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ORIGINAL RESEARCH

Evaluating Elements of the Care Partner Experience in Individuals Who Care for People with Alzheimer's Disease Across the Severity Spectrum

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ABSTRACT

Introduction: Non-professional care partners play an important and often evolving role in the care of persons living with Alzheimer's disease (PLWAD). We investigated two elements of the care partner experience, namely time and strain incurred by care partners providing care to PLWAD across the severity spectrum.

Methods: Data gathered from the Alzheimer's Disease Patient and Caregiver Engagement (AD PACE) What Matters Most (WMM) study series were analyzed to determine how much time care partners spent providing care to PLWAD based on where the care recipients lived. Additionally, quantitative assessments of weekly hours providing care and the strain experienced by care partners were conducted using the UsAgainstAlzheimer's A-LIST Insights Series survey, which included the Modified Caregiver Strain Index (MCSI). Finally, a targeted literature review was conducted to contextualize findings and characterize the existing literature landscape.

Results: Care partners in the AD PACE WMM studies ($n = 139$) spent significantly more hours providing care for recipients who lived with someone (mean ± standard deviation [SD], 57.3 ± 44.3 h/week) than for recipients who lived alone (26.0 ± 12.0 h/week) ($P = 0.0096$) or lived in assisted living/nursing home (23.6 ± 14.4 h/week) ($P = 0.0002$). In the A-LIST Insights Series survey, care partners provided an overall mean (± SD) 58.1 ± 53.0 h of direct care each week, with caregiving hours increasing with increasing severity of AD/AD-related dementias (AD/ADRD). Additionally, care partners for recipients with mild ($n = 14$), moderate ($n = 111$), and severe AD/ADRD ($n = 91$) had overall mean MCSI scores of 9.0 ± 3.8 (range 2–14), 13.3 ± 4.8 (range 4–23), and 17.5 ± 5.3 (range 4–26), respectively, with higher scores suggesting greater care partner strain.

Conclusions: Persons living with AD require increasing levels of care along the spectrum of disease, and even individuals with early disease need care from partners. Early interventions that slow progression of AD and programs that improve family function may have beneficial

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impact on the experiences of care partners for recipients with mild, moderate, or severe AD.

Keywords: Alzheimer's disease; Care partner; Caregiving; Experience; Hours; Mild; Moderate; Severe; Time

Key Summary Points

Why carry out this study?

A better understanding of the evolving role of non-professional care partners for persons living with Alzheimer's disease (PLWAD) is needed from the care partner perspective.

The impact on non-professional care partners' time and overall strain across the AD severity spectrum has not been adequately studied.

What was learned from this study?

Non-professional care partners of people with AD reported experiencing significant strain across multiple areas of daily living while providing a substantial amount of care each week. Care partners provided the greatest amount of care each week for PLWAD living with spouses or children, although these care partners did not necessarily live with their care recipients.

Early interventions that slow progression of AD and programs designed to improve family function may have beneficial impact on the experiences of care partners of recipients with mild, moderate, or severe AD.

INTRODUCTION

An estimated 6.5 million Americans aged ≥ 65 years were living with Alzheimer's disease (AD) in 2022, with a projected 11% increase to 7.2 million Americans by 2025 [1]. Notably, AD evolves along a severity spectrum from asymptomatic through severe AD, with a greater severity level corresponding to an increasingly impaired clinical state [2]. Given the potential for asymptomatic disease states and, until very recently, the lack of effective marketed therapies, early phases of disease may be underdiagnosed [1, 3]. Early-stage symptomatic disease, such as mild cognitive impairment (MCI) or mild AD, is most often characterized by changes in cognitive and behavioral domains that may manifest as short-term memory impairment, alterations in mood, increased anxiety or depression, apathy, and impacts to sleep [4, 5]. Middle-stage or moderate AD is marked by increased disorientation of time or place, as well as by a decreased ability to perform basic activities of daily living [1, 6]. Signs of late-stage or severe AD include dyspraxia, agitation, social withdrawal, wandering, psychosis, incontinence, and need for continuous care [5]. However, overlap can exist in observed signs or symptoms of this spectrum condition, especially during transitions between AD severity levels.

As the proportion of Americans aged ≥ 65 years increases over the coming decades, there will be a greater need for non-professional (e.g., family, friends) caregiving [1]. Primarily, such care partners [7] consist of spouses and children, in addition to other relatives, friends, and neighbors, who provide care to persons living with AD (PLWAD) in homes and residential long-term care facilities [8]. These care partners may help recipients in instrumental activities of daily living (e.g., transportation, financial management, communication), aid in basic activities of daily living (e.g., mobility, feeding, dressing), and provide emotional support [9]. The roles of care partners frequently change and evolve over time in response to the increasing severity of AD and changes in the needs of care recipients [10].

