

Portraits of CARE



Research Summary Report: USA

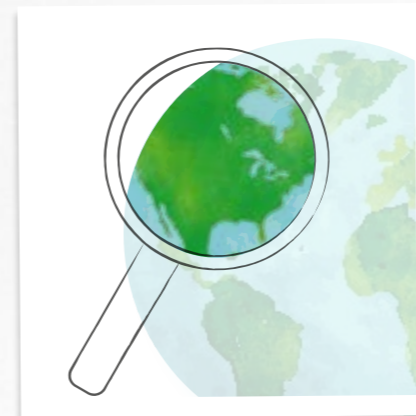


What is the purpose of this research?

The Portraits of Care study was designed to understand more about what it is like to care for someone living with Alzheimer's disease.

The researchers used both surveys and interviews with informal care-givers (a term which means people who are not being paid to care for someone) in four countries: **United Kingdom (UK), United States (US), South Africa and Brazil**. These four countries highlight the diversity of healthcare systems, cultures and average income for households.

The study was carried out by researchers at the University of Westminster (based in London, UK), in partnership with Alzheimer's Disease International (ADI) and Roche. Roche provided funding and, alongside ADI, took part in the development and design of the study. In the US, the study was supported by the Alzheimer's Association who helped communicate information about the study to people who might want to take part.



This summary describes the findings from the Portraits of Care research in the US. We want to thank everyone who took part, and especially thank the people who shared their photographs and personal experiences with us. It was a real privilege to hear these stories. We know that participating in research takes time, and finding time is difficult when you have a caring role, we are grateful for your help in being able to tell more people about these experiences. We want to thank the Alzheimer's Association for supporting our recruitment with a listing on TrialMatch®.

How did the researchers collect information?

There were two parts to this study.

The first part was a series of questions in an online survey. Caregivers' answers helped the researchers to understand more about the experience of caring for a loved one with dementia, particularly during the COVID-19 pandemic. Questions caregivers were asked included how caregiving impacted their mental health and wellbeing, the extent to which they experienced symptoms of depression and anxiety and felt lonely, and how much of their time and effort is taken up by caregiving. **In the second part of the study, a smaller number of caregivers in each country who completed the survey took part in interviews about their experiences.** Photo elicitation – a research method which involves participants taking photos of meaningful objects or places and discussing these during interviews was used in this part of the study.

What happens now?

The study partners hope that findings from Portraits of Care will help to strengthen Alzheimer advocacy efforts and guide improvements to carer support services.

By sharing care-giver experiences more widely we hope that people will learn more about what it's like to be a care-giver for someone living with Alzheimer's disease. Maybe these insights will inspire others to think about how they might be able to offer support or resources from a personal or professional perspective.



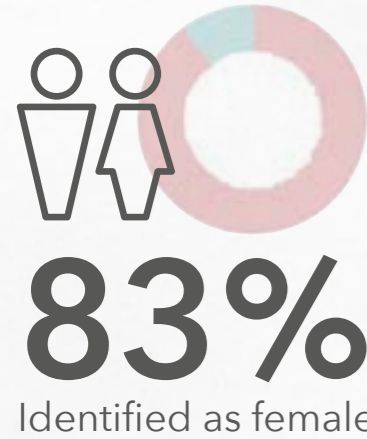
Who took part?



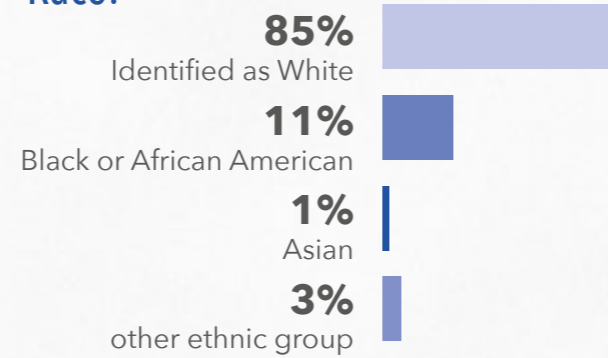
In the US, 216 caregivers completed the online survey* of these respondents, 10 took part in in-depth interviews.

