

RESEARCH ARTICLE

A look at caregivers for community-living persons with dementia: Implications for the GUIDE model

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Abstract

INTRODUCTION: Medicare's new Guiding an Improved Dementia Experience (GUIDE) model funds integrated dementia care and related caregiver supports for community-living persons with dementia (PwD). Caregiver strain is a factor in provider payment and performance.**METHODS:** We examined national survey data on community-living PwD and their caregivers to identify which caregivers would receive support under GUIDE and characterize caregiver strain and use of supportive services.**RESULTS:** Half of GUIDE-eligible PwD received care from multiple caregivers and high strain was common even among caregivers considered "low-complexity" under GUIDE. Use of role-related training, respite care, and support groups were low (11%, 18%, and 4%, respectively) and did not vary with caregiver strain.**DISCUSSION:** Caregiver identification and assessment standards under GUIDE may overlook a significant number of caregivers. To maximize impact, innovative models like GUIDE should align caregiver engagement and services with the unique realities of care networks for PwD.

KEYWORDS

Alzheimer's disease, caregiving, dementia, medicare

Highlights

- Half of GUIDE-eligible persons with dementia have multiple caregivers.
- 32% of caregivers for community-living PwD report high strain.
- 11% of caregivers for community-living PwD received training and 18% used respite care.

1 | BACKGROUND

Most (67%) persons with dementia (PwD) live in the community and rely heavily on family and unpaid caregiver assistance.^{1,2} PwD have significant and unique care needs, and they often receive help from

care networks, comprised of multiple caregivers who share responsibility for complex care tasks.^{3,4} Most caregivers of PwD report unmet needs for caregiving-related training and supportive resources and many experience role-related strain.^{5,6} Although PwD often co-manage their health care with caregivers, including jointly attending

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medical appointments,⁷ no national estimates exist regarding presence of caregivers for PwD at the point of care or supportive services use among caregivers for PwD. This information has acquired heightened policy relevance with the July 2024 launch of Centers for Medicare & Medicaid Services' (CMS) Guiding an Improved Dementia Experience (GUIDE) model.

GUIDE is an integrated care and payment model designed to facilitate improved support for community-living PwD and their caregivers.⁸ GUIDE participants (Medicare Part B enrolled providers) receive per-beneficiary per-month payments covering a suite of services including care management and coordination, annual wellness visits, advance care planning, and more. Participants identify eligible patients and extend them the opportunity to take part; those who consent are then "aligned" to the participating provider. Patients are eligible if they are enrolled in Medicare Parts A and B, community-living, meet clinical criteria for dementia as attested to by a GUIDE provider, and are not enrolled in Medicare Advantage or hospice.

GUIDE defines a "caregiver" as a relative or unpaid nonrelative who assists with activities of daily living (ADLs) or instrumental activities of daily living (IADLs).⁹ During an initial comprehensive assessment visit, GUIDE-participating providers gather and report relevant information on the aligned patients and their primary caregiver (if this caregiver is present at the visit). Providers receive higher payments if the patient is not receiving caregiver assistance, presumably to reflect greater difficulty in coordinating care for an individual without caregiver involvement.

For those with an involved caregiver, evidence of high caregiver strain (determined by the participating provider using a standardized assessment) leads to higher payments, but only for PwD with moderate or severe (compared to mild) dementia.⁹ Reducing caregiver strain is a major identified goal of GUIDE. GUIDE-participating providers must offer caregiver support services including a hotline and training sessions on dementia behavioral symptom management, although providers have broad latitude in how to connect caregivers to these supports. If the PwD has moderate or severe dementia, the model also funds respite services for their caregivers.⁹ CMS plans to incorporate measures of caregiver strain in future performance-based payment adjustments, but the specific metrics to capture performance in this area are in development.