Non-professional care partners may be affected by both positive and negative experiences in their roles. Positive experiences are sometimes associated with care partners having supportive relationships with families and friends [11]. Negative experiences of non-professional care partners may include financial strain, job performance challenges, sacrifice of time, social isolation, harmful physical health outcomes, and emotional burdens [11, 12]. Notably, non-professional care partners of recipients with greater severity of AD have reported increased feelings of loneliness and an inability to physically provide required care [8]. These humanistic and financial impacts on care partners can greatly affect care recipients, as care partners who feel isolated or overwhelmed are more likely to seek institutional care for their recipient [12]. The socioeconomic impact and value of non-professional caregiving can be challenging to calculate due to the complex nature of AD and lack of sufficient real world data [13]. The time of multiple non-professional care partners, work absenteeism and presenteeism, reduced time for social activities, worsening health of care partners, and the value of care or supervision provided to recipients during daily activities of living all should be factored into assessing the socioeconomic impact [9, 14].

We have conducted an ongoing series of What Matters Most (WMM) studies [15–17] to better understand what is important to PLWAD and their care partners. Post hoc analysis of data from WMM studies can be used to explore how much time care partners spend providing care based on the living location and severity level of care recipients with AD. This area of research addresses an important gap since much of the current literature landscape focuses on impacts to care partners based on a narrow range of AD severity levels and not on levels that span the entire AD severity spectrum. Furthermore, data from an UsAgainstAlzheimer's A-LIST Insights Series survey can also be used to evaluate social, financial, employment, physical, and time strain incurred by care partners while providing care to recipients. The A-LIST Insights Series study is an ongoing study that distributes surveys on an approximately monthly basis to a cohort of more than 10,000 individuals.

Here we present a compilation of evidence from WMM mixed methods research studies and an A-LIST Insights Series survey that investigated the time and strain incurred by care partners providing care to PLWAD across the severity spectrum. We also conducted a targeted literature review of the current literature landscape to better contextualize the time and strain incurred by care partners from these research findings.

METHODS

Study Design

The evidence presented here about the time and strain incurred by care partners providing care to PLWAD across the severity spectrum was compiled from research conducted by a collaboration of organizations and individuals and has three components. The first component included a targeted review conducted to understand and characterize the existing literature landscape in order to contextualize the findings of the second and third components. The second component involved understanding the time care partners spend providing care to PLWAD, by conducting post hoc analyses on data gathered as part of the published phase 1 [15] and phase 2 [16] of AD PACE's WMM studies. The third component used an UsAgainstAlzheimer's A-LIST Insights Series survey (clinicaltrials.gov: NCT04466722), which included the Modified Caregiver Strain Index (MCSI), to conduct a quantitative assessment of the strain experienced by care partners. The A-LIST Insights Series survey also collected weekly data on the direct care hours provided by care partners.

Due to the differences in data collection methods between the AD PACE WMM studies and the A-LIST Insights Series survey, estimates of care partner time from these sources should not be combined into a single dataset and are instead presented as separate findings. These differences in data collection limited analysis of care recipient living location to the AD PACE WMM data and restricted analysis of care partner strain to the A-LIST Insights Series survey data. The RTI International Institutional Review Board (IRB) granted approval for the AD PACE WMM interviews and deemed the survey exempt. Participants provided written informed consent. The A-LIST Insights Series survey was approved by the Advarra IRB. All study components were conducted in accordance with the Helsinki declaration.

Targeted Review Methodology

We conducted a targeted review to understand the current literature landscape on the impact on care partners of providing care to PLWAD. This understanding allowed us to better contextualize the time and strain incurred by care partners from the WMM studies and A-LIST Insights Series survey findings. This targeted review focused on understanding the relationship between care partners and PLWAD, the roles and responsibilities of the care partner(s), the types of impacts felt by care partners, and any associated measures implemented in the reviewed studies. The search was conducted using the PubMed database and restricted to English-language–only articles published from 2000 to 2020. Key items related to impacts on care partners or tools for measuring these impacts were extracted to an Excel (Microsoft Corp., Redmond, WA, USA) spreadsheet for consolidation by topic.

AD PACE WMM Care Partner Time Methodology

The AD PACE WMM mixed-method studies explored the potential treatment-related outcomes that matter to people with AD and their care partners [15, 16]. As part of these AD PACE WMM studies, data were gathered on the relationship between care partners and recipients. DiBenedetti et al. [15] conducted a series of in-depth interviews that included a sample subset of pairs of individuals with moderate or severe AD and their care partners (*n* = 24). During the interview, which covered topics that generated data for the post hoc analysis presented here, care partners described how the impacts of their care recipients' symptoms affected them as care partners. These data were collected to better understand the lived experience along the spectrum of AD, as well as to support development of a survey that considered input from care partners. To gather additional data on treatment preferences [16], the survey was distributed to a larger sample of individuals (*n* = 274) that included a subset of care partners of recipients with moderate or severe AD (*n* = 119).

