

Portraits
of
CARE



Research Summary
Report: South Africa

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 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 South Africa, the study was supported by Alzheimer's South Africa 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 South Africa. 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 Alzheimer's South Africa, our local partner for their support, and the Bessie Makatini Foundation.

How did the researchers collect information?

The larger study had two parts. 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 in-depth 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.

Survey uptake was low in South Africa due to technological challenges. This summary presents findings from the interviews.

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 caregiver experiences more widely we hope that people will learn more about what it's like to be a caregiver 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?



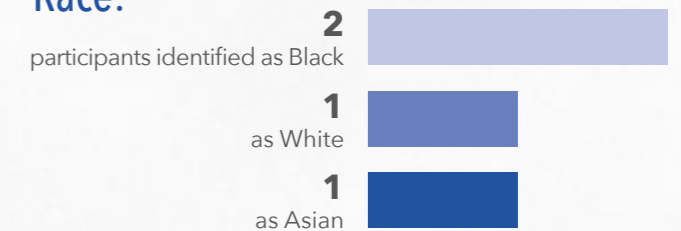
In South Africa, four caregivers took part in in-depth interviews.

Among those interviewed:

Gender:



Race:



Age:



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.

Who did they care for?

Caregivers shared information about the people they cared for:

Carer relationship:



All participants identified themselves to be their loved one's main caregiver



All participants cared for a parent



2 shared that their parent(s) could still manage simple activities at home,



and 2 shared that they could no longer function independently due to their condition



3/4  of the participants lived with the person they cared for

What were the impacts of caregiving?

Attitudes towards caring for a parent

Acceptance of the caregiving role and responsibilities that come with caring for a parent was a strong theme identified in interviews with all caregivers in South Africa. Family members talked about coming to terms with difficult emotions.

Some caregivers shared how this acceptance contributed to their own psychological wellbeing, though challenges were still faced and acknowledged.

“
Don't try to fix it. Don't try to fight it, learn... learn as much as you can”

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

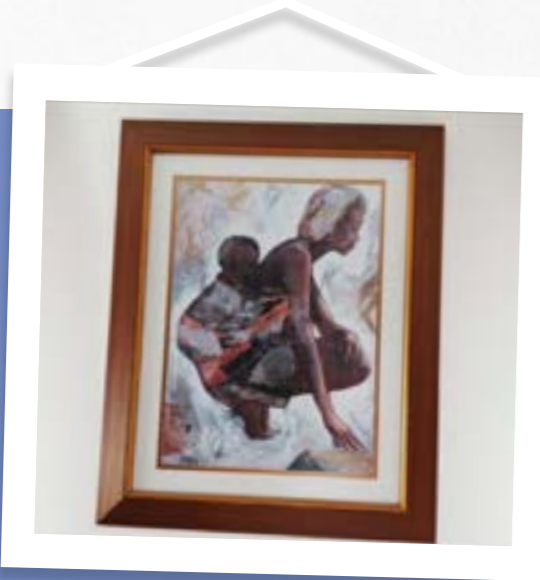
“
...I felt with my mom's condition, not understanding a long time, very ashamed that I can have this ambivalence. I love my mom, but hell. She's playing a mind game with me...I felt totally out of control.”

“
I think I'm in acceptance phase now”

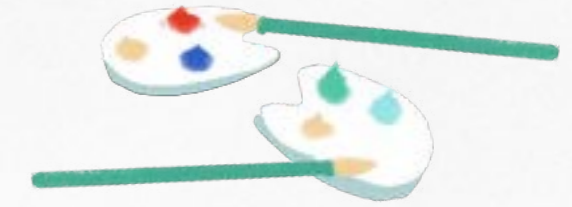
(Mara, F, 59, caring for her mother)

“
at times I do feel like, you know, that lady...with the baby on the back... Because, you know, life almost goes full circle or that's what I've seen...it's not a burden... but you...you still get frustrated”

(Asanda, F, 47, caring for both her parents)



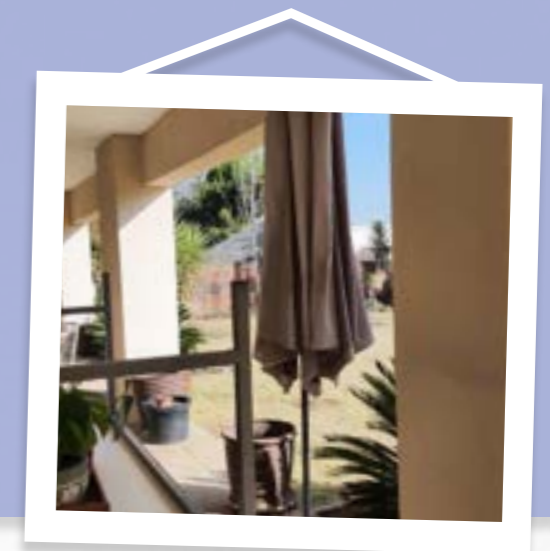
Emotional impacts of caregiving



“
...I think the umbrella, I think the only reason why I took a picture of that is it...it provides shade from the heat...And I think it's been like that, you know, to look after my parents, you know.”

“
Some days are hot and beautiful. Some days are stormy and rainy. Some days are windy. Um, and...and that umbrella, it can take it, but it does get damaged.”

(Asanda, F, 47, caring for both her parents)



“
INTERVIEWER:
So on that note, what is being a caregiver like for you?”

“
PARTICIPANT:
A caregiver? Difficult... [laughs] frustrating, one has to have a lot of patience”

(Akira, F, 58, caring for her mother)

“
it was for me, a lot of guilt.”