As policymakers, providers, and advocates navigate the GUIDE launch, there is an absence of national-level evidence regarding the caregiving context of community-living PwD. We rely on national, linked surveys of older PwD and their caregivers to (1) describe care network size and the characteristics of caregivers who are present at point of care for GUIDE-eligible older adults; (2) examine and compare role-related strain among caregivers of GUIDE-eligible older adults, across various measures and by virtue of whether caregiver strain would or would not affect payments under GUIDE; and (3) characterize supportive services use among these caregivers overall and by strain level. This foundational information is key to contextualizing the structure and potential impact of GUIDE and informing revisions and refinements to the payment structure and quality monitoring efforts.

RESEARCH IN CONTEXT

1. **Systematic review:** Authors reviewed the existing literature via searches of PubMed and conference presentations/abstracts. No prior work describes care context for Medicare's Guiding an Improved Dementia Experience (GUIDE) -eligible persons with dementia (PwD). Prior work indicates larger care networks and higher levels of caregiver strain for PwD, compared to those without dementia, and these studies are appropriately cited.
2. **Interpretation:** This is the first study to describe caregiving context for GUIDE-eligible PwD and to provide national estimates of supportive service use among caregivers of community-living PwD. Findings indicate reliance on multiple caregivers, substantial levels of caregiving-related strain, and low use of supportive services.
3. **Future directions:** This article suggests a need to refine GUIDE's approach to caregiver identification and assessment (namely, considering care networks and assessing strain regardless of dementia severity) and highlights the critical need for programs, like GUIDE, aimed at facilitating engagement and support of caregivers for PwD at the point of care.

2 | METHODS

2.1 | Datasets

This cross-sectional study analyzed data from the 2022 National Health and Aging Trends Study (NHATS) and linked National Study of Caregiving (NSOC). NHATS is an annual, nationally representative survey of Medicare beneficiaries 65 and older, with rich information on respondents' health, function, cognition, and social supports. In 2022, NHATS replenished its sample; in that year, the response rate was 59%. NSOC is a companion survey administered to family and unpaid caregivers of NHATS respondents who receive help with self-care, mobility, or household activities (for health and function reasons).¹⁰ Reflecting the realities of care networks for older adults with disability, NSOC is not limited to a single "primary" caregiver and is fielded with up to five caregivers for each NHATS respondent. NSOC includes information regarding caregivers' sociodemographic characteristics, health and function, and experiences of caregiving. Approximately 60% of NHATS caregivers who were invited to complete NSOC did so. With weights provided by the studies, NHATS represents Medicare enrollees ages 65 and older in 2022 and NSOC represents their family caregivers.

2.2 | Sample

We first identified NHATS respondents who met GUIDE eligibility criteria. Of 6327 respondents, 671 had probable dementia as determined by a previously validated composite measure¹¹ from self- or proxy-reported formal diagnosis, responses to the AD8 dementia screening tool, and performance on cognitive tests evaluating memory, orientation, and executive function. We excluded those living in skilled nursing facilities ($n = 47$) and who reported having no regular doctor ($n = 59$). The final analytic sample included 565 GUIDE-eligible PwD (weighted $n = 2.9$ million).

We then identified NSOC respondents who were caring for an individual in our sample of GUIDE-eligible PwD (555 of 2431 respondents). NSOC eligibility criteria mirror the GUIDE model definition of a "caregiver" (relative or unpaid nonrelative who assists the patient with ADLs or IADLs).⁹ Specifically, family and unpaid caregivers are eligible for NSOC if they (1) assisted an NHATS participant who received help with ADLs or IADLs (for health/functioning reasons) in the past month and (2) helped that NHATS participant with ADLs, IADLs, health care tasks, transportation, or money management. We excluded seven NSOC respondents who did not report helping with ADLs or IADLs in the past month. The final analytic sample of caregivers for GUIDE-eligible PwD included 548 caregivers (weighted $n = 4.6$ million) caring for 349 unique PwD. (See [Supplemental Materials Figure A1](#) for additional detail regarding sample construction.)

