



Title Universal challenges of caring for someone living with dementia: experiences from the UK and Brazil

Item Type	Journal Article (Version of Record)
UoW Affiliated Authors	Masterson Algar, P., Naunton Morgan, B., Hedd Jones, Catrin, Torres Mattos Bezerra, E. and Windle, G.
Full Citation	Masterson Algar, P., Naunton Morgan, B., Hedd Jones, Catrin , Torres Mattos Bezerra, E. and Windle, G. (2025) Universal challenges of caring for someone living with dementia: experiences from the UK and Brazil. Journal of Dementia Care, 33 (MarApr). pp. 32-35. ISSN Print: 1351-8372
DOI/ISBN/ISSN	ISSN 1351-8372
Journal/Publisher	Journal of Dementia Care Dementia Community
Rights/Publisher Set Statement	© 2026 Dementia Community Permission to post copyedited version received via email from editor on 27/09/24
License	n/a
Link	<a href="https://journalofdementiacare.co.uk/article/universal-challenges-of-caring-for-someone-living-with-dementia-experiences-from-the-uk-and-brazil">https://journalofdementiacare.co.uk/article/universal-challenges-of-caring-for-someone-living-with-dementia-experiences-from-the-uk-and-brazil</a>



# Universal challenges of caring for someone living with dementia – experiences from the UK and Brazil

*Masterson Algar P et al (2025) Universal challenges of caring for someone living with dementia . Experiences from the UK and Brazil. Journal of Dementia Care 33(2) 32-35.*

**Patricia Masterson-Algar and colleagues in Wales and Brazil engaged with family carers in both countries to explore the similarities and differences in their experience of their caring roles. They identified common themes and produced a short film that can be used for discussion and training.**

This article discusses the experiences of families in the UK and Brazil caring for someone living with dementia. As our populations age, dementia becomes a significant global health concern. In the UK, where the average age is rising, it is estimated that by 2051, over 2 million people will be living with dementia (Prince *et al* 2015). Globally, approximately 50 million people are living with dementia, with a significant portion residing in low to mid-income countries like Brazil (Alzheimer’s Disease International [ADI] 2016). Around 77% of people with dementia in Brazil are undiagnosed, posing challenges for awareness and treatment efforts (Nakamura *et al* 2015). Despite the World Health Organization labelling dementia as one of the greatest healthcare challenges of the 21st century, Brazil has yet to develop a national dementia plan. While 31 countries have such plans, including the UK (WHO 2017; ADI 2020; Engedal & Laks 2016;

Oliveira *et al* 2021), there is still much progress needed globally to support nations in addressing dementia comprehensively.

With more people expected to take on caregiving roles for family members with dementia, understanding the experiences of carers becomes crucial. In both the UK and Brazil, the majority of care for people living with dementia is provided by family members, often women (WHO 2017; ADI 2020; Walter & Pinquart 2020). These caregivers, though often termed ‘informal’, perform tasks akin to professional caregivers, significantly impacting both the person living with dementia’s sense of self and their own mental well-being.

Research consistently shows that dementia caregivers face higher levels of stress, depression, and anxiety compared to those caring for people with other conditions (Yoon & Kim 2019; Gilhooly *et al* 2016; Lindeza *et al* 2020; ADI 2020). This burden was exacerbated by the COVID-19 pandemic, leading to reduced support services and increased stress for caregivers. Despite the challenges, the work of caregivers benefits not only the person they care for but also society at large. Recognising this, the WHO emphasises supporting caregivers through accessible information and skills training to mitigate stress and health issues (WHO 2017).

Given the globalised nature of our world, understanding how different societies approach dementia caregiving is vital. However, most research in this area has been focused on developed countries, leaving a gap in understanding the experiences of caregivers in developing nations like Brazil. In response to this gap, our study explores British and Brazilian caregiving experiences, aiming to uncover common beliefs, challenges, and cultural influences. Additionally, we have created a teaching resource in the form of a short film to aid practitioners working with dementia patients and their caregivers in both countries. In essence, our research seeks to shed light on the diverse experiences of dementia caregiving, bridging gaps between nations and providing valuable insights to support caregivers globally.

