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“Been there, done that:” A grounded theory of future caregiver preparedness in former caregivers of parents living with dementia

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Abstract

Background: Family caregivers offer essential support to persons living with dementia (PLWD). Providing care for more than one family member or close other across adulthood is becoming increasingly common, yet little is known about the ways that caregiving experiences shape caregiver preparedness. The current study presents a grounded theory of *future caregiver preparedness* in former caregivers of PLWD.

Method: A coding team (five coders and two auditors) used Consensual Qualitative Research and grounded theory techniques to analyze transcripts from 32 semi-structured interviews with midlife former caregivers of parents who died following advanced Alzheimer's disease and related dementias.

Results: Qualitative analysis revealed two dimensions of future caregiver preparedness: *caregiving confidence* and *caregiving insights*. Narratives from caregiving experiences informed participants' descriptions of their future caregiver preparedness. Though some former caregivers described a positive (i.e., *boosted* or *sustained*) sense of *caregiving confidence* following care for their parents, others described a diminished (i.e., *restricted* or *impeded*) sense of confidence. Regardless of their confidence, all caregivers described specific *caregiving insights* related to one or more categories (i.e., *caregiving self-conduct, care systems and resources*, and *relating with a care partner*).

Conclusions: Preparedness for future caregiving following recent care for a PLWD varies: For some, past experiences appear to offer cumulative advantages in anticipating future care roles, whereas for others, past experiences may contribute to apprehension towards, or rejection of, future care roles. Entering new caregiving roles with diminished confidence may have negative consequences for caregivers' and care partners' wellbeing. Multidimensional assessment of future caregiver preparedness in former caregivers of PLWD may support development of resources for former caregivers entering new caregiving roles.

KEYWORDS

Alzheimer's disease and related dementias, caregiving trajectories, narrative identity, qualitative research, self-efficacy

Key points

- Caregiving for a parent living with dementia (PLWD) provides scaffolding for caregiving for another loved one in the future.
- *Future caregiver preparedness* is defined by two distinct dimensions: *caregiving confidence* and *caregiving insights*
- Some former caregivers describe diminished ability to act as caregivers again after caring for a PLWD (i.e., *impeded confidence*)

Why does this paper matter?

As reliance on family caregivers grows, public policy and health promotion strategies must address cumulative impacts of multiple caregiving experiences across the adult lifespan.

Millions of family caregivers provide essential emotional, physical, and social care to persons living with dementia (PLWD). Given expanding need,[1,2] caregiving for PLWD is now described as a public health priority,[3] and dementia care organizations are calling for actions to ensure a capable workforce of family caregivers for PLWD is available.[4] A first step towards this goal is increasing attention to factors that promote *caregiver preparedness*.[5] Thus far, caregiver preparedness has been assessed primarily in terms of caregiver readiness to provide physical care, access supportive services, and problem solve in support of their care partner, defined for this study as the PLWD receiving care.[6] High caregiver preparedness acts as a protective factor against role strain,[7] promotes maintenance of mental health,[8,9] and predicts care partner quality of life,[10,11] including in populations caring for PLWD.[12] Caregivers often report modest levels of preparedness within care roles,[13,14] but preparedness appears to improve across a given care experience.[13,15,16] These trends imply that more time spent in caregiving roles offers a cumulative advantage, allowing caregivers to cultivate preparedness over time.

As family caregiving needs grow,[13,17–19] there is an increasing likelihood of serving as a caregiver to more than one close other across adulthood.[18] Evidence from a Canadian national sample suggests that, in many cases, trajectories of caregiving across adulthood involve providing care for more than one family member before age 65.[20] For example, an *intensive parent care* trajectory often begins in midlife with the care of a parent and is followed by care for one or more additional family members. Other, similar trajectories have been defined[2,20] (e.g., *serial caregiving*, overlapping care experiences across adulthood). Despite the growing likelihood of caring for more than one PLWD across adulthood, we know little about how previous caregiving experiences promote preparedness for future caregiving, and extant research does not account for the ways that negative consequences from former caregiving experiences (e.g., burden, isolation) persist into new care roles.