2.3 | Measures

Descriptive characteristics of GUIDE-eligible PwD were drawn from NHATS responses and included age, sex, race, Medicaid enrollment, and self-rated health status. Descriptive characteristics of caregivers to GUIDE-eligible PwD were drawn from NSOC and included age, sex, race, and relationship to the care recipient.

2.3.1 | GUIDE-eligible PwD as unit of analysis

Dementia severity

Among PwD, we considered individuals to have moderate or severe (compared to mild) dementia if they scored below the sample median on memory (measured via 20-word delayed recall) or orientation (measured via statement of date, time, names of President and Vice President), or if a proxy responded to the NHATS on their behalf for the stated reason of dementia.¹¹

Care network size

Care network size for GUIDE-eligible PwD was derived from the NHATS "Other Person" file in which each survey participant reports the types of help received and from whom. We delineate between reported caregivers who meet the GUIDE definition of a caregiver (see above) and those who do not.

2.3.2 | Caregiver as unit of analysis

Caregiving-related strain

Under GUIDE, caregiver strain is a factor that is used to determine payment if the PwD has moderate or severe dementia and the clinician is aware of/in contact with the caregiver. We therefore identified caregivers whose strain would likely be considered as those who were helping an older adult with moderate or severe dementia (as defined above) and attended doctor visits with them in the past year. GUIDE assesses role strain for a "primary" caregiver. In cases of multiple caregivers, we contend that most providers would identify the person attending medical visits with the older adult to be the primary caregiver, based on practical considerations and evidence from national survey indicating that caregivers who attend medical visits provide more hours of care¹² and are persistently involved over time.¹³ Thus, if multiple caregivers attended doctor visits, we identified the caregiver who the older adult reported "most often" attended doctor visits with them as the primary caregiver. Additionally, due to the documented challenges providers face in identifying and engaging with caregivers of PwD,^{14–18} it is unlikely that caregivers who do not interact with the provider during medical visits would be consistently identified and assessed outside the point of care.

Caregiver strain was determined from NSOC, drawing on questions asking caregivers whether helping the care recipient was emotionally, physically, and/or financially difficult, and to what degree on a scale of 1 ("a little difficult") to 5 ("very difficult"). Following an approach used by Wolff et al (2016),⁷ we created measures indicating whether the caregiver reported no, moderate (1-3), or high (4-5) difficulty within each category. We then created a measure of overall strain denoting "low/no strain" for those reporting no difficulty in any category; "moderate strain" for those reporting moderate difficulty in one to two categories and/or high difficulty in 1 category; and "high strain" for those reporting moderate difficulty in three categories or high difficulty in two or more categories.

Strain was also measured through a separate set of NSOC questions which ask caregivers how much the following statements apply to their caregiving situation: "You have no time for yourself," "You have more things to do than you can handle," "As soon as you get a routine going, [care recipient's] needs change," and "[care recipient] gets on your nerves." Response options offered were "not so much," "somewhat," and "very much". These questions were chosen for their similarity to prompts in the Zarit Burden Interview (ZBI) four-item screen,¹⁹ as GUIDE instructs physicians to use the ZBI to evaluate caregiver strain. (Additional detail regarding wording of the ZBI screen questions compared to the NSOC items is included in [Supplemental Material section 2](#).)

Supportive service use

Binary indicators of supportive service use were drawn from caregiver reports in the NSOC across three categories: skills training, sharing task load, and emotional supports. Skills training included overall training ("any role-related training"), health-related training ("train-

ing...needed to help [care recipient] with their health treatments”), post-hospital care training (training from hospital providers “to manage [care recipient’s] post-hospital care”), and whether the care recipient’s physician usually or always asked if the caregiver “needed help managing [care recipient’s] health treatments.” The receipt of health-related and post-hospital care training was only measured for the subset of care partners who reported helping with these activities.

