

# Portraits of CARE



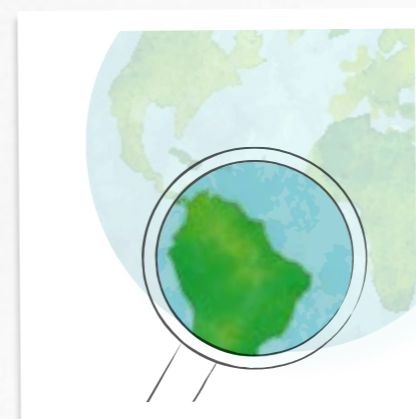
## Research Summary Report: Brazil

## 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 caregivers (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 Brazil, the study was supported by Febraz (Federação Brasileira das Associações de Alzheimer) 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 Brazil. 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 also want to thank Febraz, our local association partner in Brazil and the Universidade de Londrina who supported our research.*



## 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 Brazil**, 109 caregivers completed the online survey and of these respondents, 10 took part in in-depth interviews.

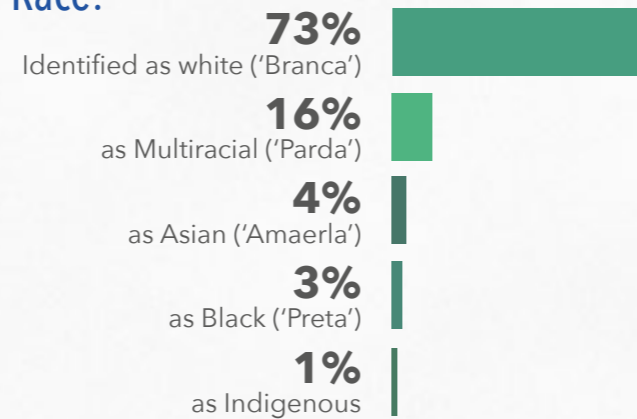
### Among the survey participants:

#### Gender:



**80%**  
Identified as female

#### Race:



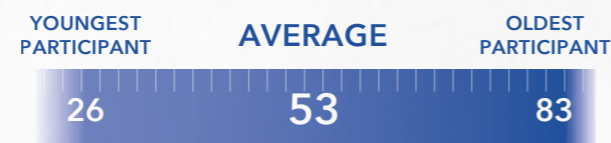
The study partners and local organisations aimed to recruit as diverse a sample of participants as possible to take part in Portraits of Care. However we recognise that despite best efforts our sample is not as representative as we would have liked. We acknowledge there is more to do to encourage participation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

#### Employment:



**37%** were employed either full- or part-time

#### Age:



#### Health:

**69%** of caregivers rated themselves to be in **good, very good, or excellent** overall health

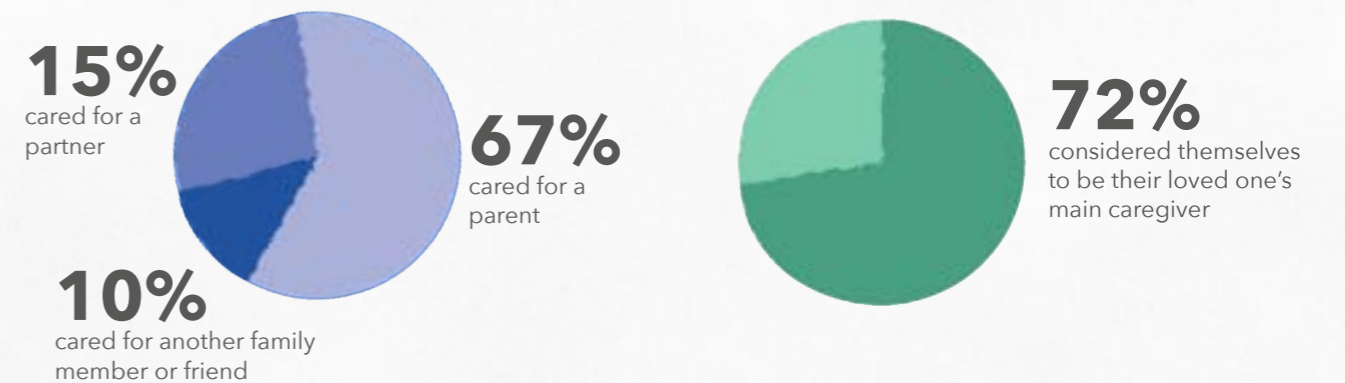


\*Please note that some participants chose not to answer every question within the survey.