This study addresses this gap by developing a novel theory of *future caregiver preparedness*, grounded qualitatively in the lived experiences of former caregivers of PLWD. This topic has thus far received little attention, so an inductive, qualitative approach is ideal. This study addresses the growing population of midlife adults who formerly provided care to a parent who died following advanced Alzheimer's disease or dementia, and who anticipate additional care roles across adulthood. We also focused on midlife because a sense of obligation toward the care needs of family members tends to peak in midlife as individuals recognize the escalating care needs of close others.[21]

METHODS

Participants

This study was approved by the lead author's Institutional Review Board. We recruited participants through national caregiving support networks (e.g., CareManity, Caregiver Action Network, Alzheimer's Association), research recruitment services (e.g., ResearchMatch), and social media (e.g., Reddit) between October 2021 and February 2022. Flyers and study information were sent out through each of these platforms. Eligible participants were U.S. citizens ages 40–65 years who had acted as the primary family caregiver for a parent with advanced Alzheimer's disease or dementia who died between 3 months and 3 years prior. As male caregivers are underrepresented in research, we purposely sampled for a relatively equal distribution of male- and female-identifying participants. Eligibility was determined through a brief Qualtrics screening survey or over the phone. Participants were excluded if they did not meet the above criteria, or if they neither identified as a primary caregiver for their parent nor participated in activities to support their parent's daily living. Some individuals were assigned an identification number but did not participate due to: (1) personal time constraints ($n = 5$), halt on the inclusion of female participants ($n = 4$), or for undisclosed reasons ($n = 9$). Participants were compensated with $25 gift cards.

Data collection method and procedure

Method and results followed the Consolidated criteria for Reporting Qualitative research (COREQ).[22] To structure data collection and analysis, we used Consensual Qualitative Research[23] (CQR) and grounded theory,[24] two techniques with conceptual and pragmatic overlap that both emphasize iterative cycling through data to develop rich themes. CQR is considered an ideal technique for exploring relatively understudied areas and for providing descriptive findings.[23] Grounded theory techniques were incorporated to ensure that inductive findings resulted in a meaningful, accurate, and novel theory that has direct application to real-world public health priorities.[25] A three-section semi-structured interview guided participants through describing: (1) Their caregiving experience, from the PLWD's early signs of Alzheimer's disease or dementia through their death; (2) specific high- and low-point memories from their caregiving experiences;[26] and (3) the ways caregiving experiences shaped beliefs and behaviors, including their future caregiver preparedness. All participants were given the interview guide prior to the study session so they could review the questions and prepare responses.

First, the interview guide was pilot tested with three female midlife former caregivers of PLWD, who suggested small changes to pacing and wording. Once the interview guide was established, participant recruitment began. Eligible participants (i.e., those who completed the screener and met inclusion criteria) were scheduled for a one-time virtual interview with the first author, who has qualitative interviewing experience.

Before the qualitative interview, participants provided some basic information about themselves (e.g., age, gender identification, race) and responded to a brief set of questions about their caregiving experiences. Namely, participants described their satisfaction with their relationship with their care partner through a single-item measure adopted from the Kansas Marital Satisfaction Scale[27] (*how satisfied were you with your relationship with your parent*?) and a Likert scale (1 = *extremely dissatisfied*, 7 = *extremely satisfied*). Participants also described any family members, friends, or others they expected to be caregivers for in the future. The interviewer recorded all information using a Qualtrics survey form, and then began the interview.

On average, study sessions lasted 92 min ($SD = 25.30$). At the end of each interview, participants were given time to ask any questions about the study topic or the research team's interests, as well as share anything salient but not prompted by interview questions. The audio recordings were transcribed using a professional transcription service and checked by the first author. Transcriptions were managed using Nvivo software. On average, participants spoke 6812 words during the interview ($SD = 3216$).