Sharing task load included using respite care (a service that took care of the care recipient so the caregiver could “take some time away from helping”), help completing daily activities (i.e., errands, chores) from family/friends, being part of a caregiving network with multiple caregivers, and the presence of any paid caregiver in the care recipient’s care network. Finally, emotional supports included attending a support group and having family or friends to “talk to about important things in life.”

2.4 | Statistical analyses

We described GUIDE-eligible PwD and their caregivers using frequencies and weighted proportions, and means and standard deviations. We then described care network sizes among GUIDE-eligible PwD using weighted proportions and calculated the weighted mean number of caregivers.

Next, among caregivers of GUIDE-eligible PwD, we characterized level of strain experienced, both overall and comparing caregivers whose strain would (versus would not) affect payments to providers under the GUIDE model. Finally, we calculated rates of supportive services use, both overall and comparing caregivers with low, moderate, or high strain. For all analyses, we present unweighted frequencies and weighted proportions, used Pearson’s χ^2 test to detect between-group differences, and applied survey weights and design variables to account for complex survey design and produce nationally representative estimates. Analyses were performed in Stata 17 (StataCorp LLC, College Station, TX, USA).

3 | RESULTS

Of 565 (weighted $n = 2.9$ million) GUIDE-eligible PwD who responded to the 2022 NHATS, 62.1% were female, 67.0% were non-Hispanic White, 12.3% non-Hispanic Black, and 20.7% Other racial and ethnic groups (including Hispanic) (Table 1). Altogether, 33.5% were dually enrolled in Medicaid, 39.5% were characterized as having moderate/high dementia severity, and 45.8% reported fair or poor overall health.

3.1 | Care networks for GUIDE-eligible PwD

Nearly all (95.7%) GUIDE-eligible PwD had at least one caregiver (Figure 1). Most (79.8%) had at least one caregiver who met the

TABLE 1 Characteristics of GUIDE-eligible persons with dementia and their caregivers.^a

Characteristic	N (weighted %) or mean \pm SD
<i>GUIDE-eligible persons with dementia (NHATS survey respondents)</i> <i>n = 565, weighted n = 2.9 million</i>	
Age (years)	
65–74	60 (23.9%)
75–84	220 (41.5%)
85+	285 (34.6%)
Female sex	358 (62.1%)
Race	
White	280 (67.0%)
Black	152 (12.3%)
Other	133 (20.7%)
Medicaid-enrolled	175 (33.5%)
Dementia severity	
Mild	298 (60.5%)
Moderate/high	267 (39.5%)
Self-reported overall health status	
Excellent/very good	123 (21.5%)
Good	173 (32.7%)
Fair/poor	268 (45.8%)
<i>Caregivers of GUIDE-eligible persons with dementia (NSOC survey respondents)</i> <i>n = 555, weighted n = 4.7 million</i>	
Age (years)	59.0 (18.9)
Female sex	370 (62.2%)
Race	
White	275 (61.5%)
Black	158 (17.1%)
Other	96 (21.4%)
Relationship to care recipient	
Spouse or partner	104 (18.7%)
Child	303 (54.6%)
Other	148 (26.7%)
Attended doctor visits with the person with dementia in the last year ^b	253 (45.0%)

^aData drawn from 2022 National Health and Aging Trends Study (NHATS) and National Study of Caregiving (NSOC).

^bIf multiple caregivers in a network attended doctor visits, limited to the caregiver identified as attending “most often.”

GUIDE program definition by virtue of being a relative or unpaid nonrelative assisting with IADLs or ADLs; among these, 17.5% attended doctor visits without an accompanying caregiver. Half (49.4%) had two or more caregivers meeting the GUIDE program definition.