Among the survey participants:

Gender:



Race:



The study partners and local organisations aimed to recruit as diverse a sample of participants as possible to take part in Portraits of Care. However we recognise that despite best efforts our sample is not as representative as we would have liked. We acknowledge there is more to do to encourage participation in dementia research.

Employment:



Age:



Health:

85% of caregivers rated themselves to be in **good, very good, or excellent** overall health



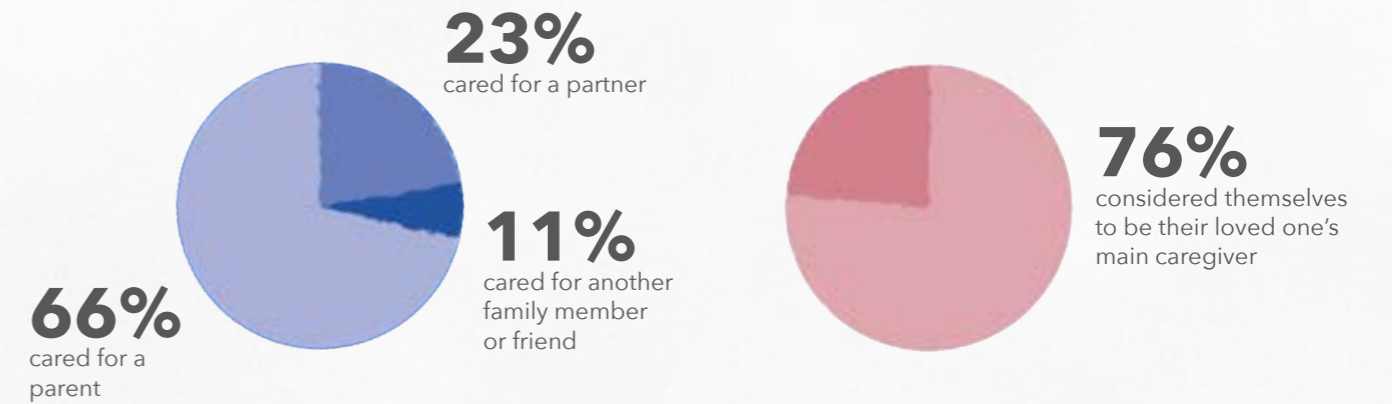
*Please note that some participants chose not to answer every question within the survey.

Who did they care for?



Caregivers shared information about the people they cared for:

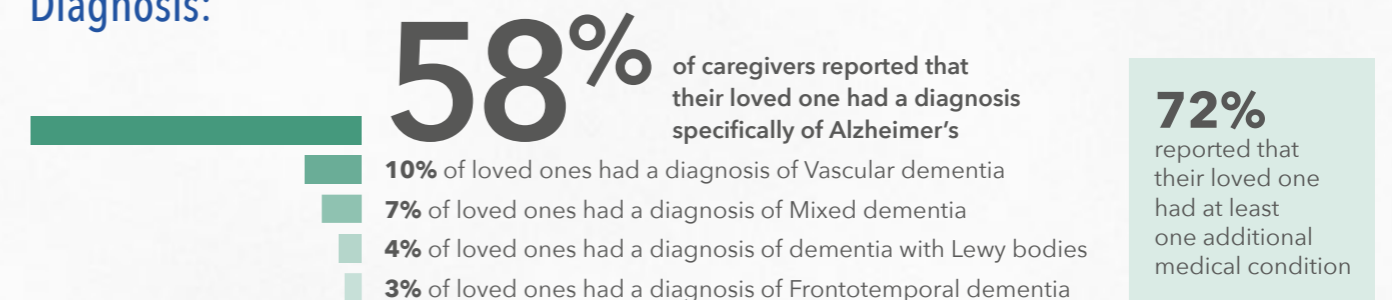
Carer relationship:



Severity:

41% of caregivers said that their loved one could not function independently or be taken outside the home because of their dementia