Data analysis

Research team

CQR guidelines recommend having a large and diverse team of coders[23] as well as one or more auditor(s), who work with the data independent of the coding team to monitor the analysis process, combat confirmation bias, and improve data trustworthiness.[23] Our research team included five members conducting qualitative analysis, two auditors, and three senior researchers who guided study design. The seven members who had direct contact with the data provided positionality statements to enhance the trustworthiness of their findings (see Data S1). CQR emphasizes consensus among coders; as such, the entire coding process was conducted consensually, with decisions about the pacing, shaping of the findings, and naming and defining of domains and categories (described below) mutually agreed upon.

Analytic procedure

CQR guidelines recommend that transitions from data collection to analysis are not prompted by evaluation of data saturation, but rather by reaching a target sample size (typically within 13–19 participants per subgroup; in

TABLE 1 Participant demographic information

Characteristic	Mean (SD) range/*N* (%)
Participant mean age	56.90 (6.06) 40–65
Participant gender	
Male	14 (43.80)
Female	17 (53.10)
Non-binary	1 (3.10)
Parent mean age at death	84.09 (7.02)
Parent gender no.	
Male	9 (28.1)
Female	22 (68.8)
Mean time since parent's death, in months	15.25 (12.40) 3–36
Mean length of care for parent, in months	84.90 (56.00) 2–216
Relationship satisfaction with parent	5.88 (1.29) 2–7
Participant race	
White/Caucasian	28 (87.50)
Asian	1 (3.10)
Black/African American	2 (6.3)
Other	1 (3.10)
Participant ethnicity	
Hispanic/latinx	3 (9.4)
Non-hispanic/latinx	29 (90.60)
Participant marital status	
Single, never married	11 (34.40)
Married	19 (59.4)
Widowed	1 (3.10)
Divorced	1 (3.10)
Participant completed education	
High school diploma/GED	6 (18.80)
AA/ AS (2-year college)	5 (15.60)
BA/ BS (4-year college)	11 (34.40)
Master's degree or equivalent	7 (21.90)
Doctorate degree or equivalent	3 (9.40)
Participant employment status	
Employed full time	16 (50.00)
Employed part time	5 (15.60)
Retired	7 (21.90)
Unemployed	3 (9.40)
Self-employed	1 (3.10)

Note: Participants self-reported their relationship satisfaction with parent using a Likert scale where 1 = *extremely dissatisfied* and 7 = *extremely satisfied*.

this case, subgroups were based on purposive sampling for male and female caregivers).[23] When the target sample was reached, the coding team engaged in training and met weekly to perform analysis.[23] The analysis process first involved the analysis of whole transcripts to develop domains and subdomains (i.e., broad subject areas) across transcripts. Coders created new domains or revised existing domains until consensus was reached. Once the list of domains was established, defined, and audited, all transcripts were reviewed again and parsed into these domains. Coders then created a concise list of core ideas (i.e., short, clear summaries of participants' statements) for cross analysis. During cross analysis, all core ideas related to a given domain across transcripts were reviewed together for common themes.[23] These themes were sorted into categories (i.e., specific subject areas representing thematic patterns) that nested inside domains and were again reviewed by the auditors. Transcripts were then re-explored so that links between past caregiving experiences and future caregiver preparedness were described to enrich the final results. We maintained rigor throughout the analysis process by, for example, using multiple quotes in codebooks to ground the theory in lived experiences[28] and saving memos in transcripts to support theory-building.

RESULTS

The sample comprised 32 midlife former caregivers of PLWD who participated from 19 U.S. states and territories. Purposive sampling resulted in a sample of one non-binary, 19 female, and 14 male participants. The majority (71.88%) nominated at least one close other that they expected to care for in the future, often another parent, spouse, or sibling. See Table 1 for sample characteristics.

