codes; (2) hospitalized due to an unplanned acute care encounter (hereinafter referred to as "index acute care encounter") or discharged in the previous seven days after an index acute care encounter; and (3) had an identifiable next of kin. The research coordinator [E.I.] contacted 446 "next of kin" for screening. Care partners were eligible if they were (1) aged 18 years or older, (2) self-identified as involved in managing the older people's healthcare (e.g., scheduling and accompanying them to medical appointments), (3) able to read and speak English, (4) those whose care recipient lived in the private residence settings before the health crises, and (5) reporting their care recipient a score of 1 or higher on the proxy-reported AD-8 dementia screening tool (as all the care recipient had a dementia diagnosis in the medical record) (Cordell et al., 2013). Ethical approval was granted on 6/24/2016 by the Institutional Review Board at the

University of Washington [STUDY00002012]. Written consent was obtained from participants before commencing the interviews.

The parent study collected data from (1) EMR from 30 days before index acute care encounter until discharge; (2) quantitative measures about health and function of older people with dementia and care partners' mental and physical health; and (3) qualitative interviews about care partners' experiences of the health crisis that resulted in the index acute care encounter. The interviews were face-to-face or via phone call, conducted by experienced master-level social workers, lasted an average of 60–90 minutes, and were audio recorded and transcribed verbatim. The interview guide was organized into the following topic categories: (1) their experiences of managing care recipients' health before the crisis, (2) their interactions with service systems, (3) how they overcame these challenges, and (4) care partners' experiences to care for themselves during the crisis. Care partners completed informed consent before participation in the parent study.

### *Participant selection and data extraction for the secondary analysis*

The first author reviewed the interview data from 100 care partners in the parent study and identified 58 care partners who mentioned fall-related terms (“fall,” “fell”). Then, the first and second authors reviewed these 58 participants' data independently to select care partners who volunteered unprompted narratives about experiences with a care recipient's fall incidents and fall risks (usually multiple) and spontaneously reflected on the personal toll related to fall incidents and fall risks experienced by older people with dementia and how they dealt with the consequences. Those who mentioned falls without describing their experiences were excluded ( $N = 10$ ). Forty-eight care partners were included for the following reasons: Some reported falls or fall concerns associated with health problems that led to the index acute care encounter ( $N = 32$ ), some reflected on falls that took place after the discharge ( $N = 11$ ), and some reported a more remote history of fall incidents or fall concerns ( $N = 22$ ).

These 48 care partners were, therefore, selected as the sample for the current secondary study. Because this is a secondary analysis, the interview guide was not created to address the aims of the current study, and participants were not directly asked about the fall risk/events that made them eligible for the study. Interview guide questions that appeared to generate the most content that contributed to the current study included: (1) When you first noticed something was wrong, that your loved one was becoming more ill, what did you do at first? (2) Was there anything that you did to obtain information about how to best manage this worsening health issue? (3) Are you satisfied with the care provided during the health crisis? If you are not 100% satisfied, what would need to happen for you to be satisfied? (4) What situations were most difficult, challenging, or stressful? How did you handle it? Overall, did you feel you recovered from the challenging situations?

### *Data analysis*

As we identified no prior conceptual framework for understanding how falls among older people with dementia affected their care partners, we used inductive thematic analysis to identify, analyze, and report patterns (themes) without using a prior template of codes (Braun & Clarke, 2006; Fereday & Muir-Cochrane, 2006).

Initially, the two reviewers [Y.Z. & N.T.] independently reviewed the transcripts of the participant interviews ( $N = 48$ ). They captured and assigned codes to the text that described dementia care partners' experienced challenges associated with care recipients' fall risk and fall incidents. Reviewers met weekly to compare and reconcile coding results and to develop the code book.

For the second stage, two reviewers collaborated on collating codes into potential themes through comparison, creating broad themes and sub-themes. After the initial set of themes was created, both reviewers returned to the data and initial codes, checking if the themes “worked” in relation to the code and the entire data set. Any needed revisions were brought up and addressed via weekly discussion.