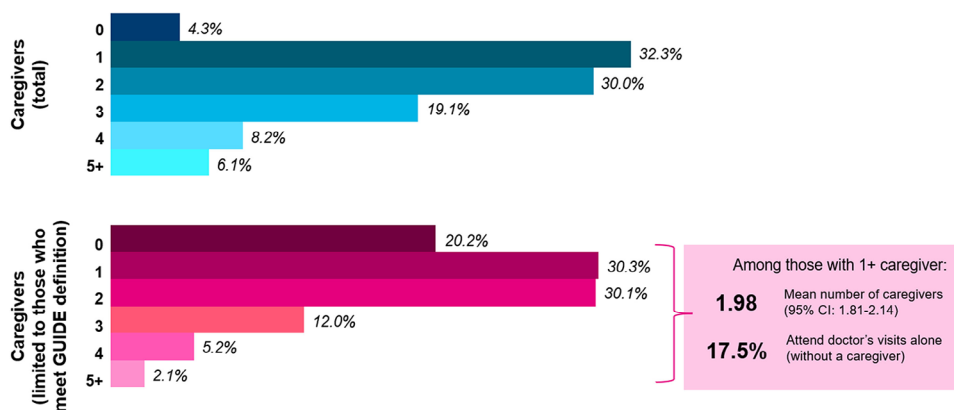


FIGURE 1 Number of caregivers for GUIDE-eligible persons with dementia.

3.2 | Strain among caregivers for GUIDE-eligible PwD

Among 555 (weighted $n = 4.7$ million) caregivers of GUIDE-eligible PwD who responded to the 2022 NSOC, average age was 59 years, 62.2% were female, and 61.5% were non-Hispanic White, 17.1% non-Hispanic Black, and 21.4% Other racial and ethnic groups (Table 1). Most (54.6%) were the child of the PwD, 18.7% were helping a spouse or partner, and 26.7% had another relationship to the PwD. Nearly one-third (32.0%) of caregivers reported high caregiving-related strain (Table 2). The most common indicators of strain were high emotional difficulty (20.9%), feeling “very much” that they had no time for themselves (16.5%), and feeling “very much” that they had more to do than they could handle (13.0%).

In three-quarters ($n = 379$; 73.7%) of cases, caregiver strain would not affect payment level, due to helping a person categorized as having mild dementia ($n = 180$), because the caregiver was not the primary caregiver ($n = 161$; primary caregiver defined as the caregiver in a network who most often attended doctor visits with the care recipient), or because the caregiver was a sole caregiver but did not attend doctor visits ($n = 38$). Among those whose strain would not be considered relevant to payment level, 29.0% reported high strain. Those whose strain would be considered in determining payments were more likely to report substantial emotional difficulty (24.1% vs. 19.7%; $p = 0.05$), feeling “very much” that they had no time for themselves (25.5% vs. 13.3%; $p = 0.003$), and that they had “more to do than they could handle” (16.5% vs. 11.7%; $p = 0.05$). No other statistically significant differences in reported strain were observed between these groups.

3.3 | Supportive service use among caregivers for GUIDE-eligible PwD

Caregivers reported low rates of supportive service use: 11.4% received role-related training, 17.5% used respite care, and 3.8% attended a support group (Figure 2). Half of caregivers (45.6%) were asked by the PwD's doctor whether they needed help managing the

PwD's health treatments, and 37.8% of those helping with health care tasks reported receiving training related to these tasks. Most (85.6%) were part of a caregiving network with multiple caregivers assisting the PwD, and one-quarter (25.3%) were part of a caregiving network that included at least one paid caregiver. Respite use was higher among caregivers reporting greater strain (26.1% of those with substantial strain vs. 20.6% of those with moderate strain vs. 9.0% of those with low strain; $p = 0.002$). Other supportive services use did not vary with respect to caregivers' strain. (See [Supplemental Material Table A1](#) for unweighted frequencies and results of testing for between-group differences.)