## Who did they care for?

### Caregivers shared information about the people they cared for:

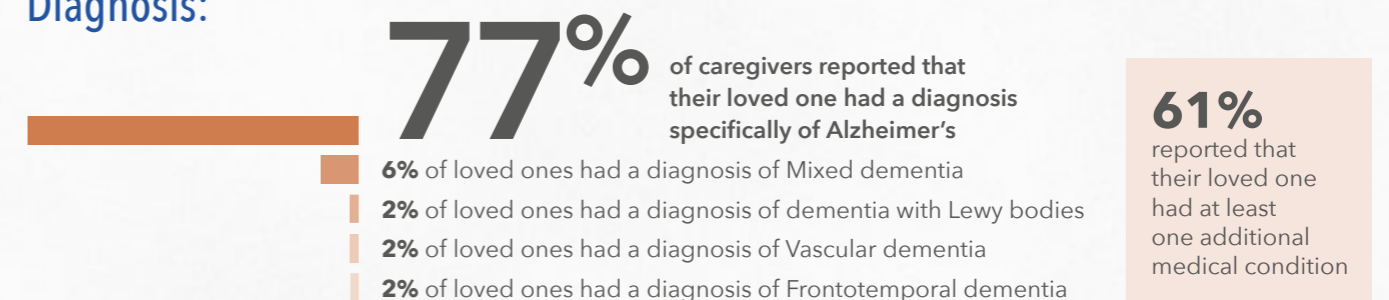
#### Carer relationship:



#### Severity:

**47%** of caregivers said that their loved one could not function independently or be taken outside the home because of their dementia

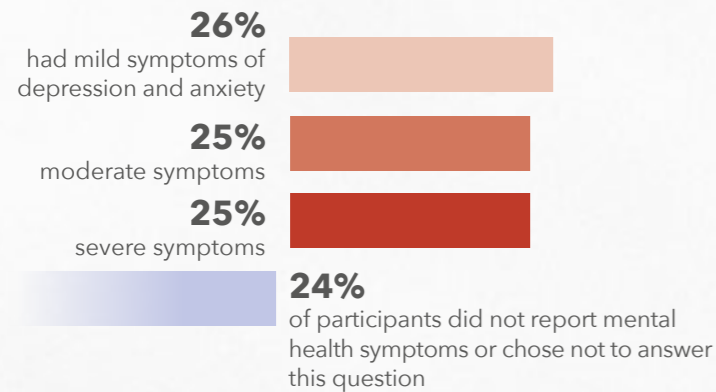
#### Diagnosis:



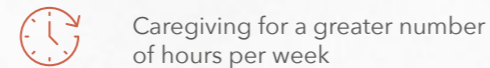
The remaining percentage indicated an "other" form of dementia or did not answer this question

## What were the impacts of caregiving?

### Mental health:



#### Poorer mental health was linked to:

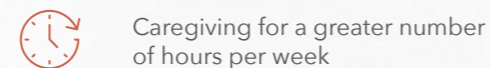


### Loneliness:

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 Brazil were found to be lonely (based on how they responded to the survey questions).

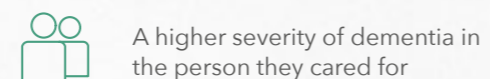
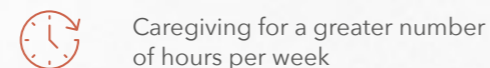
#### Increased loneliness was linked to:



### 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.

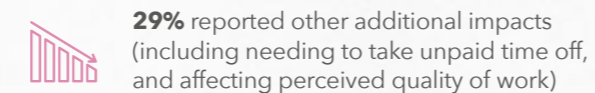
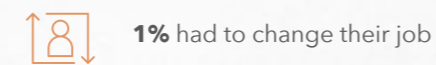
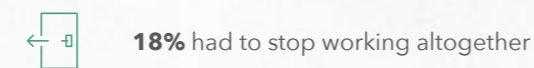
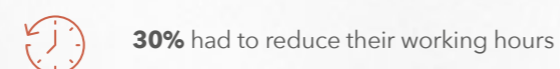
#### Higher caregiver burden was linked to:



### Employment changes:

# 78%

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



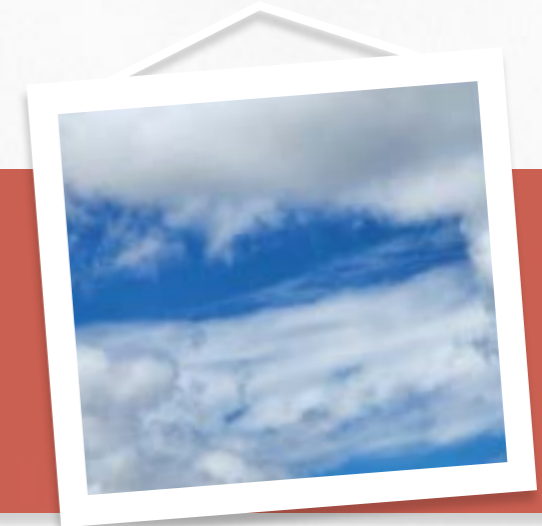
## Interview Insights

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.

“

**It's a metaphor for a prison, that you are looking at the sky...the passage of the world out there (...) the caregiver is trapped"**

(Antonio, M, 42, co-caring for his father)



“

**Over time...I constructed my own understanding of caring. Today, I view it as playing a significant role in the community"**

(Camila, F, 28, co-caring for extended family member)

Interviews revealed that some caregivers in Brazil also perceived important positive aspects to caregiving and found that there could be moments of joy within this. For some, recognising these helped foster increased acceptance of their role and positively impacted the caregiver's own wellbeing.