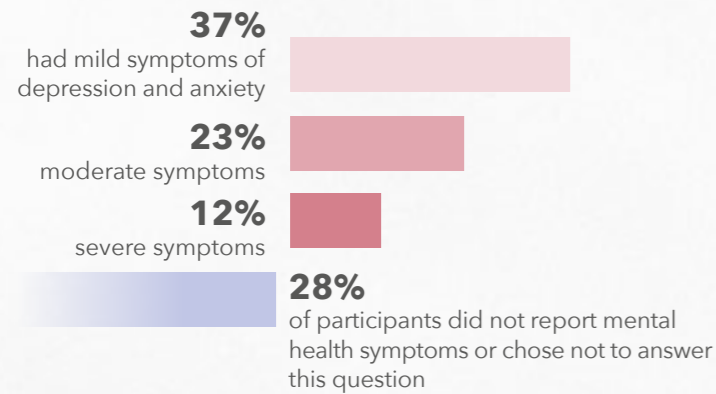
Diagnosis:



The remaining percentage indicated an "other" form of dementia or did not answer this question

What were the impacts of caregiving?

Mental health:



Poorer mental health was linked to:

- Being a younger caregiver
- Caring for someone with more severe dementia
- and lower perceived community standing (how they saw themselves in relation to others in their community)

Loneliness:

Participants were asked about the extent to which they felt they lacked companionship, felt left out, or felt isolated from others.

On average, participants in the US were found to be on the borderline of loneliness (based on how they responded to the survey questions).

Increased loneliness was linked to:

- Caregiving for a greater number of hours per week
- Lower perceived community standing
- And identifying as female

Caregiver burden:

Caregivers also shared information about how much time and effort was taken up by their caregiving role: the extent to which the person they care for is dependent on them and needs their help with day-to-day tasks.

Higher caregiver burden was linked to:

- A higher severity of dementia in the person they cared for
- And living with the person they cared for

Employment changes:

71%

reported changes to their working status since taking on their caregiving role, in which:

- 24% had to reduce their working hours
- 20% had to stop working altogether
- 2% had to change their job
- 27% reported other additional impacts (including needing to take unpaid time off, and affecting perceived quality of work)

Interview Insights

Interviews revealed additional impacts of the caring role in several different areas. There were **financial, physical, and mental** burdens all associated with caregiving. Sometimes these were complex and resulted in guilt around decision-making (for example deciding to place a loved one in a care home full-time).

Caregivers talked about financial and practical considerations, and emphasised how impacted they were by the physical aspects of caregiving (for example increased laundry and helping loved ones with personal care).

“

There's all kind of difficulty associated with that [relative's end of life care], whether it's just the grief of seeing a loved one there, or the ...you know, quite honestly, the expense of having a loved one in a... you know, that has no quality of life, and you're still paying a lot of money for their care.”

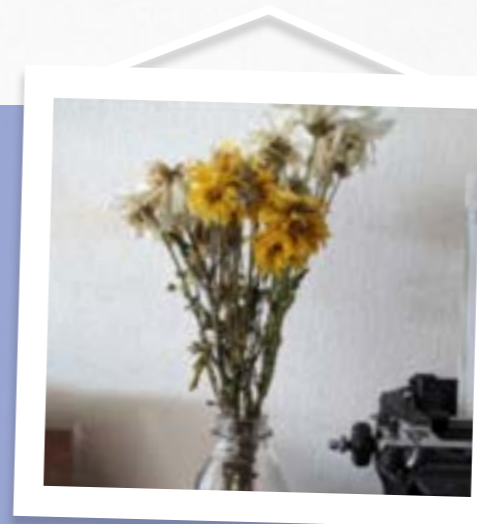


(Lorraine, F, 66, caring for her mother)

...my mother has taken a sharp decline um, with the onset of some physical problems and the continued cognitive decline. And I feel as a care giver, I'm feeling a bit overwhelmed. I feel like I'm flying near a flame.”

“

...after working eight hours a day, um, I log off my computer and I have another job to go to.”



(Ellen, F, 40, caring for her mother)

...I feel like, dried up, and wilted, and (Laughs) there are pieces of me all over the place (Laughs). So, yeah, I mean, definitely, that would, that's what that picture embodies, for sure.”

How satisfied were caregivers with the support they received?