Further details about the AD PACE WMM interview and survey methodologies can be found in DiBenedetti et al. [15] and Hauber et al. [16]. Here, we conducted post hoc analyses to explore evidence generated by the WMM studies around the time spent by non-professional care partners providing care to recipients with moderate or severe AD (severity determined by clinician assessment). More specifically, we examined the number of hours in a typical week spent on providing direct care, including by subgroups based on where the care recipient lived (where data were available). Care recipients lived by themselves, with someone else in a residential household setting (i.e., a spouse, children, other relatives, a friend), or in a residential long-term care setting (i.e., nursing home, rehabilitation center, or assisted living facility). For care partner participants who selected two different living locations for their care recipients, the primary locations were used in the analysis. Care partner respondents with missing data for hours spent providing care in a typical week were excluded from analysis. Statistical significance was calculated using *t*-tests with an alpha of 0.05. The RTI International IRB granted approval for the AD PACE WMM interviews and deemed the survey exempt. Participants provided written informed consent.

A-LIST Insights Series Care Partner Strain Methodology

A survey to evaluate care partner strain was distributed in March 2021 to non-professional care partners of individuals with mild, moderate, or severe AD and AD–related dementias (AD/ADRD) as part of the A-LIST Insights Series study (severity as self-identified by participants).[1] The surveys, often developed with the input of care partners and individuals with AD/ADRD, focus on a range of topics relevant to

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[1] *A-LIST What Matters Most Insight Series*; clinicaltrials.gov: NCT04466722.

AD/ADRD. Here, we report the findings of a care partner strain survey that included an estimation of weekly direct care hours and the MCSI [18], a 13-item self-administered tool that was updated for contemporary family care partners [19]. The MCSI assesses strain related to providing care across five domains: Social, Employment, Financial, Physical, and Time. While a higher score correlates with increased care partner strain, there are not categories of strain (e.g., mild, moderate, severe) that correspond with particular scores. Accordingly, survey administrators are expected to use their judgement when determining the degree of strain experienced by care partners.

To have been eligible for inclusion, participants must have been an adult care partner of an individual with AD/ADRD, lived in the USA or Canada, and been able to communicate in English. Respondents who were unable to comply with study requirements were excluded from participation. Respondents with missing data were excluded from analysis. For the estimation of direct care hours provided per week, non-numerical responses and numerical responses over 168 hours were excluded from analysis. Estimated hours provided as a range were converted to the midpoint. Statistical significance between scores was calculated using *t*-tests with an alpha of 0.05. This survey was approved by the Advarra IRB (Advarra Inc., Columbia, MD, USA). All participants provided written informed consent.

RESULTS

Targeted Review Findings

A total of 20 articles were identified and reviewed that contained insights on the relationship between care partners and PLWAD or any associated measures (Table 1). We found general agreement across the reviewed literature that the quality of life of the care partner decreased as care recipient disease severity increased, with substantial impacts on care partners at each stage of the AD severity spectrum [20–33]. While the published literature typically focused on the impacts on care partners associated with moderate and severe dementia, substantial burdens to care partners were also associated with mild dementia [31]. Notably, the types of impacts experienced by care partners may differ depending on the severity level of AD. Gallagher et al. [24] reported that care partners of individuals with mild AD were most strongly impacted by declining function, as measured by the Disability Assessment for Dementia scale, which assesses both instrumental and basic activities of daily living (e.g., performing housework, managing finances, eating), and increasing dependence, as measured by the Dependence Scale, which assesses mild to severe dependence (e.g., reliance on care partner for eating). Further, the study authors found that behavioral symptoms (e.g., depression, anxiety) had a greater impact on care partner burden as the disease progressed. Yu et al. [32] similarly reported that the cognitive impairment of individuals with mild AD was the primary determinant of associated burden on care partners. These authors noted that the lack of impact on care partners from functional disability and problem behaviors was surprising but attributed this finding to the study sample being composed of individuals with mild AD and their caregivers. While multiple studies have reported an inverse relationship between AD severity and health-related quality of life (HRQOL) in care partners [20, 25, 26, 28, 32], the onset of comorbid conditions in care partners, including anxiety, hypertension, and insomnia, may not be correlated with the severity of AD [28].