After identifying themes, two reviewers used the data and literature to refine the specifics of each theme and generate clear definitions and names for these themes. The multidisciplinary research team (social work, nursing, medicine, and occupational therapy) reviewed and refined the themes, sub-themes, and definitions. Raw data, coding records, and notes of weekly meetings and team meetings were filed by date to provide an audit trail.

## Results

### Sample description

Forty-one of the 48 participants were primary care partners (providing regular hands-on care), five self-identified as secondary care partners (helping the primary care partner with care tasks), and two provided long-distance support; more than half were adult children ( $n = 28$ ), and the majority were women ( $n = 34$ ). The average duration of caregiving was 11 years (0.25–27 years). Other characteristics of older people with dementia and their care partners are presented in [Table 1](#).

### Main findings

Participants reported five major challenges associated with falls/fall risk in their experience as care partners. The challenges include: (1) *increased care demands* – experiencing the need for heightened vigilance and provision of more intensive care, (2) *self-sacrificing* – giving up social and leisure activities and altering life plans (i.e., education, career), (3) *dissatisfaction with healthcare providers* – not feeling included in care decisions and not receiving sufficient guidance and support from healthcare providers, (4) *increased conflicts with the older person with dementia* – usually centering on managing their resistance to prescribed management, and (5) *intense emotions* – strong emotions evoked by fall-related stress, such as anger, constant worry, and fear.

The adaptations that care partners employed to address these challenges included: (1) *cultivating acceptance* – coming to understand that not all falls are preventable; (2) *approaching falls as an opportunity* – viewing falls/fall risks as warning signs or ‘sentinels’ of unmet needs for themselves and care recipients, (3) *getting help from informal and formal care networks* – taking action to strengthen informal and formal care networks, (4) *collaborating with older people with dementia* – engaging the care recipient in care decisions that balance autonomy and safety, and (5) *modifying the physical environment* – identifying and reducing safety hazards in the home environment or using assistive devices such as walkers or wheelchairs. The two major categories and sub-themes are presented in [Table 2](#), along with representative quotes.

### Challenges

*Increased care demands.* Care partners described increased care demands related to preventing falls and managing their aftermath, including injury, escalating behavioral symptoms, pain, giving new medications, or incontinence, and the resulting need to provide more physical help with basic activities of daily living. For example, one care partner (wife, primary care partner, age 80) reported difficulty providing mobility assistance to her care recipient before and after fall incidents: “When he

**Table 1.** Characteristics of the study sample ( $N = 48$ ).

		Characteristics of older people with dementia
		Mean $\pm$ SD (range) or $N$
Age, years, mean $\pm$ SD <sup>a</sup> (range)		82 $\pm$ 9 (64–96)
Gender	Man	21
	Woman	27
Dementia type	Alzheimer's disease	15
	Lewy body dementia	1
	Frontotemporal dementia	1
	Vascular dementia	13
	Parkinson's disease dementia	6
	Unspecified dementia	22
	Mixed dementia	9
Dementia stage	Mild (DSRS <sup>b</sup> : 0–18)	14
	Moderate (DSRS: 19–36)	27
	Severe (DSRS: 37–54)	7
Characteristics of dementia care partners		
		Mean $\pm$ SD (range) or $N$
Age, years, mean $\pm$ SD (range)		61 $\pm$ 12 (33–86)
Gender	Man	14
	Woman	34
Race/ethnicity	Non-Hispanic white	36
	Non-Hispanic black	4
	Asian	7
	Hispanic white	1
	American Indian/Alaska Native	2
	Native Hawaiian or other Pacific Islander	2
Highest level of education	High school or less	7
	Some college	11
	College graduate	21
	Post-graduate education	7
	Vocational training	2
Employment	Full time	14
	Part time	9
	Not working	25
Difficulty paying for basics for older people with dementia	1 Not difficult	23
	2	9
	3	9
	4	5
	5 Extremely difficult	2