**"I had the chance to repay my mum and father for some of the things they had done for me."**

(Rehira, 58, caring for her mother)

“

**It's not an obligation, it doesn't have to be that way, it doesn't have to be that heavy."**

Participant is describing how her mother, living with Alzheimer's, became positively involved when the participant adopted two children and helped to prepare their rooms for their arrival.



(Vida, F, 48, caring for her mother)

## 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 with support was lower than in the US and UK, with:



**Over 40%** reporting poor satisfaction with support from friends and family

And **over half** being unsatisfied with support from their local community



The majority of caregivers did not utilise Alzheimer charity groups or online support groups



## Interview Insights

However, interviews also revealed some positive experiences with particular sources of support, particularly Brazil's Unified Health System (SUS). Additionally, several participants expressed satisfaction and gratitude for practical support they had accessed from both the state and private sectors. It was recognised that access to high quality support was not universal across the country.



**It was [paid caregiver], who I considered to be an angel in my life"**

(Vida, F, 48, caring for her mother)

Dissatisfaction was however expressed with the financial cost of additional support (e.g., additional medications) in addition to the cost of therapy for caregivers to support their own mental health, and it was recognised by a few participants that access to high quality support was not universal across the country.



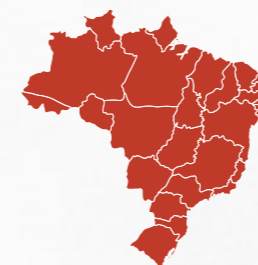
*The treatment is very expensive and those who don't have the money, the government gives a diaper (...) how can someone in retirement afford medication?"*

(Vicente, M, 75, caring for his wife)



**I think I pretty much use SUS. I feel like I am in excellent hands"**

(Rosa, 65, caring for her mother)

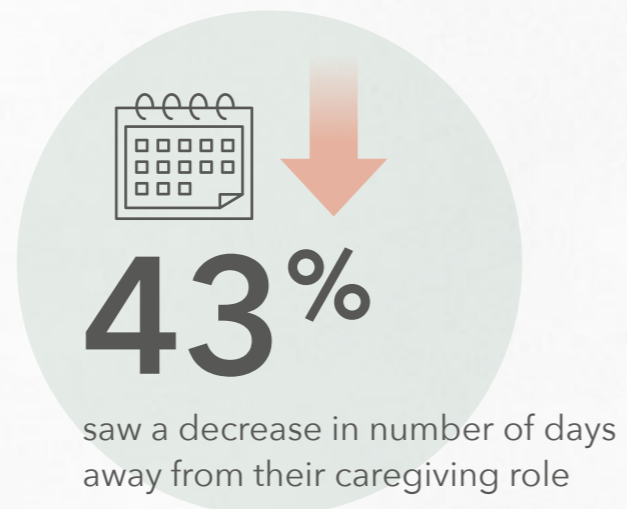


Caregivers in Brazil who took part in interviews were generally unaware of available support from Febraz. Several mentioned not knowing about available support in their specific region when asked.



## 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.



The COVID-19 pandemic changed how caregivers could access and use services. Caregivers told us that some services moved online, some services were cancelled and that overall services became more difficult to access. Only a minority of survey respondents reported using more services during this time.

## Interview Insights

In interviews several caregivers shared how the isolation that came about due to the pandemic had negative impacts such as increased mental burden from worry about exposing vulnerable relatives to COVID, in addition to impacts on their own wellbeing and support systems.

“  
*There was fear and increasing insecurity, along with a genuine fear of getting ill and passing away as a result of the situation (...) it didn't increase any workload because it's a full time here (laughter). What happened was increased seclusion... we abstained from going outside”*

(Girassol, M, 38, caring for his parent)

“  
**I had severe COVID, I was hospitalized for nine days (...) It was pretty traumatic. And I worried about her a lot”**

(Bruna, F, 45, caring for mother)

“  
**Being the one who stayed with her the longest throughout the pandemic made things really difficult [comparing to other family members]. Mostly due to our fear. Fear of her having COVID...The mask in the photo is one I frequently wore throughout the pandemic. I used it frequently... it was my partner.”**

(Camila, F, 28, caring for extended family member)



## 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.



93%

felt more emotional support would be helpful



92%

more practical support



84%

more breaks from their caregiving role



84%

felt more information and classes about Alzheimer's



77%

more financial support

## Interview Insights

Several participants mentioned the need for financial support to cover the costs of medication, home-help and support equipment. Other suggestions included educational training, respite care, therapy for carer's mental health, and support from Alzheimer's experts.

“

*The Alzheimer's association should give full support to caregivers”*

(Vicente, M, 75, caring for his wife)

“

*Financial support... because it is very expensive.”*

(Bruna, F, 45, caring for her mother)

It emerged during interviews that a number of caregivers felt that more information about Alzheimer's and how to be a good caregiver would have been particularly helpful to them - particularly after their loved one's initial diagnosis - after which several shared how they felt lost or out of their depth.

“

**I would say that having a ton of information... is vital”**

(Camila, F, 28, co-caring for extended family member)

“

*Though mental illness is still a stigma and is the hardest thing in the world... I believe it has less impact if you have access to information.”*

(Rosa, F, 65, caring for her mother)