Studies also found that time spent caregiving increased with the disease severity of the care recipient [26, 32]. Jutkowitz et al. [26] reported a mean of 4.8 h of care provided per day at onset of AD ($n = 1158$) compared with a mean of 9 h of care provided per day at 8 years after AD onset ($n = 30$). The reported number of functional limitations increased over this timespan from 3.2 limitations at incidence to 4.9 limitations at 8 years after onset. Yu et al. [32] found a significant correlation between greater hours of caregiving and higher scores on the Caregiver Burden Index measure. Furthermore, caregiver hours were significantly inversely correlated with scores on the Positive Aspects of

Table 1 Study characteristics of reviewed articles

References	Study disease states	Care partner population	Measurement tools	Key findings
Bell et al. [20]	AD	N = 679 (USA)	HUI2, SF-36	Caregiving time and burden increased with increased disease severity; generic preference-based measures may lack sensitivity to capture burden
Connors et al. [21]	MCI	N = 185 (Australia)	Not reported	Care partner burden increased with breadth of AD symptoms
Dauphinot et al. [22]	SCD and NCD	N = 222 (France)	ZBI (short version)	Care partner burden increased with breadth of AD symptoms
Dawood [23]	Dementia and AD	N = 60 (Pakistan)	ZBI, WHO QOL Scale (brief version)	Care partner burden negatively affected care partner QOL
Gallagher et al. [24]	AD and MCI	N = 100 (Ireland)	ZBI, dependence scale	Care partners experienced burden even in cases of mild disease; factors differed in severe disease
Gaugler et al. [35]	Dementia	N = 1116 and 1610 (USA)	Not reported	Nursing home placement may not relieve care partner burden in all care partners
Gaugler et al. [34]	Dementia	N = 1116–1610 (USA)	Not reported	Female care partners, particularly wives, may experience continued and growing burden post nursing home placement
Jones et al. [25]	AD	N = 249 (UK)	Dependence scale	Care partner burden is related to dependence and disease severity
Jutkowitz et al. [26]	Dementia	N = 30 (USA)	Not reported	Caregiving time and burden increased with increased disease severity
Landeiro et al. [33]	AD, MCI, and dementia	Compilation of 61 studies	EQ-5D, HUI2, HUI3, DEMQOL, QWB	Rate of cognitive decline is associated with reduced utilities; PLWAD and care partner views on PLWAD QOL were highly divergent
Lin et al. [14]	AD	Compilation of 44 studies	Not reported	There remains a gap in assessment of care partner burden using economic models
Liu et al. [27]	AD	N = 309 (China)	Not reported	Care partner burden was related to disease severity
Livingston et al. [44]	Dementia	Compilation of studies	Not reported	Support was needed for distressed care partners; psychiatric dementia symptoms added additional burden on care partners
Montgomery et al. [28]	AD	N = 300 (Japan)	EQ-5D, PHQ-9	Reduced care partner QOL with increased AD severity

Table 1 continued

References	Study disease states	Care partner population	Measurement tools	Key findings
Nikzad-Terhune et al. [29]	Dementia	*N* = 634 (USA)	Series of quantitative scales, including ZBI	Functional dependency may increase with disease severity
Reed et al. [30]	AD	*N* = 1497 (France, Germany, UK)	ZBI, EQ-5D	Care partner burden increased with functional dependency
Reed et al. [37]	AD	*N* = 1495 (France, Germany, UK)	EQ-5D, ZBI	EQ-5D may not capture full impact of care partner burden
Robinson et al. [31]	AD	*N* = 1198 (USA)	Not reported	Considerable care partner burden exists even in early disease
Schulz et al. [36]	Dementia	*N* = 1222 (USA)	Not reported	Care partner depression and anxiety may not be reduced with nursing home placement
Yu et al. [32]	AD	*N* = 200 (China)	Chinese version of CBI	Disease severity and time spent caregiving are related to care partner burden

AD Alzheimer's disease, *CBI* Care partner Burden Inventory, *DEMQOL* Dementia Quality of Life, *EQ-5D* EuroQol 5 Dimension, *HUI2* Health Utilities Index Mark 2, *HUI3* Health Utilities Index Mark 3, *MCI* Mild cognitive impairment, *NCD* Neurocognitive disorder, *PHQ-9* Patient Health Questionnaire 9, *PLWAD* person living with Alzheimer's disease, *QOL* Quality of life, *QWB* Quality of Well Being, *SCD* Subjective cognitive decline, *SF-36* 36-Item Short Form Survey, *UK* United Kingdom, *US* United States, *WHO* World Health Organization, *ZBI* Zarit Burden Inventory

Caregiving (PAC) and the Family Adaptation, Partnership, Growth, Affection and Resolve (APGAR) Index measures, which assess care partners' experiences with caregiving and the level of family function, respectively. Beneficial caregiving experiences included a discovery of meaning and feelings of pride, appreciation, or usefulness. The authors concluded that encouraging recognition of positive caregiving experiences and improving family function could reduce the perceived burden felt by care partners.