*(continued)*

**Table 1.** (continued)

Characteristics of dementia care partners		Mean $\pm$ SD (range) or N
Relationship to older people with dementia	Adult child	28
	Spouse	14
	Friend	1
	Other relative	5
Care partner type	Primary	41
	Secondary	5
	Long-distance support	2
Caregiving responsibilities for more than one person	Yes	16
	No	31
	Missing	1
Years as care partner, mean $\pm$ SD (range)		11 $\pm$ 6 (0.25–27)
Years since dementia diagnosis, mean $\pm$ SD (range)		4 $\pm$ 9 (0–30)
Living situation	Residing with older people with dementia	22
	Not residing with older people with dementia	26
Care partner self-rated health <sup>c</sup>	Very good	15
	Good	26
	Fair	7
Nature of involvement with falls among older people with dementia	Managing through a fall-related health crisis	32
	Managing falls before a health crisis	22
	Managing falls after a health crisis	11

<sup>a</sup>SD: standard deviation.

<sup>b</sup>DSRS: Dementia Severity Rating Scale (Clark & Ewbank, 1996). 0–18: Mild 19–36: Moderate 37–54: Severe.

<sup>c</sup>The question for care partners was “Would you consider your general health to be...”. The options included: 1 poor, 2 fair, 3 good, and 4 very good. No participants reported “poor” for the self-rated health assessment question.

fell, he couldn't get up. He doesn't know how to get up. I tried to teach him; because of the memory problem it is very hard to teach.” Care partners also expressed concerns about injuring themselves while helping older people with dementia get up after falls.

*Self-sacrificing.* Falls among older people with dementia intensified the care partners' sense of responsibility for ensuring safety and worry over leaving care recipients alone. Concerns about falls led care partners to sacrifice their routines, self-care, social relationships, and careers. One daughter care partner (primary care partner, age 59) shared that she had to change to a part-time job after her mother had multiple falls due to seizures/stroke. Care partners reported how self-sacrificing behaviors impacted their mental and physical health, quality of life, and long-term well-being. One husband (primary care partner, age 63) shared how his wife's frequent falls and fall risk impacted his employment and his ability to care for himself:

There were days when I couldn't come in (to work) because she had fallen, and I had taken her to a clinic over there. Her clinic is about two blocks from me, but I have to go over (with her) or she'll fall...I didn't

**Table 2.** Care partners' lived experience of fall incidents and fall risks among older people with dementia.

Major theme	Sub-theme	Illustrative quotes
Challenges	Increased care demands	<p>"He (older people with dementia) won't, if he has a bowel movement then he'll just, he'll get up and stumble and fall into everything. I just make sure he lets me know, so I have to take him to the bathroom." (other relative, woman, primary care partner, age 59)</p> <p>"My wife told her that she'd fallen earlier that morning also. But she never told me. And her memory is so bad that I don't know, she could've maybe fallen a dozen times. Who knows?" (Husband, primary care partner, age 60)</p>
	Self-sacrificing	<p>There were days when I couldn't come in (to work) because [older people with dementia] had fallen and I had taken her to a clinic over there. Her clinic is about two blocks from me, but I have to go over or she'll fall... I didn't get the temp job at the end of 90 days because I was absent too many times which I knew I was. So, I've been unemployed and mainly just taking care of her. I have depression... and I have been drinking... I was supposed to have a doctor's appointment at the VA, but I keep putting that off (Husband, primary care partner, age 63).</p> <p>"[The doctor was] talking to me about it like it was something that was going to happen to my mom like she's a piece of meat, you know what I mean?" (daughter, primary care partner, age 59)</p>
Dissatisfaction with healthcare providers	Increased conflicts with older people with dementia	<p>"You know, she got up and started doing it (cook food) herself and almost fell, so I pushed her back in the chair and she kept trying to get up and I kept holding her down because I knew she was going to fall if she stood up. She called 911. Instead of paramedics, the police came and took me away." (Husband, primary care partner, age 63)</p>
	Intense emotions	<p>Fear and worry: "I don't sleep much. I was really freaked. I didn't know if her use of her right side would come back. If that's permanent, I don't know what I'm going to do (Husband, primary care partner, age 60)."</p> <p>Traumatic experiences: "I keep kicking myself for it for a long time after her hospitalization last year...it was the most frightening thing I have seen in a long time." (daughter, primary care partner, age 62)</p> <p>Physical exhaustion: "I was pretty overwhelmed and frustrated because you know, you can't think of everything. You got discharged and you are just like, okay, she's accepted she's going to go to a facility instead of home. Even then we pulled up, and she went, "what are we doing here? Why didn't we go home? What are you, leaving me here? What are you doing?" I mean there's so much you are dealing with minute by minute." (daughter, primary care partner, age 59)</p> <p>Anger: "Everything was taken care of. But her memory part started coming when she hit her head. When she fell, I was very upset because she took the medication change. She should've never taken that pill. 'Cause that- and so- and that's when she said she don't want to have the doctor." (Husband, primary care partner, age 84)</p>