(Mara, F, 59, caring for her mother)

How were caregivers supported?

Charity support

Some caregivers shared that they were not familiar with Alzheimer's SA. Other charities which participants had used included the Bessie Makatini Foundation (BMF), Caritas, and smaller regional not-for-profits who offered education about dementia and support to caregivers.

“our NGO sector is under severe, severe strain...Financially, argh all the ways. Yes. It is under severe strain.”

(Mara, F, 59, caring for her parent)

“I had the BMF Foundation helping me with the information and whatnot and how to treat her and everything. So at least I was a bit more equipped on how to deal with it.”

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

Keeping in touch via messaging apps

All participants spoke about using the messaging app WhatsApp to connect with and receive support from others. This included using it to speak with the Bessie Makatini Foundation staff, engaging in a virtual support group for education about dementia and caregiver wellbeing, and for staying in touch with healthcare services. This was seen as an important and convenient way of reaching out for support and feeling connected to others.

“The BMF foundation sister, I think that's the only person that at times I speak to... On a WhatsApp.”

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

“She [lady who runs support group] has virtual, you know, meetings where she invites specific guests... That specialize in dementia.”

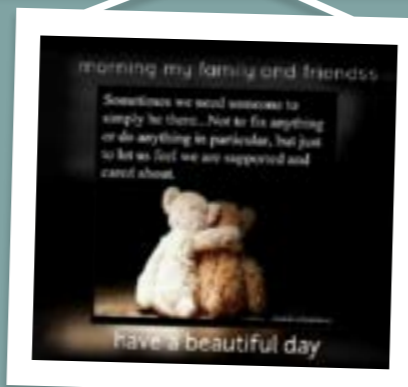
(Asanda, F, 47, caring for both her parents)

“..they've got a support going and I'm very grateful...we are in touch on WhatsApp. I'm looking young again and yeah, it's just shar...sharing the emotions and maybe all the guilt and the stuff that you actually don't want to acknowledge. It's a very good platform and it's a growing... growing platform.”

(Mara, F, 59, caring for a parent)

“...thanks God, that I actually have friends that care.”

(Akira, F, 58, caring for her mother)



How did the COVID-19 pandemic impact caregivers?

Getting support

The COVID-19 pandemic impacted on caregiving in a number of ways. This included challenges in accessing medical support. For example, it could be difficult to get local doctor's appointments, which were still face to face. And when there was a medical emergency, such as a loved one having a fall, it could be a long wait for medical treatment because of COVID. In hospital, also, family members were not usually allowed to be with their loved one, which could cause additional stress.

“I didn't really get in touch with them [charity group, during pandemic]...I didn't really have a, uh, contact number...It's only basically after the pandemic that, um, there was a new social worker that would actually, um, you know, get in touch and say to me, listen, here's my WhatsApp, here's my email, here's my contact number.”

(Akira, F, 58, caring for her mother)

Adjusting to COVID-19

There was a period of lockdown when people were having to adjust to being at home with their loved one. This could be more difficult where there were three generations living together in a small home. One woman caring for her mother moved her mother in with her during the pandemic and found it a big adjustment:

“She's just washing the whole day. One pants in the washing machine, second cups of coffee, the one after the other, you know, so that the whole extent... actually, of my mom's disease thing was sort of... really living with us now.”

(Mara, F, 59, caring for a parent)

“I think we, we all suffered from cabin fever ... it was difficult to even leave the house to just have a moment to yourself”

(Asanda, F, 47, caring for both her parents)

“That part was kind of difficult having to get her to... to put on her mask. Having to... to sanitize all the time. Cause she just couldn't like, uh, follow those kind of rules all the time. So I had to be constantly around her. Reminding, sanitized, reminding her when she's going out to put on your mask.”

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

What would make the caregiving role easier?

All caregivers who took part made suggestions as to what they felt would make caring for a family member easier and what might help other family carers feel more supported. Increased mental health support for informal caregivers emerged as particularly important, in addition to further practical support in relation to the person living with Alzheimer's, for example more availability of outreach visits and respite care in order to enable caregivers to have time for themselves.

"I would like her to be looked after during the day and then come back in the afternoon and fetch her...we don't have something like that [in town]"

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

"I think I would also like some psychological help."

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

"maybe a bit of emotional support for carers"

(Asanda, F, 47, caring for both her parents)

A common theme was also the importance of connecting with others going through the same experience, whether it is for emotional support or practical information.

"talk to the people who walk the road"

(Mara, F, 59, caring for her mother)

"Google's not the same as maybe someone explaining that knows and understands what that person is going through."

(Akira, F, 58, caring for her mother)

Some caregivers recounted difficulties with healthcare professionals which made them feel less supported and informed and could contribute to feelings of frustration. These included limited information and guidance given by medical professionals, and seemingly limited specialist understanding of Alzheimer's from these services (e.g., viewing it as just 'old age') in several cases, suggesting a need for more widespread awareness of Alzheimer's within broader healthcare services and increased input from specialists.

"I wouldn't say there was any help from the health sector, except for me going to the appointments, getting a medication and then coming back, there's nothing much"

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

"[The doctor] he was very, um, helpful you know and the questions that he had actually asked, and I thought, wow, you know, that's not something that I would've thought of"

(Akira, F, 58, caring for her mother)

INTERVIEWER:
"And do you think that they [doctor] understood about the Alzheimer's?"

PARTICIPANT:
"No. No. No. She's just old. No, she's just old."

(Mara, F, 59, caring for her mother)