Jutkowitz et al. [26] found that spouses and adult children provided approximately equivalent proportions of family caregiving at AD onset (33% and 32%, respectively). However, adult children later provided a greater proportion of caregiving hours in response to increased needs from care recipients with AD. The authors attributed this change in the primary care partner to the decreasing capability of spouses to provide care over time, as well as the possibility of multiple adult children being able to distribute caregiving duties among themselves. Articles also reported that time spent caregiving after the care recipient has transitioned into long-term care may depend on the relationship of the caregiver to the recipient [34–36]. The transition from family caregiving to institutional care can be especially challenging for spousal care partners compared with other caregivers [34–36]. In particular, spousal care partners may be significantly more likely than other types of care partners to experience care burden and depressive symptoms at up to 1 year following admission of a care recipient to a nursing home [35]. Gaugler et al. [34] noted that while caregiver-reported burden significantly decreased at 6 and 12 months post admission of a care recipient to a nursing home, care partners who were wives had the highest likelihood of experiencing persistent burden. In contrast, husband care partners were more likely to experience depression during this transition time, which the authors suggested could be due in part to a weaker social support system.

Finally, health-state utility measures may not adequately capture caregiver burden and QOL impact [20, 37]. Generic measures, such as the Health Utilities Index Mark 2 (HUI2) and Medical Outcomes Study 36-Item Short-Form Health Survey (SF-36), can be affected by AD severity and care setting [20]. The focus on physical health in some preference measures, like the EuroQol 5 Dimension (EQ-5D), may reduce the sensitivity of such instruments to capturing the impact of providing care for AD [37].

AD PACE WMM Care Partner Time Findings

A total of 139 care partners from the AD PACE WMM studies provided details about the time spent providing care to PLWAD. Approximately half of the sample provided care to individuals with moderate AD (54.7%, $n = 76$); the remaining 63 participants (45.3%) provided care to individuals with severe AD. Reported caregiving hours varied widely across the sample and both subgroups. Care partners spent a mean (± standard deviation [SD]) of 47.1 ± 40.3 h/week providing direct care to their care recipients (range 1–168 h/week) (Fig. 1). Care partners in the moderate AD subgroup spent a mean of 44.3 ± 39.3 (range 1–168) h/week compared with the mean of 50.4 ± 41.6 (range 2–168) h/week reported by care partners in the severe AD subgroup ($P = 0.3789$).

Most participants ($n = 95$) reported that their care recipient lived with someone (i.e., spouse, $n = 55$; children, $n = 29$; other relatives, $n = 10$; friend, $n = 1$); followed by in a residential long-term care setting (i.e., nursing home, rehabilitation center, or assisted living facility; $n = 27$); or by themselves ($n = 14$). Notably, for care recipients living with someone, the person the recipient lived with was not necessarily their care partner (e.g., a care recipient lived with their spouse, but the recipient's child identified as their care partner). Care partners spent significantly more hours providing care for recipients who lived with someone (57.3 ± 44.3 h/week [mean ± SD]) compared with recipients who lived alone (26.0 ± 12.0 h/week) ($P = 0.0099$) or compared with those who lived in a residential long-term care setting (23.6 ± 14.4 h/week) ($P = 0.0002$) (Fig. 2). However, there was no significant difference in the time care partners spent providing care for recipients who lived alone versus recipients who lived in a residential long-term care setting ($P = 0.5951$).

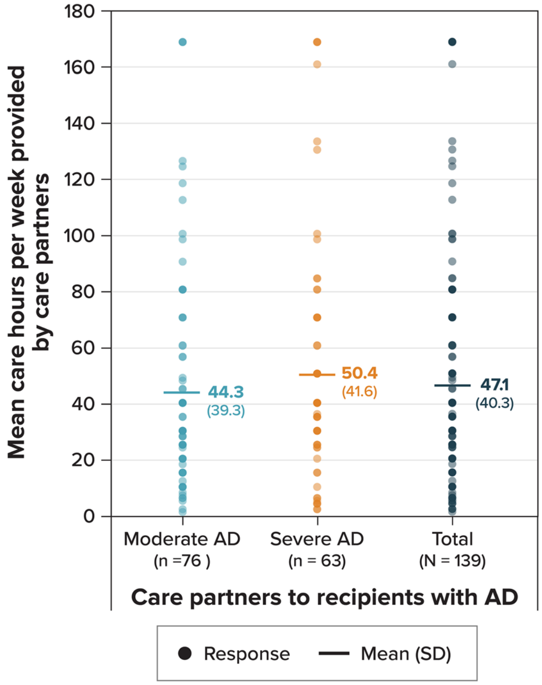

Fig. 1 Number of hours per week spent by care partners in providing direct care. Data from AD PACE WMM Care Partner studies. *AD* Alzheimer's disease, *AD PACE WMM* Alzheimer's Disease Patient and Caregiver Engagement What Matters Most, *SD* standard deviation