(continued)



Table 2. (continued)

Major theme	Sub-theme	Illustrative quotes
Adaptations with dementia's falls	Cultivating acceptance of older people with dementia's falls	"I learned what I can from it and then we move on and then we try not to repeat the same things again or it's unfortunate that it happened but it's fortunate that it happened if that makes sense. I can hold both of those ideas in tension, you know. That dichotomy is okay for me." (Son, secondary care partner, age 52)
	Approaching falls as an opportunity	"Well I've finally had a chat with everybody about the safety issue and my deep-rooted feelings on the need for 24/7 care, and it's time." (daughter, primary care partner, age 59)
	Getting help from informal and formal care networks	Facilitating collaborations within informal care networks: "And embracing the tension between those things and knowing how to...use your network of folks who want to be helpful. And still set boundaries (other relative, primary care partner, age 48)."
	Collaborating with older people with dementia	Facilitating collaborations within formal care networks: "I asked one physical therapist, show me what you want me to do and I'll do it, I'm here all day." (Husband, primary care partner, age 60)
Modifying the physical environment	Collaborating with older people with dementia	"No one wants to get the phone call that your mom's on the floor, you know, could we have avoided that? But at the same time, she was so fiercely independent and her identity was that. We wanted to give that to her as long as she could take care of herself." (Son, secondary care partner, age 52)
	Modifying the physical environment	"(Alzheimer's Association) provide equipment, like shower holders, the fire department comes, they call the fire department, they come and put new shower head in, and put all stuff for equipment to prevent him from falling in the shower and all that stuff." (Son, primary care partner, age 58)

get the temp job at the end of 90 days because I was absent too many times, which I knew I was. So, I've been unemployed and mainly just taking care of her. I have depression... and I have been drinking... I was supposed to have a doctor's appointment myself, but I keep putting that off.

*Dissatisfaction with healthcare providers.* Care partners expressed dissatisfaction with the lack of help from healthcare providers in managing falls/fall risk. They reported receiving few instructions about what to do when discussing their fall-related concerns with clinicians. One husband (primary care partner, age 60) shared, "Her cognition was getting really bad before this fall. We went to our family doctor, and he just blew us off and said, you have a little cognitive memory loss, so what? ... I had to ask a friend who's a chiropractor, which was more helpful than our family doctor." Another care partner (primary care partner, age 63) said he was told by care providers that his wife's falls might be because of (undiagnosed) Parkinson's disease, but he received no information about how to pursue a diagnosis or how to understand her condition (dementia). He did not know "what's coming up," "how long she would have it," or "a plan to take care of her." Therefore, he experienced "stress that's been going on and on and on for years."

Care partners felt they did not receive enough support from physical therapists to provide rehabilitation and training for older people with dementia:

At home, they did home physical therapy and the physical therapist would come here. Mom doesn't cooperate and we say just do it anyway. And they like, they come like three times and then they're like well she won't cooperate so we're not coming anymore. And I am just like, that's why she needs you to come. (son, primary care partner, age 62)

Care partners reported challenges during emergency room visits, hospitalization, and care transitions after fall events. One wife (primary care partner, age 75) related: "I was expecting (the hospital) to maybe give me some social workers or some kind of help to talk about her (older people with dementia) fall and safety problem, you know, some advice or direction or something like this. And I did not get it."