We found that future caregiver preparedness in midlife former caregivers of PLWD consists of both confidence in one's abilities as a caregiver (Subdomain 1: *caregiving confidence*; see Table 2) and skills, knowledge, or meaningful takeaways for engaging in caregiving (Subdomain 2: *caregiving insights*; see Table 3). Additional analysis of the relationship between lived experiences and subdomains of *future caregiver preparedness* revealed that preparedness across these subdomains was guided by participants' subjective interpretations (i.e., personal narratives) of their caregiving experiences. See Figure 1 for a presentation of this grounded theoretical framework.

TABLE 2 Caregiving confidence categories and illustrative participant quotations

Category	Exemplar quotation
Sustained confidence	*Participant 6*: Because my dad at this point thought I was some lady, I went into patient mode, like, "This is a patient. I'm a nurse. I'm his daughter, and I'm gonna give him the best care that I can give." I was able to compartmentalize a little bit differently than my sister.... I think what *[caring for my dad]* showed me was that, even though I do not practice at the bedside anymore, that's still something that is at the core of who I am and what I do... the hands-on things that I had to do came right back to me.
Boosted confidence	*Participant 32*: To see my mom happy in the facility was very rewarding and satisfying. I knew I made the right decision. I never walked in and she was sitting in a corner drooling in a wheelchair. I think the main thing was once you make the decision to put them in a place and it works out, then you feel good about that, and you feel like she's safe.... Had I never put my mom into a facility, I would always have that same stigma of, "I cannot put anybody in a facility." You learn a lot about the medical field, how doctors think, and what your family is saying. If I had to take care of somebody else, I would absolutely do it. I do not want somebody else to do it. I wanna do it. I wanna make the decisions.
Restricted confidence	*Participant 14*: I had to inject *[my mom's]* medication so she would not get clots because she had to stay in bed. If she felt pain, I felt so bad. I was so scared of putting those shots in her, but they expected me to do it. I think that's one of the hardest things I had to do. I was so scared that I would hurt her. Oh, my God. What if I do something wrong? It was scary. It was hard.... I definitely did learn some things. I *[also got]* very depressed. I know I would be a good caregiver because I learned a lot. If I have to do it, would I do it? Probably I would say yes because *[that's]* the kind of person I am. *[But]* God, I really do not wanna have to go through that again emotionally.
Impeded confidence	*Participant 9*: I told *[my siblings]* I needed a stipend of $600 a week because that was what my take-home pay used to be. I needed it, and it took 8 months for them to ever send me anything. They never visited... I wanted to get *[my father]* into an adult activity program. Unfortunately, my sister did not sign off on that. It took her 6 months. If I could've got him there when I wanted to get him there, it would've done so much for him.... Here it is: you cannot do it repeatedly because there's no support. I must not have the correct skills to be able to enlist the support I need because I have asked for help, and I did not get any help. I do not know how to do that. When people tell you no when you feel very vulnerable, it basically changes your biology. I'm burnt out right now. You do not get to see all of me because I'm burnt out.

Note: Participant exemplar quotations are presented in two parts. The first part presents salient descriptions of narratives from their care for their parent living with dementia. The second part describes their views on their *caregiving confidence*.

Subdomain 1: Caregiving confidence

This subdomain describes former caregivers' willingness and perceived ability to engage in caregiving for family, friends, or others in the future. The first two of four *caregiving confidence* categories detail strong, positive senses of confidence. The first, *sustained confidence*, was described by participants who had extended histories in care roles (e.g., experience in caring professions) and felt their confidence as a caregiver was reinforced, but not necessarily enhanced, by their experiences providing care for a PLWD. The second category, *boosted confidence*, describes those who felt increasingly capable as caregivers following their experiences providing care to a PLWD. In this case, participants explained that they will be better able to act as caregivers in the future *because* of their recent caregiving experiences, which could not be replicated through other sources of preparation (e.g., educational resources, anecdotes from others). Though they often referred to caring for a PLWD as a process of trial and error, participants with *boosted confidence* described that having gone through the process with a PLWD primarily gave them self-assurance. Importantly, those with *boosted confidence* describe enthusiasm or fervor for future caregiving, recognizing how rewarding "successful" caregiving experiences can be.