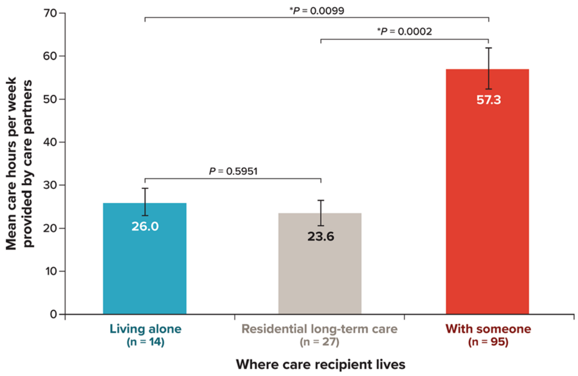

Fig. 2 Mean number of care hours per week provided by care partners based on where recipients lived. The "with someone" category included care recipients who lived in a residential household setting with a spouse (*n* = 55), child (*n* = 29), other relative (*n* = 10), or friend (*n* = 1). Error bars display standard error. Data are from the AD PACE WMM care partner studies. Asterisk indicates significant difference at *$P < 0.05$

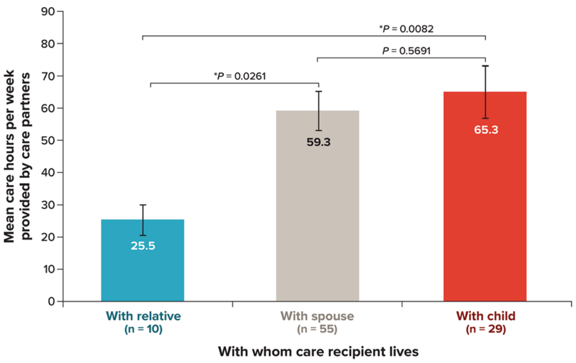

Fig. 3 Mean number of care hours per week provided by care partners for recipients who lived with someone in a residential household setting. Care recipients did not necessarily live with their care partners. Error bars display standard error. Data from AD PACE WMM Care Partner studies. Asterisk indicates significant difference at *$P < 0.05$

Care partners spent significantly more time providing care when the recipients lived with their children (65.3 ± 43.8 h/week [mean ± SD]) or spouses (59.3 ± 46.3 h/week) than when the recipients lived with other relatives who were not spouses or children (25.5 ± 14.8 h/week; $P = 0.0082$ and $P = 0.0261$, respectively) (Fig. 3). However, there was no difference in the time care partners spent providing care to recipients living with spouses or with children ($P = 0.5691$). There were also no differences in time spent providing care for recipients based on severity of AD (i.e., moderate vs. severe AD) for any of the three subgroups within the "someone else" category ($P \geq 0.05$).

A-LIST Insights Series Care Partner Strain Findings

A total of 216 care partners completed the MCSI and estimated the number of hours spent weekly providing direct care to recipients with AD/ADRD. Across all AD/ADRD severity levels, respondents reported a mean (± SD) MCSI score of 14.5 ± 5.5 (range 2–26). However, significant variation was observed across both the mean overall and mean item scores (e.g., financial strain, physical strain) when comparing by the AD/ADRD severity of the care recipients (Fig. 4). Care partners for recipients with mild (*n* = 14), moderate (*n* = 111), and severe AD/ADRD (*n* = 91) had overall mean (± SD) MCSI scores of 9.0 ± 3.8 (range 2–14), 13.3 ± 4.8 (range 4–23), and 17.5 ± 5 0.3 (range 4–26), respectively. Care partners of recipients with mild AD/ADRD reported significantly less strain on the MCSI than care partners of recipients with moderate AD/ADRD ($P = 0.0014$) or severe AD/ADRD ($P < 0.0001$). Similarly, care partners of recipients with moderate AD/ADRD reported significantly less strain on the MCSI than care partners of recipients with severe AD/ADRD ($P < 0.0001$).

Care partners provided an overall mean (± SD) of 58.1 ± 53.0 h of direct care each week (range 1–168), with caregiving hours increasing with increasing AD/ADRD severity (Fig. 5). Care partners of recipients with mild AD/ADRD (*n* = 14) reported a mean 21.2 ± 19.2 h of care per week, which was significantly less time providing care than care partners of recipients with moderate (*n* = 109; 53.9 ± 50.4 h; $P = 0.0179$) or severe AD/ADRD (*n* = 86; 69.5 ± 56.7 h; $P = 0.0022$). Mean weekly hours providing care were also significantly different

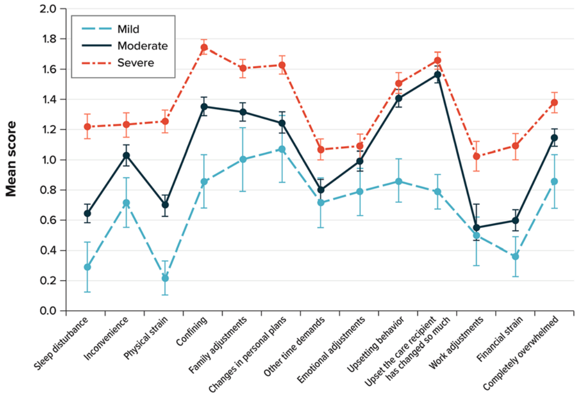

Fig. 4 Mean item scores for the Modified Caregiver Strain Index by AD/ADRD severity of recipient. Error bars display standard error. Item names have been abbreviated to represent item concepts. Data are from the A-LIST Insights Series. *AD/ADRD* Alzheimer's disease and Alzheimer's disease-related dementias

between care partners of recipients with moderate AD/ADRD and recipients with severe AD/ADRD ($P = 0.0446$).