Caregivers rated how satisfied they felt with support they received from the following sources for their caring role:

- Family
- Friends
- Local community
- Support groups (carer groups, Alzheimer's charity groups, and online groups)
- Healthcare services
- Practical/physical support (for example paid carers within the home).

Satisfaction ratings were:



Highest for support from family, friends, and health services



And lower for support from the local community and organized groups

However, many caregivers did not use formal support groups at all:



38% didn't access carer groups



44% did not access Alzheimer's charity organized groups



And **45%** did not access online support groups

Interview Insights

Interviews revealed that peer support (by others with informal caregiving experience) in particular had several unique benefits, including promoting a sense of shared understanding and companionship, which could help caregivers feel less alone.

Many caregivers stressed how grateful they were for this type of support during challenging times. One caregiver highlighted increased challenges to accessing support for caregivers of loved ones with less common presentations of dementia.



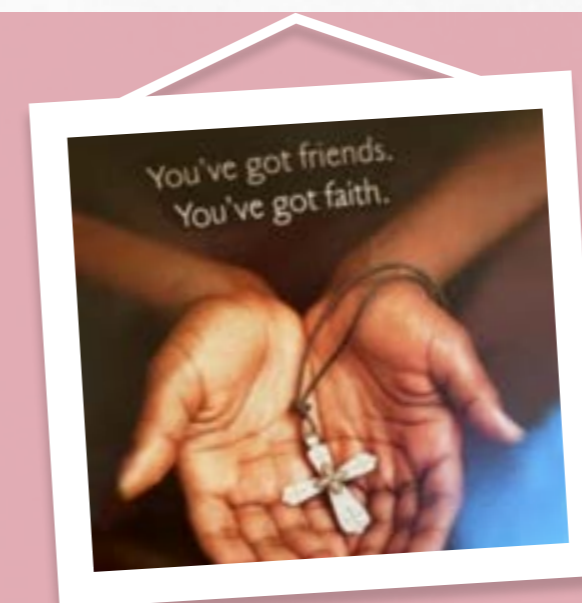
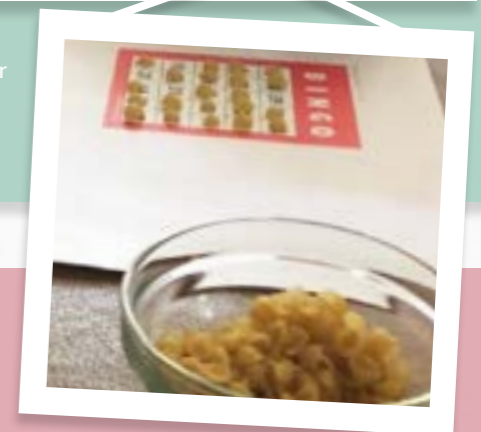
...it does seem like the Alzheimer's Association is more involved with the, the larger part of the Alzheimer's community...And there's just not a lot of support for early-onset, um, patient management. So, I think that's been a frustration, a little bit..."

(Cole, M, 60, caring for his 58-year-old brother with early onset Alzheimer's)



what really help, helped us get through, I would say saved us was, um, the Triple-R programme (...) every day they had something different. One day they'd have like chair exercises, uh, they played bingo. The picture of [my husband] playing bingo online, um, he liked doing that."

(Sarah, F, 75, caring for her partner)

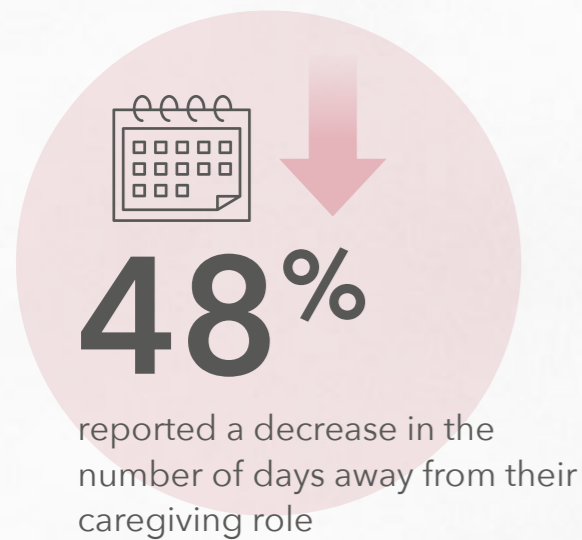


My cousin gave me... that card [photo pictured]. He, his mother had uh, Alzheimer's, um, and it got really, really bad. And he was the caretaker for his mom, my aunt...he wrote...some very encouraging words for me as a caretaker to mom. And um, that really meant a lot."