### **How we gathered carers’ experiences in both countries**

This mixed-methods study explored the experiences of British and Brazilian carers of people with dementia, using arts and social science techniques. Participants were recruited from established dementia support groups in both

countries, facilitated by local authorities and third-sector organisations. Ethical approval was obtained, and data collection occurred through two focus group sessions at each site, led by experienced researchers. The first session explored carers' beliefs, challenges, and support systems, while the second session involved using visual arts to delve deeper into these topics. Carers used simple doodles to express their thoughts, which were later discussed within the groups. Data analysis involved thematic analysis of transcribed discussions, with common themes identified across both countries through iterative discussions amongst all research team members. Video recordings from the focus groups in both countries were edited into a fifteen-minute film produced in both English and Portuguese, summarising carers' testimonies and showcasing their doodles.

## Key points

- This article provides insights into how different societies view and experience living with dementia and the provision of family care.
- Focus groups were held with family carers from Brazil and Wales to explore the similarities and differences in how they approach their caring role.
- Carers were invited to share their thoughts and experiences in group discussions and also using simple art materials to doodle (draw).
- Common themes were identified between both groups, demonstrating a shared experience of caregiving across the globe.
- A short film that can be used for the training of practitioners who work with people living with dementia and their carers in both the UK and Brazil was created, available here: <https://youtu.be/oTCdQh7uhU0>

## Author Details

*Patricia Masterson-Algar\*, Bethan Naunton Morgan, Catrin Hedd Jones, Gill Windle, all at*

*Dementia Services Development Centre, School of Health Sciences, Bangor University, Bangor, UK.*

*Emanuela Bezerra Torres Mattos, Federal University of São Paulo, Santos, Brazil.*

*\*Email: [p.m.algar@bangor.ac.uk](mailto:p.m.algar@bangor.ac.uk)*

## Summary

As populations worldwide age, dementia becomes a pressing global health concern, which requires an understanding of caregiving experiences from different societies and cultures. This article examines the caregiving dynamics for people living with dementia in the UK and Brazil, where family members predominantly undertake caregiving roles. Through focus groups and art-based discussions involving carers from both countries, common themes of caregiving emerged, reflecting universal challenges and shared experiences.

The research highlights the significant burden faced by carers of people with dementia, including stress, depression, and a sense of isolation, exacerbated by the COVID-19 pandemic. Despite these challenges, caregivers play a vital role in supporting both the individuals with dementia and society at large. However, their own well-being often remains neglected, highlighting the need for comprehensive support systems.

Through thematic analysis, three overarching themes emerged: the struggle to accept changes, the lack of support for caregivers themselves, and the multitude of emotions experienced in the caregiving journey. These findings emphasise the importance of tailored support and peer networks to address caregivers' needs effectively.

Practitioners are urged to provide accessible information and skills training to empower caregivers, leveraging online interventions and peer support networks. Additionally, nature-based interventions are highlighted as beneficial for both caregivers and people living with dementia, promoting physical and mental well-being.

While this study sheds light on the shared challenges faced by dementia caregivers in the UK and Brazil, future research should explore the efficacy of e-health interventions and nature-based therapies in diverse caregiving contexts. Practitioners play an important role in advocating for caregivers' needs and implementing evidence-based interventions to enhance their well-being and resilience, ultimately improving the quality of dementia care globally.

## What we learned: Insights from carers' experiences

Participants from both countries eagerly shared their experiences as dementia carers during the focus groups. They also took part in a doodling activity, expressing their thoughts and feelings through art. Some drew their families, homes, or scenes from nature, while others used abstract designs to convey confusion and uncertainty (see Figures 1 and 2 further below).

We identified three main themes from the discussions, these are outlined below and illustrated with quotes from participants in Table 1, directly below.