*Increased conflicts with older people with dementia.* Falls in older people with dementia were often the stimulus for conflict when not recognizing their fall risk, they didn't pay attention to their care partner's safety reminders. One care partner (wife, primary care partner, aged 51) shared how she felt hurt by her husband's resistance: "I take the chair behind him and I say, you sit down. And he doesn't want to sit down, he doesn't want to trust me and he is afraid I will make him lie down, and I feel so sad because (he) always doesn't trust me and (he) always doesn't listen to me." Conflicts arose around using mobility devices, seeking help from healthcare providers, and making decisions related to a care transition: "He's gotten mad at me in the hospital when I have told people you know he lives in a two-story house. ... he thinks, 'this is my business and I'm getting up and down the stairs right now, we'll deal with it when I do fall down the stairs.'" (daughter, primary care partner, age 53) Some care partners reported physical confrontations (e.g., trying to prevent a fall by forcing older people with dementia to stay seated).

*Intense emotions.* Many care partners reported a range of intense emotions, including constant worry, fear, trauma symptoms (e.g., flashbacks), frustration, and anger as they worked through the challenges of dealing with the falls mentioned above.

Care partners expressed anxiety over future fall events. One participant (wife, primary care partner, age 76) expressed how constant worry about falls experienced by the person with dementia

for whom she was providing care threatened her ability to continue to provide care: “And sometimes I call my sister, I say, ‘Oh I worry so much.’ I can’t do it anymore because I worry too much...” Some care partners reported trauma related to previous fall events experienced by their care recipients and how they suffered from witnessing their loved one experience pain, severe trauma, and injuries, especially when falls were unexpected and when they were unable to provide help. The effects endured long after the fall event and caused lasting stress. One (husband, primary care partner, age 83) said, “She fell, ... I saw the fall. I can still see it in slow motion.”

Care partners expressed a constant preoccupation with making sure their care recipient did not fall and noted the toll this took on their own health. One participant (wife, primary care partner, aged 58) described:

I poured myself into being the best caregiver and doing everything and waking up in the middle of the night to make sure he didn’t fall, getting out of bed and not sleeping well myself. And I just overdid it. I overdid it. And that was hard on my health. Reigning that back in and finding a balance was hard.

Care partners expressed feelings of frustration and anger as they tried to manage fall risk for older people with dementia, often without any perceived help from the healthcare system. For example, one care partner (husband, primary care partner, age 60) was angry because of insufficient inpatient rehabilitation services to make discharge from the acute care setting possible after a fall:

They just gave us four different rehab places. I was getting really upset. I was like, why are we still here? You say she has got to be able to stand before you’ll discharge her but your therapy sucks here... we see one guy every three days for 10 minutes. She’s never going to get up to the point where she can be discharged by your rules.

Some care partners experienced anger when trying to manage the risky behaviors of older people with dementia and remain continuously vigilant: “I’m about to explode. I’d been doing dishes and stuff at night because I can’t do it during the day.... She can’t remember that she’s not supposed to get up and she tries to get up.” (husband, primary care partner, age 71)

### *Adaptations*

*Cultivating acceptance.* Some care partners developed a sense of acceptance that their care recipients might fall regardless of their best efforts to prevent it. One care partner (daughter, primary care partner, age 59) reflected on how she was able to make difficult care decisions because of this recognition:

These people, social work, PT (physical therapists), they’re going to say my mother can’t go home and not appreciate the fact that...there’s a degree of risk that I think she’s willing to accept and that as her daughter, out of loyalty and in spite of the fact that I’m a nurse, I’m willing to accept because that’s real life.

*Approaching falls as an opportunity.* Some care partners shared how they used fall incidents as an opportunity to leverage care that the older people with dementia may previously have resisted – for example, using a mobility aid, or moving to a new living situation. For example, one care partner (other relative, primary care partner, age 70) shared how she always knew that “only a medical emergency would let us intervene” as her sibling (older people with dementia) was very avoidant: “She doesn’t have children, she’s never married, she pushes away anybody who wants to be a friend,

avoids you if she doesn't want to deal with it." One care partner (daughter, primary care partner, age 47) related how she was able to "leverage the crisis" and view the fall event as "a gift in that we're trying to move her and we're trying to get her to accept this is her new place to sleep." Care partners described how these falls provided the impetus to schedule a comprehensive health assessment for older people with dementia.