(Denise, F, 51, caring for her mother)

How did the COVID-19 pandemic impact caregivers?

Participants reflected on how they felt the COVID-19 pandemic affected their caregiving role and access to both practical support and support for their own wellbeing.



When asked about access to support throughout the pandemic, caregivers reported impacts on both accessibility of different sources of support during this time, and the mediums by which support was received.

All support systems were disrupted in some way for at least some caregivers, whilst only a minority experienced increased access to support during this time.

Interview Insights

In interviews, several caregivers shared how they felt the pandemic had accelerated the worsening of their loved one's dementia through the increased social isolation forced upon them.

There were also additional burdens associated with caregiving during this time, such as looking after a relative who was now clinically vulnerable to COVID.



...I wonder if, um, if that level of socialisation [pre-pandemic] remained, where she was, you know, going and talking to people and having conversations, um, you know, if, if her communication would have not declined, or... if it was going to decline, not as, as bad as it is now "

(Ellen, F, 40, caring for her mother)



So, during the pandemic, we'd get kind of antsy and we'd go over, a couple of times we went over to the park. That's where we took our sandwich, just to get out"

(Sarah, F, 75, caring for her partner)



She [participant's mother] used to attend a wonderful adult day care programme, they closed. And when they reopened..they had reorganised...they no longer were going to accept severe people [dementia severity] because they had laid off their personal care staff to save money. So that was the biggest change in terms of trying to get my household responsibilities, my administrative stuff, my self-care done during the day, and also take care of her."

(Lorraine, F, 66, caring for her mother)



I sew but I had no time to be sewing with trying to care for him. So, his sister made the masks that I sent in the pictures...Trying to put that on his was a super challenge"



(Eloise, F, 73, caring for her husband)

What would make the caregiving role easier?

In the survey, participants gave insight into what things they felt would make caring for their loved one easier for them.



83%

more practical support



81%

more emotional support



78%

more breaks from their caregiving role



70%

more financial support



42%

felt more information and classes about Alzheimer's would be helpful



Interview Insights

In interviews the need for additional financial support (and increased awareness of available support) came through particularly strongly due to the significant expense of long-term care in the US.

The value of having financial assistance was often highlighted, with several caregivers also mentioning Medicaid (a health insurance programme for people with limited resources) as a useful way of relieving some of the financial burdens of caregiving. Interviews also highlighted nuances to support needs, for example emphasising how crucial it was that practical support was high quality and appropriate to the specific situation. If this was not the case, this could make the caregiving role more stressful.

“

Here in the US especially, like, it's so expensive [professional assistance such as paid carers] that people go without, and then their lives are ruined ...Um, I don't know that everyone necessarily knows that you can get free support out there. Making that information more well-known, so people don't have to go digging around for it.”

(Ellen, F, 40, caring for her mother)

“

I think the carers just need, um, a respite every now and then. It doesn't have to be three times a week, like I'm lucky to have. It can be even once a week, but you know, even two hours helps a lot

(JLS, F, 39, caring for her mother-in-law)

“

I, I had one agency...who gave me a gal who it turned out, um, had, um, a phobia I guess you could say, uh, to, um...changing him. And, um, I (laughs), just said, “She is not suited for this work, you, you know? You've got to be able to do this. This is not acceptable.”

(Eloise, F, 73, caring for her husband)

“

There is so much research being done about the disease, um, and about prevention, and about, um, you know, medical interventions and, and testing, and stuff like that. Um, and I feel like caregivers, a lot of the time, are an afterthought.

(Ellen, F, 40, caring for her mother)