DISCUSSION

Our research presents a compilation of preliminary evidence characterizing elements of the experience of care partners providing care for individuals across the AD spectrum. Care partners reported wide variability in both the time providing care each week and the strain incurred from providing care. Relationships also differed widely between care partners and recipients, as did the locations where the recipients lived. The variations in time, stress, relationships, and locations may have been due to the spectrum nature of AD, since care recipients require correspondingly greater amounts of care over time as the severity of their AD increases. However, despite the differences in magnitude, care providers of recipients across the AD severity spectrum generally experienced substantial impacts from the time spent providing care and the associated caregiving strain.

While care partners of recipients with moderate and severe AD reported a greater number of weekly care hours in the A-LIST Insight Series study than did care partners in phases 1 and 2 of the AD PACE WMM studies, the number of care hours was consistently high across both studies and further increased with AD severity level. These findings provide additional support to results reported in the literature [24, 26, 32], which indicate that time provided by care partners is positively correlated with the severity level of AD in care recipients. However, care hour estimates in the literature often focus on a population with mild AD or are presented in relation to the number of functional limitations in care recipients [24, 26, 32]. Our estimates therefore offer needed context by providing weekly care hours stratified by AD severity level across the entire AD spectrum.

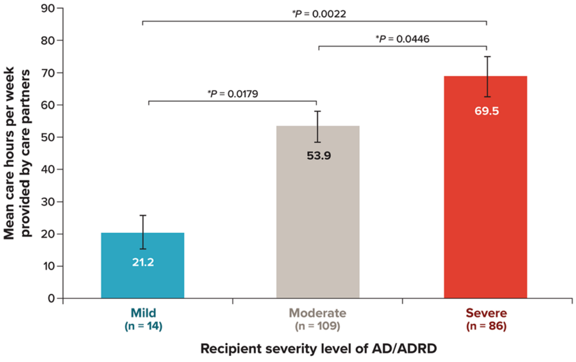

Fig. 5 Mean weekly number of caregiving hours by AD/ADRD severity. Error bars display standard error. Data are from A-LIST Insights Series. *AD/ADRD* Alzheimer's disease and Alzheimer's disease related dementias

Our research also provides additional context on the differences in care hours provided by care partners in different care settings. Care partners spent significantly more time providing care when the recipient lived with another person in a residential household setting (although not necessarily the care partner), as opposed to the care recipient living alone or in a residential long-term care setting. Importantly, among care recipients living with another person, reported care hours were not significantly different for recipients with moderate AD compared to those with severe AD. While total care hours may increase in proportion to AD severity [24, 26, 32, 38], our findings suggest that the living location of the PLWAD, as opposed to their AD severity, may be a greater predictor of non-professional care hours.

The use of professional caregivers in residential long-term care settings likely offsets much of the need for non-professional care, driving this reduction in non-professional care partner time. However, research has shown that the role of non-professional care partners begins shifting during this transition from providing personal care and instrumental care to offering socioemotional support, monitoring of the long-term care facility, and acting as an advocate [39, 40]. Thus, the role of the care partner does not diminish, but rather rebalances to reflect the evolving needs of the care recipient while incorporating professional care [38].

Notably, we found that care partners also spent significantly more time providing care when the recipient lived with a spouse or children than when the recipient lived with other relatives. However, there was not a significant difference in hours providing care when the care recipients lived with spouses versus with children. Reed et al. [30] did find that adult children who were caregivers of care recipients with AD spent significantly less time providing care than spousal caregivers but experienced greater burdens while providing care. This suggests that both the relationship of the care partner to the recipient and the setting where the recipient lives are important factors that can substantially impact the experience of the care partner. Accordingly, further research into improving family function [32] is needed to better understand how to reduce the burden on care partners while enhancing positive impacts of caregiving.

In the A-LIST Insights Series study, we found care partner strain significantly increased with the severity of AD in care recipients. This association aligns with the findings of other studies, which found care partners experienced a decreasing HRQOL as the severity of AD increased in their care recipients [20, 25, 26, 28, 32]. While the MCSI does not correlate scores with distinct stress levels, we compared scores across the 13 items with stratification by the AD severity level of the care recipients. This provided insight into how individual stressors were experienced by care partners caring for recipients across the AD spectrum and could highlight target populations for future research into reducing care partner strain. For example, care partners reported significantly different mean scores for physical strain between each AD severity level. This could indicate that care partners experience physical strain differently at each AD severity level and that interventions or guidance for reducing physical strain in care partners may need to be tailored to the AD severity level. In contrast, care partners of recipients with severe AD reported experiencing much higher financial strain than partners or recipients with moderate or mild AD. Accordingly, treatments aimed at slowing the progress of AD at earlier stages could have the greatest positive financial impact on care partners.