Themes	Subthemes	Example quotes
<b>Accepting changes</b>	A new person	<i>'The deterioration starts, and you don't want to accept that. It's like a cycle that is going on every three to four months and I know he is never going to be the way that he was.'</i> (UK 2)
	A new reality	<i>'The problem was mine. I wanted another diagnosis, another doctor, someone who would tell me that it was something else. But that next person gave the same diagnosis and said similar things. And that was it.'</i> (Brazil 5)
<b>Who cares for the carers</b>	Nothing can prepare you – it is a 24/7 role	<i>'There is no training course; there is no manual that says, "this is the way it's going to go". And there is no time</i>

		<i>as to how things are going to progress.’ (UK4)</i>
	Family and friends	<i>‘I have only good things to say about my sons. One is an adolescent, and the other one is twenty-four, but they offer me a lot of support. But they have their lives to worry about. During holidays, they could help more, but I started to struggle when they had to return to their activities, and felt even more alone then, that was very difficult.’ (Brazil 6)</i>
<b>A million feelings</b>	The benefits of talking to others	<i>‘Those gatherings felt like going to a party. On that day, I felt alive. I had to work out how to manage to get there because my mum couldn’t be left alone. It did me good to have a commitment, to have a chance to share. You leave with ‘charged batteries’. (Brazil 8)</i>
	Finding peace in nature	<i>‘Being on the beach, walking on the sand, or taking her there and putting her feet on the sand. We go for walks by the water, to feel the</i>

		<p><i>wind, the pleasurable sound of the ocean. It's relaxing, and it's free.'</i> (Brazil 7)</p>
--	--	---

**Table 1: Main themes from the discussions**

### **Theme 1: Accepting changes**

Carers described their struggles with accepting the inevitable changes in their lives and in the lives of their family members living with dementia. Some carers conveyed their awareness of how, after diagnosis, they had remained in denial for a period of time. They explained that this was due to the fear of losing the person they love and fear of changes to their 'reality'.

### **Theme 2: Who cares for the carers?**

Unanimously, carers felt abandoned and unable to find the time to think about their own health and wellbeing. They felt as '*You can't count on anyone, so you feel lost*'. (Brazil 3). Lacking opportunities to have some time away from their caring role were recurring issues for participants. They shared their longing for enough freedom from their caring duties that would allow them to, for example, go to the doctor or simply go to the hairdressers.

### **Theme 3: A million feelings**

A wide range of feelings were reported by participants. Feelings of 'guilt' were often linked to the need to access caring facilities such as care homes. This transition was linked to the progression of the dementia and care needs of the carer and as a result not being able to provide care.

Importantly, these themes were consistent across both countries, highlighting the universal challenges faced by dementia carers.

### **Bringing it all together:**

#### **The shared challenges and hopes of dementia**

The findings of our study highlight the shared challenges experienced by dementia carers in both the UK and Brazil, underscoring the relentless nature of their role and the struggle to balance caregiving with self-care. Anticipatory grief, characterised by feelings of loss and sadness, was evident among carers as

they navigated the gradual decline of the person they care for. The pandemic exacerbated these challenges, further isolating carers and reducing access to support services.

Practitioners play a crucial role in supporting dementia carers through these challenges. It is imperative that practitioners prioritise providing accessible, evidence-based information and training to empower carers in managing their caregiving responsibilities effectively. Online interventions, such as the World Health Organisation's iSupport for dementia carers program, offers a convenient and scalable solution to address carers' needs.

Practitioners should actively promote and facilitate access to such programs, ensuring that carers are aware of the resources available to them and are equipped with the necessary skills and knowledge to navigate their caregiving journey.





**Figures 1 and 2: Doodles created by participants across both countries**

Peer support emerged as a valuable resource for British and Brazilian carers, highlighting the importance of connecting with others who share similar experiences. Practitioners should facilitate the establishment of peer support networks and encourage carers to participate in support groups where they can find understanding, validation, and practical advice from their peers. Additionally, practitioners can facilitate peer-led initiatives where experienced carers provide guidance and support to newcomers, fostering a sense of community and mutual assistance among carers.