4 | DISCUSSION

Among a national sample of community-living PwD categorized as likely meeting GUIDE program eligibility, half (49%) received help from two or more caregivers. One-third (32%) of caregivers for GUIDE-eligible PwD reported high strain, with emotional difficulty being the most common source of caregiving-related strain. Caregivers reported low rates of role-related training (11%), respite care (18%), and support group attendance (4%), and supportive service use did not notably vary by caregiver strain. Taken together, results raise questions regarding GUIDE's current approach to assessing and supporting caregivers, which relies on doctor identification and evaluation of a single, “primary” caregiver. Findings demonstrate how shifts in approaches to capturing caregiver strain alter who is considered “high-strain,” an important consideration in development of future strain-based performance measures. Additionally, findings illustrate notable gaps between needs of caregivers for community-living PwD and their access to supportive services and reinforce the importance of innovative programs, like GUIDE, aimed at facilitating dementia care planning²⁰ and expanding access to high-quality dementia care for community-living PwD and their families.

One of GUIDE's primary goals is to reduce care-related strain for unpaid caregivers of people living with dementia.⁸ Because GUIDE only considers a single, “primary” caregiver, many caregivers the

TABLE 2 Self-reported strain among caregivers of GUIDE-eligible persons with dementia.

Strain measure	Full sample <i>n</i> = 555	Caregivers whose strain is considered in determining payments <i>n</i> = 379 (73.7%)	Caregivers whose strain is not considered in determining payments <i>n</i> = 176 (26.3%)	<i>p</i> -value
Overall strain				0.08
Low	228 (41.2%)	173 (44.3%)	55 (32.4%)	
Moderate	119 (26.9%)	80 (26.7%)	39 (27.2%)	
High	191 (32.0%)	114 (29.0%)	77 (40.4%)	
Physical difficulty				0.67
Low	417 (80.1%)	294 (81.2%)	123 (76.9%)	
Moderate	65 (9.5%)	35 (8.8%)	30 (11.6%)	
High	64 (10.4%)	42 (10.0%)	22 (11.6%)	
Emotional difficulty				0.05
Low	265 (46.9%)	201 (50.8%)	64 (36.1%)	
Moderate	164 (32.3%)	98 (30.0%)	66 (39.9%)	
High	114 (20.9%)	71 (19.7%)	43 (24.1%)	
Financial difficulty				0.11
Low	449 (83.6%)	312 (85.3%)	137 (78.7%)	
Moderate	58 (9.7%)	41 (9.5%)	17 (10.2%)	
High	39 (6.8%)	21 (5.2%)	18 (11.2%)	
Feel like "you have no time for yourself"				0.003
Not so much	260 (52.6%)	197 (57.0%)	63 (39.9%)	
Somewhat	189 (31.0%)	123 (29.7%)	66 (34.6%)	
Very much	96 (16.5%)	52 (13.3%)	44 (25.5%)	
Feel like "you have more to do than you can handle"				0.05
Not so much	282 (55.1%)	214 (59.5%)	68 (42.8%)	
Somewhat	183 (31.9%)	113 (28.8%)	70 (40.7%)	
Very much	81 (13.0%)	46 (11.7%)	35 (16.5%)	
Feel like care recipient "gets on your nerves"				0.23
Not so much	204 (33.8%)	155 (36.5%)	49 (26.1%)	
Somewhat	299 (58.0%)	191 (55.7%)	108 (64.3%)	
Very much	43 (8.2%)	26 (7.8%)	17 (9.5%)	
Feel like "as soon as you get a routine going, care needs change"				0.24
Not so much	368 (67.0%)	268 (69.4%)	100 (60.3%)	
Somewhat	121 (22.5%)	74 (21.9%)	47 (24.3%)	
Very much	53 (10.5%)	30 (8.8%)	23 (15.4%)	

*Data drawn from 2022 National Study of Caregiving (NSOC).