Interestingly, mean scores for the strain of emotional adjustments were similar across all three stages of AD severity (mild, moderate, and severe). This overlap may reflect that spouse and children care partners experience emotional strain differently during this journey, which balances strain across the severity stages. For example, spouse care partners of PLWAD have reported experiencing greater emotional trauma than children care partners when the care recipient moves into an assisted living facility, while children care partners have reported greater emotional trauma when their care recipient transitions from assisted living into memory care [41].

Other individual items in the MCSI demonstrated varying degrees of overlap across severity stages. As anticipated, strain from upsetting behavior was greater for care partners of recipients with moderate/severe AD compared to care partners of recipients with mild AD. This finding aligns with prior research that found care partners were initially more affected by cognitive impairment in recipients with earlier stages of AD and then became increasingly impacted by behavioral symptoms as AD severity intensified in care recipients [24, 32]. Strain from work adjustment was greater for care partners of recipients with severe AD than for care partners of recipients with mild/moderate AD. This corresponds with findings from prior research focusing on work-related stress and impacts in care partners for PLWAD [42, 43], although our study provides additional context by presenting care partner work adjustment strain by recipient AD severity.

The findings of the present study highlighted several complexities in the care partner-recipient relationship that included the location of where the recipient lived (e.g., with their care partner or with someone else), the familial or social connection between care partners and recipients, and that care recipients may have several care partners. Furthermore, changes may occur within each of these areas over time in response to increased AD severity in care recipients. Our research was not designed to explore these changes over time, especially regarding the familial or social relationships between care partners and recipients. Future studies should explore these relationships over time while also formally assessing the number of care partners that each person living with AD may have since care partner teams are often composed of multiple caregivers.

While our compilation of research across multiple studies highlights consistent themes, direct comparisons between studies were limited due to differing designs. This targeted review provided an approach for contextualizing the research findings but lacked systematic rigor. Additionally, the convenience sample used for the A-LIST Insights Series study may constrain the generalizability of the findings. Finally, the descriptive statistical analyses allowed for comparison between the designated subgroups, but these analyses did not adjust for the impact of multiple variables on time providing care or care partner strain (e.g., education level, household income, race/ethnicity). As such, this evidence should be considered to be preliminary and to be used for indicating future areas of research that could beneficially affect the experience of care partners. However, the diversity of multiple collaborating institutions and authors, including care partners of PLWAD, provides a strength in this exploration of the humanistic and economic impact on care partners.

CONCLUSION

Persons living with AD require increasing levels of care along the spectrum of disease, and even individuals with early disease benefit from care partners. While some care partners may report positive aspects of providing close care to loved ones, many care partners of people with AD report experiencing significant strain across multiple areas of daily living while providing a substantial amount of care each week. Care partners of recipients living with spouses or children provided the greatest amount of care each week, although these care partners did not necessarily live with their recipients. Early interventions that slow progression of AD and programs designed to improve family function may have the greatest beneficial impact on the experiences of care partners for recipients with mild, moderate, or severe AD.

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Data Availability. Data generated or analyzed as part of the AD PACE WMM studies and A-LIST Insights Series are the property of UsAgainstAlzheimer's and are maintained in the proprietary AD PACE Data Commons. Please contact Terry Frangiosa (tfrangiosa@usagainstalzheimers.org) for information about accessing the Data Commons or the data specific to this study.

Declarations

Conflict of Interest. Leigh F Callahan is an employee of the University of North Carolina, Chapel Hill. Brian Samsell, Dana DiBenedetti, Christina Slota, William L Herring, and Carla Romano are full-time employees of RTI Health Solutions, an independent nonprofit research organization, which was retained by AD PACE to conduct the research that is the subject of this manuscript. Their compensation is unconnected to the studies on which they work. William L Herring is affiliated to research at the Karolinska Institute and receives no compensation as part of this affiliation. Terry Frangiosa was a consultant for UsAgainstAlzheimer's at the time of the study and now is an employee of Faegre Drinker. Russ Paulsen is an employee of UsAgainstAlzheimer's. Virginia Biggar was an employee of UsAgainstAlzheimer's at the time this study was conducted and is now an employee of USAging. Debra Lappin is an employee of Faegre Drinker Consulting.

Ethical Approval. The RTI International Institutional Review Board (IRB) granted approval for the AD PACE WMM interviews and deemed the survey exempt. Participants provided written informed consent. The A-LIST Insights Series survey was approved by the Advarra IRB. All study components were conducted in accordance with the Helsinki declaration.

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