Furthermore, practitioners should recognise the therapeutic potential of nature-based interventions for dementia carers. Spending time in nature, through activities like gardening, not only provides physical and mental health benefits for carers but also enhances the quality of life for people with dementia. Practitioners can collaborate with community organisations and environmental initiatives to facilitate access to nature-based activities and promote the integration of green spaces into dementia care settings.

### **Supporting dementia carers: A global endeavour**

While our study provides valuable insights into the experiences of dementia

carers, practitioners should remain mindful of the limitations, including a small sample size and reliance on support group attendees. Future research should explore the efficacy of e-health support programs and the potential of social and nature prescribing to support carers in diverse contexts. Practitioners have a crucial role to play in advocating for the needs of dementia carers and implementing evidence-based interventions to enhance their well-being and resilience.

## References

*Alzheimer's Disease International. (2015) Women and Dementia A global research review. London, UK: ADI – <https://www.alzint.org/u/Women-and-Dementia.pdf>*

*Engedal, K., and Laks, J. (2016) Towards a Brazilian dementia plan? Lessons to be learned from Europe. Dementia & neuropsychologia, 10(2):74–78. [doi.org/10.1590/S1980-5764-2016DN1002002](https://doi.org/10.1590/S1980-5764-2016DN1002002)*

*Gilhooly, K.J., Gilhooly, M.L.M., Sullivan, M.P., McIntyre, A., Wilson, L., Harding, E., Woodbridge, R. and Crutch, S. (2016) A meta-review of stress, coping and interventions in dementia and dementia caregiving. BMC Geriatrics, 16(106). [doi.org/10.1186/s12877-016-0280-8](https://doi.org/10.1186/s12877-016-0280-8)*

*Lindeza, P., Rodrigues, M., Costa, J., Guerreiro, M. and Rosa, M. M. (2020) Impact of dementia on informal care: a systematic review of family carers' perceptions. BMJ supportive & palliative care. Advance online publication. [doi.org/10.1136/bmjspcare-2020-002242](https://doi.org/10.1136/bmjspcare-2020-002242)*

*Prince, M., Wimo, A., Guerchet, M., Ali, G.C., Wu, Y.T. and Prina, M. (2015) World Alzheimer's Report 2015, The Global Impact of Dementia: An analysis of prevalence, incidence, cost and trends. Alzheimer's Disease International. <https://www.alzint.org/u/WorldAlzheimerReport2015.pdf>*

*Nakamura, A.E., Opaleye, D., Tani, G. and Ferri, C.P. (2015) Dementia underdiagnosis in Brazil. Lancet, 385:418-419.*

*Oliveira, D., Da Mata, F., Mateus, E., Musyimi, C., Farina, N., Ferri, C. and Evans-Lacko, S. (2021) Experiences of stigma and discrimination among people living with dementia and family carers in Brazil: Qualitative study. Ageing and Society, 1-22. [doi.org/10.1017/S0144686X21000660](https://doi.org/10.1017/S0144686X21000660)*

*Walter, E. and Pinguart, M. (2020) How effective are dementia carer interventions? An updated comprehensive meta-analysis. The Gerontologist, 60(8):e609–e619. [doi.org/10.1093/geront/gnz118](https://doi.org/10.1093/geront/gnz118)*

*World Health Organisation (2017) Global action plan on the public health response to dementia 2017–2025. 2017. Retrieved from [https://www.who.int/mental\\_health/neurology/dementia/action\\_plan\\_2017\\_2025/en/](https://www.who.int/mental_health/neurology/dementia/action_plan_2017_2025/en/)*

*Yoon, H.K. and Kim, GS. (2019) An empowerment program for family carers of people with dementia. Public Health Nurs., 00:1–12. [doi.org/10.1111/phn.12690](https://doi.org/10.1111/phn.12690)*