The remaining two categories describe weaker or diminished confidence connected to distress, shame, or frustration, experienced in caring for a PLWD. The category of *restricted confidence* describes participants' feelings they could adequately care for a close other, but only under certain circumstances, or as a last resort. These participants describe a reluctant willingness to be caregivers again if needed; for example, some described only taking on a caregiving role if the care partner's symptoms are manageable. They recall care experiences as primarily emotionally or physically draining. Finally, some participants described *impeded confidence*, where past caregiving was considered so depleting or damaging that participants felt wholly unable to provide future care. When describing their former care for a PLWD, these

TABLE 3 Caregiving insights categories and illustrative participant quotations

Category	Exemplar quotation
Caregiving self-conduct	*Participant 46*: I was struggling with realizing *[that]* my mother was going in a direction of not going to be here in five, 10 years. I wasn't married. I had no kids. I was in a really bad place. I never did a drug in my life, and I became addicted for a good year, and my life fell apart, trying to take care of her at the same time. That's the way I dealt with it until I could not. And then I had a breakdown and went to a mental hospital. It's so hard when you are acting as a caregiver because you are like, "I'm the one that needs to support. I do not need to be supported." But you do… I would talk about it a lot more. I finally feel like I'm understanding how to deal with my feelings… How do you deal with it without talking about it or facing it? I would know that I would need to not only discuss it in a therapy setting-- It could be a group setting, also, but to reach out and not be so afraid to discuss it.
Care system and resources	*Participant 7*: When home health was coming in, they helped put together his advance directive *[and]* he did assign me as his surrogate. He had put his paperwork in place, but *[my siblings]* were not happy with it. They did not like that he had chosen me to be his spokesperson. Neither one of us anticipated that they would go through the legal procedures to challenge it—Unfortunately, my dad and I did not think to put some reserves in place *[for]* if I needed a lawyer to protect what he had established. I was not prepared. I was caught totally off guard…. What I learn from it is, once you put those directives in place, you have to have somethin' in place to protect it… Going with the confidence of having the right legal means in place to ensure that I could do what I need to do… That was the mistake because I did not know any better when we were doing this back in 2010. Now, I know better. If I'm goin' to go into a situation like that, then I would have to make sure that I have the authorities that I need to do what I need to do.
Relating with Care partner	*Participant 43*: My mom, I'd make her this glorious dinner. I'd bring her to the table. I'd give her a glass of water with a straw. She'd start picking around. Then, she'd take her glass of water and pour it on top of the food and start sucking up the water with her straw. When she first started doing that, I thought, "oh, no, Mom." My first reaction was to correct her. Then, I just took a deep breath, and I let it go. My mom wasn't gonna hurt herself or hurt anyone else…. I learned a tremendous lesson doing this. It was related to patience. My whole purpose here was to keep *[my mom]* safe and happy. Those became my two goals. Safe and happy. As long as she wasn't potentially getting hurt, Who cares?

Note: Participant exemplar quotations are presented in two parts. The first part presents salient descriptions of narratives from their care for their parent living with dementia. The second part describes their views on their *caregiving insights*.