*Getting help from informal and formal care networks.* Following fall risk identification or a fall in older people with dementia, care partners often sought help and support from friends and family and facilitated collaborations within informal and formal networks. Care partners found informal care networks were essential, especially after their care recipient fell. Some care partners reported that they could not lift their older people with dementia from the floor after they fell; they had to call for help from other family members and friends to send care recipients to the emergency department for care. Informal care networks provided important financial and material support to address care recipients' falls, especially regarding modifications of the physical environment.

Care partners also asked questions related to their care recipient's fall risk or fall-related care needs when working with health professionals such as physicians and physical therapists. They appreciated being asked for their input and included in care planning. One care partner (daughter, primary care partner, aged 62) explained how she collaborated with healthcare providers to come up with a safety plan for her care recipient:

OT [Occupational therapists], PT [physical therapists], and nurses came in and they assessed, but they didn't really think much about the commode piece or something. So- I was just in conversation with him too. One of the days with the OT, I was just saying 'I'm thinking of the commode. I'm just thinking about the safety of getting from A to B'. And they said that's a great idea. They said, why didn't we think of that?

Another care partner (son, secondary care partner, 52) shared how they appreciated a doctor's invitation to participate in the decision-making process about using medications that could increase fall risk: "I don't feel pressured by any medical professional at all when I am asked what I wanted to do. They've explained it all to me and then say, let's make a decision together."

Care partners looked to formal health and social care systems to support their caregiving after older people with dementia experienced falls, including utilizing the Family and Medical Leave Act, calling home health agencies, seeking advice and assistance on environmental modifications, and receiving training from therapists. Care partners utilizing these services described them as essential to enabling them to support their care recipients and tend to their own well-being.

*Collaborating with older people with dementia.* Care partners described their efforts to find a balance between maintaining autonomy and safety for older people with dementia via collaborating with older people with dementia and respecting their wishes. This balance had important meanings for care partners as they believed both autonomy and safety were essential to the quality of life of older people with dementia. One care partner (daughter, primary care partner, 53) described how she collaborated with her care recipient in managing fall risk: "(After [older people with dementia] fell several times in a row) we had a discussion the next day about his diet, and I just said, this is it, you know, it's either you choose, we're at this place where you either choose or you're just not going to be able to have a choice anymore." This discussion motivated older people with dementia to accept a healthy diet recommended by doctors and reduced the care partner's stress.

*Modifying the physical environment.* Care partners reported modifying the physical environment, including both the home and mobility aids, to help avoid falls, especially once a fall had occurred. Care partners mentioned that these efforts might reduce falls in older people with dementia and make it easier for them to provide care at home and take them out for activities or doctor visits and reduce their care burden and worry about falls. One care partner (son, primary care partner, age 58) reached out to a local community service organization after his dad fell, hoping to make the home environment safer: “[the community service organization] provided equipment, like shower holders; and then the fire department came and put new shower holders in, and put all the stuff to prevent him [older people with dementia] from falling.”

Another care partner discussed using mobility aids with older people with dementia and prepared their care recipients to use them: “We bought him a walker a long time ago and encouraged him to use it if he felt like he needed it but he never did. But he was always open-minded about using it. And then when the time comes, I have it.” (son, long-distance support care partner, age 61).

## Discussion

Our study explored dementia care partners’ experiences of fall risk and fall incidents that impact their care recipients and how they responded to the challenges they encountered. Prior studies have extensively shown the negative impact of older people with dementia’s unmet health needs on care partners, especially behavioral and psychological symptoms of dementia (Feast et al., 2016; Isik et al., 2019), pains (Regier et al., 2021), and medical comorbidities (diabetes and osteoporosis) (Polenick et al., 2020). Only a few studies described the negative impact of falls on dementia care partners (Kamiya et al., 2014; Leggett et al., 2018). Our findings add to this literature, emphasizing the complexity of the negative impacts of falls on care partners. Our study also highlighted the resilience of dementia care partners, as they reported different adaptive coping behaviors to overcome these challenges (Zhou, Ishado, et al., 2021). Overall, our results underscore the importance for healthcare providers and systems to view care partners not as “an assistant” that follows instructions to manage fall risk for older people with dementia. They are “second clients” – an at-risk population that is impacted by their care recipients’ falls, and “competent collaborators” – who can bring unique strengths and perspectives in fall risk management.