program is intended to help are likely to be overlooked. Findings that GUIDE-eligible PwD often have two or more caregivers align with evidence that PwD, regardless of residential setting, more often rely on larger caregiving networks with more task-sharing between caregivers.^{3,4,21} Amid time pressures and limited guidance, it is likely that clinicians will rely on caregiver presence at the initial assessment

visit to determine whether the PwD is receiving caregiver assistance and to field questions regarding caregiver strain. Importantly, as providers receive higher payments when caring for PwD who do not have caregiver involvement, GUIDE participants have no financial incentive to seek out and engage with caregivers who are not present at the initial visit.⁹ Options to address this difficulty include: (a) amend-

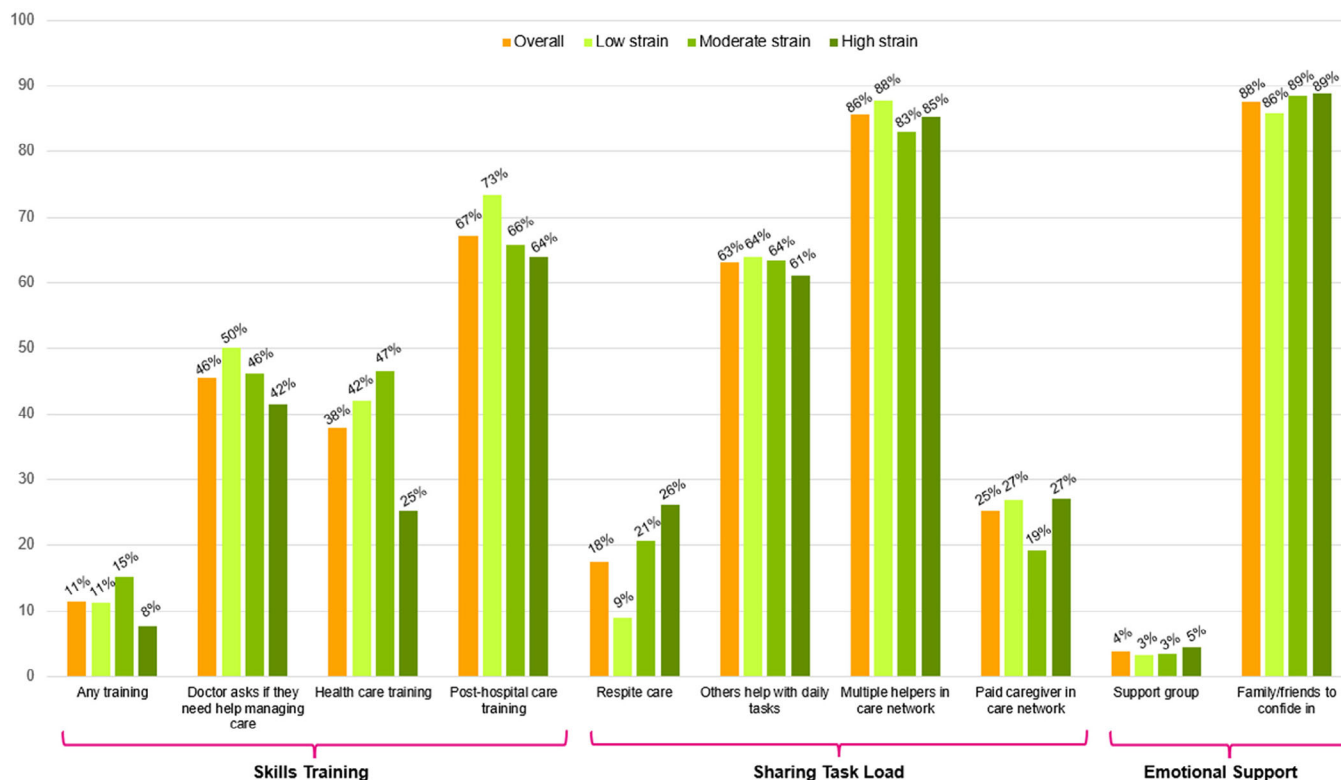


FIGURE 2 Supportive service use among caregivers for Guiding an Improved Dementia Experience (GUIDE)-eligible persons with dementia.

ing the initial assessment instructions to include specific prompts regarding the types of care received and who provides assistance; (b) abandoning the notion of a primary caregiver and instead focusing on an “accompanying” caregiver who is present at the visit; and/or (c) extending the opportunity for assessment to multiple caregivers for each PwD.