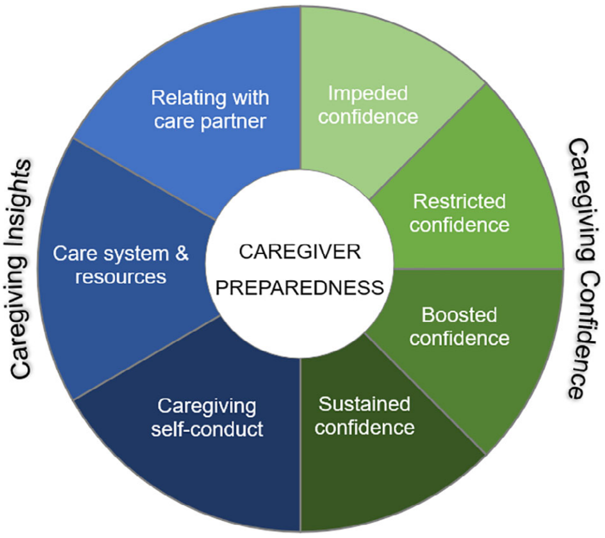

FIGURE 1 Depiction of grounded theory of future caregiver preparedness in former caregivers of persons living with dementia

participants were ruminative, focusing on frustration, alienation, or self-doubt. They explained that their past experiences caused them to question whether they were, or ever could be, adequate caregivers.

Subdomain 2: Caregiving insights

Every participant (i.e., regardless of their *caregiving confidence*) described skills, knowledge, or takeaways that they felt were essential lessons learned or wisdom gained from caring for a PLWD. The ability to identify *insights* regardless of description of *confidence* illustrates that these are distinct axes of future caregiver preparedness; a former caregiver can feel they have learned lessons without being more confident that they will be an adept caregiver in the future. For example, Participant 29 reflected, "I think I have more tools in my arsenal to try to do things if I had to, but I don't think I have any level of certainty that I would be able to deal with it any better." Three categories of lessons were observed.

The first category describes *caregiving self-conduct*, in other words, expectations and beliefs related to oneself in a caregiving role. This category involved self-compassion, self-care, and advocating for oneself. This category also involved adopting coping strategies (e.g., humor, gratitude) and being realistic rather than hoping for ideal care outcomes. The second category describes lessons about *care systems and resources*, in other words, possessing financial, legal, medical, and logistical knowledge from past experiences that promote navigation of future caregiving circumstances. These included tapping into Alzheimer's organizations to discover more about Alzheimer's or related dementias, learning about essential legal or medical activities (e.g., advance care planning, sharing access to financial accounts), and deciding if, when, and how to involve care institutions or supportive services (e.g., skilled nursing, hospice). The final category, *relating with a care partner*, encompasses interpersonal behaviors, including prioritizing the care partner's dignity and autonomy and understanding how to honor their medical preferences despite their limited communication at end-of-life. This also involves understanding how to behave when a care partner is unintentionally cruel (e.g., the importance of forgiveness, separating the person from their disease).

The role of past experiences in future caregiver preparedness

Analysis demonstrated *caregiving confidence* and *caregiving insights* were guided by participants' personal narratives of their past caregiving experiences. Objective details (e.g., experiencing aggression from a parent, having a sibling who could provide support), subjective interpretations of those details (e.g., why the aggression happened, how equally the sibling was contributing to care), and emphasis or de-emphasis of details (i.e., focused rumination on parents' aggressive behavior versus conscious efforts to avoid thinking about the aggression) all shaped narratives that guided *future caregiver preparedness*.

As one example, caregivers who faced comparable challenges while caring for their parents appraised their responses to these challenges differently, leading to more positive or negative views of their *caregiving confidence*. Often, caregivers differed in appraising past mistakes as growth opportunities versus considering them to be enduring points of failure. Participants 11 and 35 both described pushing themselves past their own limits in their care for their parents. Participant 11 described learning from this and maintaining *boosted confidence* and emphasizing *caregiving self-conduct*: “Here's my line: as long as there's somebody there who can help you. I have knowledge, and I know *[what]* limitations I have. I'm better prepared.” In contrast, Participant 35 described lingering feelings of failure that promoted his *impeded confidence*: “That was a mistake I made, not figuring out to get more help. I regret that I didn't. ‘You wanna be a caregiver?’ No. That is something I am not doing *[in the future]*. I can't emotionally handle it.”