### *Challenges experienced by the “second clients”*

The study reveals some under-recognized negative impacts of falls among older people with dementia on their care partners. Falls pose challenges to care partners not only due to intensified care demands and intense emotions but also because of their self-sacrificing behaviors, dissatisfaction with healthcare providers, and increased conflicts when care recipients do not understand or agree with efforts to prevent or manage falls.

Care partners’ self-sacrificing behaviors demonstrate their commitment to caring but reveal that caring can be detrimental to their own physical and mental health (Tatangelo et al., 2018). Our study highlights that fall and fall risk in older people with dementia may increase the likelihood of self-sacrificing behaviors, which have negative impacts on care partner self-care behaviors, social relationships, and employment, adversely impacting their well-being and self-actualization and potentially exacerbate the financial difficulty associated with providing care (Liu et al., 2019). These findings help explain why older people with dementia falls are often especially challenging for care partners who are adult children (Reed et al., 2014). It also points out the hidden cost of care for

dementia care partners when they engage in fall risk management to ensure community-dwelling older people with dementia age in place safely.

Dissatisfaction with the healthcare system was a major theme that emerged from interviews with care partners. Our study highlights care partners' need for education and training to formulate a care plan to address their concerns about falls. Care partners also experienced a lack of support to prepare for the transition after hospital discharge, rehabilitation services to facilitate their care recipients' recovery, and social services to prevent recurrent falls after discharge. This finding reinforces previous research in the U.S. and other countries that found limited fall risk education for care partners of older people (Hoffman et al., 2019), challenges in acquiring post-fall care (Gettel et al., 2020), and particularly fragmented and unclear care pathways for older people with dementia who fall (Wheatley et al., 2019). In our study, care partners reported the challenges of interacting with service providers from different disciplines, whose efforts could be inconsistent and uncoordinated. These service provision gaps contribute to care partners' frustration and burden and represent missed opportunities to bolster care partners' engagement in fall risk management.

Previous studies show that balancing safety and independence is a major source of stress and a driver of disagreement and conflict between older people with dementia and their care partners (Meyer et al., 2022). Furthermore, there is growing evidence that caregiving relationship strain and conflict negatively impact the quality of care and, consequently, the health and well-being of both members of the dyad (Meyer et al., 2022). Our findings suggest that falls among older people with dementia trigger safety concerns that may impede their autonomy and thereby drive the conflict.

### *Unique strengths and perspectives of “collaborators”*

The current study found that, despite limited professional support, dementia care partners are insightful, engaged, and creative in addressing challenges associated with falls among older people with dementia. This approach aligns with the risk enablement model (Dickins et al., 2018), which posits the coexistence of risks and opportunities.

The practice of cultivating acceptance in the face of care recipients' falls is an example of adaptive behavior. The acceptance of some degree of fall risk may complement rather than undermine more action-oriented responses. Some care partners found that focusing on preventing falls was overwhelming and made it more difficult to sustain their capacity to care. Those who accepted that not all falls could be prevented reflected on the need to shift from labor-intensive fall prevention efforts and passive, mechanical means (e.g., restraints and limiting independence) to prioritizing the quality of life and the autonomy of people with dementia. This aligns with other research findings that advocate for the use of palliative approaches in dementia fall risk management (Casey et al., 2020). Our findings indicate that a palliative fall risk management could also benefit dementia care partners.

Furthermore, some care partners in our study not only accepted the reality of ongoing fall risk but were able to use the resulting higher care complexity and urgency to engage care recipients in fall prevention efforts and secure additional caregiving support (e.g., active engagement with informal and professional care partners, communicating with the older people to balance autonomy and safety, and modifying the physical environment). Previous studies have shown that care partners often adopt these behaviors to reduce fall risk for older people with dementia (Zhou et al., 2022; Zhou, Strayer, et al., 2021). Here, we find that these efforts are not only important for those with dementia but also supportive of care partners' well-being.