To receive higher payments and an expanded set of supports under GUIDE, a dyad must include a PwD with moderate or severe dementia and a caregiver with high strain. Dementia severity is an important driver of strain, but it is far from the only determinant. We found that one in four (26%) caregivers for GUIDE-eligible PwD would be considered part of low-complexity/low-payment GUIDE tiers because the older adult had moderate dementia or because the caregiver did not accompany them to doctor visits; among these caregivers, a sizable proportion (40%) were experiencing substantial strain. Considering caregiver strain as a standalone factor in determining complexity and resource needs in all cases (regardless of care recipient dementia severity) would better reflect the multifaceted realities of individual caregiver experiences.

Results from this study highlight the critical need for programs like GUIDE, aimed at facilitating caregiver engagement and support.^{6,22,23} This is the first study to provide national estimates of supportive service use among caregivers of community-living PwD. We found use of formal supportive services to be low and unrelated to caregiver strain. This lack of variability by caregiver strain is notable given alignment of these services with person-centered care and current understanding

of best practices related to managing dementia and reducing caregiver burden.^{1,2,24–27}

Caregiving tasks and associated challenges are wide-ranging, particularly in the context of supporting community-living PwD.^{1,6} This reality points to the need for an expansive and flexible definition of support that is responsive to caregiver needs and includes diverse competencies like navigating insurance, managing aides in the home, and developing skills to cope with stress. Caregiver needs may shift across the dementia disease trajectory, from emotional support and education on dementia shortly after diagnosis, to assistance managing paid aides, to guidance with long-term care planning toward end-of-life.^{23,24,28–30} Providers, in the GUIDE model and beyond, should be prepared with standardized tools to facilitate their efforts in assessing caregiver stress and capacity, determining appropriate resources (e.g., support groups, skills training, social work), and encouraging actual uptake of these services by caregivers. Expanded and accessible guidance for participating providers, including detailed toolkits with information on cultural considerations related to acceptability of various supports^{31,32} and techniques like motivational interviewing to encourage caregivers to make use of available services^{33–35} could increase the likelihood that GUIDE will fulfill its potential as a valuable source of support for caregivers. These resources could draw on existing work from advocacy and educational organizations including the Alzheimer's Association and Administration for Community Living, and be distributed directly to providers who are approved to participate in GUIDE.

4.1 | Limitations

Estimated GUIDE eligibility and determination of caregiver strain are based on available data elements in the NHATS and NSOC and may not reflect real-world assignment to a participating GUIDE provider or provider-led determination of caregiver strain. Use of supportive services was determined by caregiver self-report and is subject to recall bias. Additionally, while nationally representative, the NSOC provides a limited unweighted sample size that limits our ability to investigate differences for important population subgroups.

5 | CONCLUSIONS

Current guidelines surrounding caregiver identification and assessment under the GUIDE model may overlook the presence and needs of a significant number of caregivers for community-living PwD. Use of formal supportive services, including training and respite care, is low among caregivers for community-living PwD and does not appear responsive to caregiver strain. Policies and programs, like GUIDE, aimed at improving access to community-based supports for caregivers of PwD are sorely needed. To be equitable and effective, these efforts require careful attention to, and flexibility to accommodate, the complex and unique needs of these caregivers.

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CONFLICT OF INTEREST STATEMENT

Authors have no conflicts of interest to disclose. Author disclosures are available in the [supporting information](#).

CONSENT STATEMENT

Informed consent was not necessary as the present research does not meet requirements for human subjects research.

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SUPPORTING INFORMATION

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

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