While a history of formal care experience (i.e., a career in a caring role) often motivated *sustained confidence*, not all individuals with histories in care roles expressed *sustained confidence*. Participant 26 and Participant 12 both worked as nurses prior to or in tandem with their caregiving experiences. Both considered their abilities in relation to specific care tasks when appraising their confidence. Differing comfort with specific tasks, for example, bathing and toileting, supported diverging appraisals of confidence. Participant 26 described having *restricted confidence*: “It definitely *[made me]* question my confidence. I'd have no problem takin' patients *[to the bathroom]* at work but when it was my own mom and dad.... I wish maybe one of the ladies would have done it and not me.” In contrast, Participant 12 described *sustained confidence*: “I was pretty confident knowing that I could be a caregiver. All parts of it, you know, the toileting, the feeding, bathing, the dressing, no problem with all that.”

Emphasis of specific *caregiving insights* was also influenced by the ways caregiving experiences were narrated. Although participants described many different elements of caring for their parents, they often focused on one or two aspects of their care role that shaped their *insights*. For example, Participants 30 and 32 both discussed *care systems and resources*. Their narratives prompted diverging reflections on navigating care systems and incorporating resources, specifically on the benefits of institutional care. Because of his interpretation of his mother's care, Participant 30 saw institutional care as inferior to home care and insisted he would secure home care for future care recipients. He described, “My mother spent a great deal of money, and in my opinion didn't get personalized care... *[care staff are]* barely trained, barely speak English, and hide when nighttime comes. That's completely different than having somebody at your house... they're there for you.” In contrast, Participant 32 (quoted in Table 2) recalls that his mother was happy, safe, and protected in a care institution at end-of-life, and describes that these memories favorably changed his impression of institutional care going forward.

DISCUSSION

The current study establishes that future caregiver preparedness in midlife former caregivers of PLWD is defined by distinct dimensions: *caregiving confidence* and *caregiving insights*. In some circumstances, former caregivers express a sense of *boosted* or *sustained confidence*, feeling both willing and able to serve as caregivers again as needs arise. They also retain useful *caregiving insights* (i.e., categories of *caregiving self-conduct, care systems and resources*, and r*elating with a care partner*). In contrast, *restricted* or *impeded confidence* may threaten successful navigation of future caregiving roles, even if insights are attained. Though caregivers often experience similar tasks and challenges, results suggest they interpret these experiences in diverging ways, forming personal narratives of their care experiences. Narratives from caregiving guided future caregiver preparedness: former caregivers' interpretations of experiences, and emphasis or de-emphasis of details in narratives, influenced their appraisal of their *confidence* and their perspectives on *insights*.

Findings are relevant to current structures of formal and family care for PLWD. Estimates suggest that family caregivers provided over 270 billion dollars of care in 2021 alone.[29] Care from family members is essential to ensuring that PLWD can continue to live at home or in independent living settings for as long as possible, saving costs and minimizing burdensome transfers between care settings.[30,31] Our results suggest that subgroups of former caregivers of PLWD (i.e., described by *restricted* or *impeded confidence*) experience psychological depletion and self-doubt that jeopardize preparedness. In these cases, narratives from caregiving act as threats to future caregiver preparedness rather than bolstering preparedness. Caregivers' underpreparedness[14] can have negative consequences for care recipients and care systems; for example, caregivers' fear of incompetence and an unanticipated care burden predict earlier institutionalization of care partners.[32] As we continue to rely on family caregivers to meet the needs of PLWD, often in home settings, we must seek ways to mitigate the impact of harmful narratives from former care roles.