### *Limitations and strengths*

There are several limitations of the current study. First, the parent study used a convenience sample and was not designed to study falls. Recruitment was conducted within a healthcare system in a single urban area of the U.S. with English-speaking participants, thereby limiting the transferability of findings. Nevertheless, our sample was relatively heterogeneous, with 25% of participants of non-white race/ethnicity, care partners with varying caregiving relationship types and duration, and care recipients with a range of types and stages of dementia.

The study utilized a secondary analysis approach, as care partners' experiences of falls were not the focus of the parent study; therefore, data were limited to any information spontaneously reported by care partners. This study is likely to underestimate the number of participants who have experienced falls, the types of challenges care partners may encounter, and the strategies they adopt to overcome these strategies. Targeted research is warranted to validate and expand the study findings. Despite this limitation, the data were rich, illuminating key impacts of falls in older people with dementia on their care partners, and we used a bottom-up, inductive approach and an iterative process to conduct the secondary analysis. The long-term impact of falls among older people with dementia on care partners' health and well-being requires further study.

The research presented herein has several strengths. Little was known about the impacts of falls in older people with dementia on their care partners in the U.S. The current study utilized a qualitative study design to address this gap. Second, our study viewed care partners as experts and elicited their innovative approaches and unique strengths in managing falls in their care recipients. Furthermore, the fact that caregivers spontaneously recounted their fall experiences reinforces the salience of falls in the lives of care partners.

### *Implications*

Although preliminary, the current study speaks to important gaps in the research about care partners' experiences of fall incidents and fall risk among community-dwelling older people with dementia. This preliminary finding remains to be corroborated with additional studies. Secondary quantitative data analysis assessing mediating and moderating factors should be conducted to validate these identified experiences of challenges and adaptive behaviors. Primary data collection with a diverse sample to identify additional challenges and adaptive behaviors that may not have emerged here due to the limitations of secondary data analysis is warranted.

Our findings suggest several practice implications. First, this review demonstrates the need to increase public awareness about the negative impact of falls on dementia care partners. Second, if service providers become more aware of dementia care partners' stress associated with managing fall risk for their care recipients, they would be ready to forge a collaborative relationship with care partners in fall risk management. Older people with dementia, especially those at earlier stages, care partners, and other family members can be informed how falls are not only an individual challenge for those afflicted but also for the entire support system. Previous studies have found that older people with dementia are concerned about reducing the burden of their care partners (Peach et al., 2017; Suttanon et al., 2012). Knowing how falls may impact the care partner-care recipient dyad may motivate them to proactively make efforts in fall risk reduction and emergency preparation together.

Fall prevention programs should include intervention components that support care partners in mitigating the negative consequences of falls that directly impact them. With such support, care partners may be more likely to adopt fall prevention strategies, as care burden is one of the barriers for dementia care partners to initiate fall prevention efforts (Faes et al., 2010; Peach et al., 2017). For

example, interventions that help care partners address conflicts with older people with dementia about safety and autonomy should be developed and provided to care partners who face such challenges. For those who are overwhelmed by their extensive worry and fear, mindfulness-based strategies (Cousineau et al., 2019) can be utilized to develop care partners' non-judgmental awareness and acceptance of their present experiences of fall risk, reduce their psycho-emotional exhaustion, and enable them to take action to address realistic care goals that satisfy their practical needs. Community-based programs such as Powerful Tools for Caregivers (Kuhn et al., 2003) and the National Family Caregiver Support Program (Zebrak & Campione, 2021) (the latter available through Area Agencies on Aging) are important resources to support dementia care partners in their role and help them tend to their own well-being in the context of chronic caregiving. Service providers should be prepared and equipped to provide fall prevention information, advice, and education that is inclusive and feasible for people with dementia and their care partners.

Our findings highlight the importance of developing assessments and interventions that build upon care partners' existing efforts to overcome the challenges when managing falls for older people with dementia. For example, service providers should work with care partners to identify informal and formal support that can help manage fall risk. Because of their important insights, care partners should be engaged to co-design new multi-level interventions to facilitate collaborations among informal care networks, older people with dementia, and service providers.

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