Our findings provide guidance for measuring future caregiver preparedness in dementia-care contexts to address associations with key variables (e.g., institutionalization of care partners). Available measures of caregiver preparedness are designed to garner retrospective or in-the-moment self-appraisals. Findings highlight the utility of measuring caregiver preparedness prior to or at the start of care experiences. Identifying caregivers with low preparedness prior to care experiences may allow for early intervention to minimize caregiver burden and maximize care partner quality of life. Further, findings support the development of novel, dementia-specific measures of caregiver preparedness. The dimensions of *caregiving confidence* and *caregiving insights* found in the current study overlap with the theorized pathways of goal-attainment thinking,[33] specifically *agency* thinking (akin to *caregiving confidence*) and *pathways* thinking (akin to *caregiving insights*), which are operationalized as independent self-report subscales.[34] Caregiver preparedness is currently measured using one unidimensional scale[6] that assesses broad skill-based abilities not tailored to dementia care. Novel, multidimensional measures should be developed to capture how *confidence* and *insights* individually and collectively influence dementia care outcomes.

Deficits in skill-based caregiving abilities may be best addressed through skill-based interventions.[35–37] Available skills-based interventions to support caregiver preparedness may not, however, address *restricted* or *impeded confidence*, as these forms of *caregiving confidence* were seen even in caregivers who could identify skill-based insights for addressing care partners' needs. We advocate for the development of interventions that target caregivers who experience *restricted* or *impeded confidence* derived from harmful narratives from past caregiving. Because narratives are malleable and caregivers seek opportunities to make meaning of their experiences,[38,39] narrative interventions[40,41] may be one effective option for reinforcing adaptive self-qualities that support future caregiver preparedness.

LIMITATIONS

This is the first study to our knowledge to examine future caregiver preparedness in midlife former caregivers of PLWD. Though we expect that findings from this work may be relevant in other populations (e.g., former caregivers of persons with cancer, young- and older-adult caregivers), further research is needed to substantiate that assumption. In addition, contextual factors (e.g., caregivers' access to resources, relationship dynamics between the caregiver, care partner, other family or friends, and clinicians) are impactful to caregiving experiences[42,43] and are likely to play major roles in the ways former caregivers develop narratives and evaluate their future caregiver preparedness. The current study did not explore these possible associations directly. The interplay between contextual factors, caregiver narratives, and future caregiver preparedness should be examined in future research.

Participants in this sample were predominantly White and U.S.-natives. This theory should be explored further in samples that prioritize other racial, ethnic, or nationality backgrounds, as family caregiving structures, burdens, and self-appraisals can vary across racial, ethnic, and immigrant-status groups.[44–46] While this study establishes that caregiving experiences are subjectively narrated and used to guide future caregiver preparedness, the study was not designed to delineate the mechanisms of this process. Relationship between caregiving narratives and future caregiver preparedness should be examined quantitatively to further support the theory developed in this study.

CONCLUSION

The millions of Americans who provide family care each year to PLWD carry meaningful narratives from caregiving with them through later life. Pervasive societal beliefs (e.g., *what does not kill you makes you stronger*) assert that caregivers necessarily benefit from recalling caregiving narratives to bolster caregiver preparedness. This study offers support for the notion that, in many cases, past caregiving experiences can offer strength and guidance as new caregiving needs arise. It also, however, highlights the variability in future caregiver preparedness and the likelihood that a proportion of former caregivers will be vulnerable to diminished confidence or fixation on unhelpful insights from past experiences. As reliance on family caregivers grows, resources to assist family caregivers should include strategies to support those whose caregiver preparedness is threatened by negative narratives from past caregiving.

AUTHOR CONTRIBUTIONS

Emily L. Mroz led study design, attainment of research funds, recruitment, data collection, data management and analysis, and manuscript writing. Amanda Piechota, Talha Ali, Tara D. Matta-Singh, and Anissa Abboud contributed to data analysis. Shubam Sharma contributed as an auditor for the data analysis process. Marney A. White, Terri R. Fried, and Joan K. Monin guided study design and conceptual framing. All authors contributed to manuscript writing and editing. All authors approved the final version of the manuscript before submission.

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CONFLICT OF INTEREST

The authors have no conflicts of interest to disclose.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

Data S1. Qualitative Analysis Team: Positionality and Reflexivity Statements.

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