

# Leveraging the Cultural Adaptation of iSupport-Portugal: Co-Developing an Add-On Module on Care Discontinuation and Institutional Transition in Dementia

Soraia Teles<sup>1</sup> Constança Paúl<sup>2</sup> Óscar Ribeiro<sup>3</sup> Sara Alves<sup>4</sup>

✉ stsousa@med.up.pt

<sup>1</sup> RISE-Health, Dept. of Clinical Neurosciences and Mental Health, Faculty of Medicine, University of Porto, Porto, Portugal | <sup>2</sup> RISE-Health, Dept. of Behavioral Sciences, School of Medicine and Biomedical Sciences, University of Porto (ICBAS-UP), Porto, Portugal | <sup>3</sup> RISE-Health, University of Aveiro, Aveiro, Portugal | <sup>4</sup> RISE-Health, University of Porto, Porto, Portugal

## BACKGROUND

iSupport-Portugal is one of the first culturally adapted versions of the World Health Organization's "iSupport for Dementia," a self-help training programme for informal carers of people living with dementia (PLWD). Following a multi-step cultural adaptation (Teles et al., 2020) and a cross-sectional study of carers' training needs (Teles et al., 2022a), the European Portuguese version was evaluated for usability (Teles et al., 2021), and a pilot randomized controlled trial provided preliminary evidence of positive effects on carers' well-being (Teles et al., 2022b). These studies identified new carer needs, particularly for information and support during the PLWD's transition to residential care.

Most PLWD prefer to age at home, where familiar environments and social connections are linked to better health-related quality of life (Barca et al., 2011; Luppá et al., 2008). However, as dementia progresses, safety concerns, compromised quality of care, and increasing caregiver burden - associated with growing dependence and challenging neuropsychiatric symptoms - may necessitate long-term care. Dementia is a leading cause of institutionalization: around 20% of PLWD are placed in institutional care within one year of diagnosis, rising to nearly 90% within eight years (Luppá et al., 2008).

The transition of a PLWD to institutional care is a critical life event requiring significant behavioral, cognitive, and emotional adjustment for both the PLWD and their caregiver. Providing caregivers with information and support around this transition is essential to enable care planning that respects PLWD preferences, facilitate the dyad's adaptation, and mitigate the risk of prolonged or worsening caregiver stress as they step back from their caregiving role.

## AIM

To co-develop an add-on iSupport-Portugal module to support carers in planning and adapting to the transition of a person with dementia to residential care.

## METHODS

- 1 Narrative literature review of interventions addressing caregiving transitions.
- 2 Co-design: two module-design focus groups with carers (n=13) of PLWD living at home or recently (<2 years) transitioned to residential care, recruited via third-sector organizations working with PLWD and their caregivers. Diversity in age, gender, kinship, and caregiving trajectory was sought.
- 3 Drafted module reviewed by health/social care professionals (n=9) and validated in a module-evaluation focus group with a new sample of carers (n=8).

All focus groups were audio-recorded, transcribed *verbatim*, and analyzed using thematic content analysis.

## RESULTS

### Participants

Caregivers were, on average, in their mid-to-late fifties and predominantly female, and most were highly educated. Most were employed, and the majority were caring for a parent, followed by a spouse/partner.

Care recipients were, on average, in their mid-seventies to early eighties, most commonly diagnosed with Alzheimer's disease, with a mean of around 8 years since diagnosis. Dependency levels were largely severe to total, and living arrangements were roughly split between community and residential care settings (see Table 1).

In addition to caregivers, 9 professionals from multiple backgrounds and with experience working with, or researching, dementia caregiving provided feedback for module evaluation only.

Table 1. Characteristics of informal caregivers across the two module-design focus groups (n = 13) and the module-evaluation focus group (n = 8).

| Variable                              | Module-design focus groups (n=13) | Module-evaluation focus group (n=8) |
|---------------------------------------|-----------------------------------|-------------------------------------|
| Caregiver age, mean (SD)              | 57.4 (8.9)                        | 53.5 (6.3)                          |
| Caregiver sex – female, n (%)         | 11 (84.6)                         | 8 (100)                             |
| Years of education, mean (SD)         | 12.9 (4.4)                        | 17.3 (3.4)                          |
| Employment status, n (%)              |                                   |                                     |
| Employed                              | 9 (69.2)                          | 8 (100)                             |
| Retired                               | 4 (30.8)                          | 0                                   |
| Relationship to care recipient, n (%) |                                   |                                     |
| Spouse/Partner                        | 5 (38.5)                          | 1 (12.5)                            |
| Parent                                | 8 (61.5)                          | 5 (62.5)                            |
| Other                                 | 0                                 | 2 (25.0)                            |
| Care recipient age, mean (SD)         | 75.1 (8.9)                        | 81.6 (7.7)                          |
| Type of dementia, n (%)               |                                   |                                     |
| Alzheimer's disease                   | 5 (38.5)                          | 4 (50.0)                            |
| Vascular dementia                     | 3 (23.1)                          | 1 (12.5)                            |
| Other type                            | 5 (38.5)                          | 3 (37.5)                            |
| Years since diagnosis, mean (SD)      | 8.2 (4.7)                         | 8.1 (3.9)                           |
| Current dependency level, n (%)       |                                   |                                     |
| Mild/moderate                         | 5 (38.5)                          | 0                                   |
| Severe/total                          | 8 (61.5)                          | 8 (100)                             |
| Living arrangement of the PLWD, n (%) |                                   |                                     |
| In the community                      | 7 (46.2)                          | 4 (50.0)                            |
| In residential care                   | 6 (46.2)                          | 4 (50.0)                            |

## CONTENT ANALYSIS

Content analysis of the two module-design focus groups (n=13) identified seven interrelated categories describing the caregiving trajectory. Continued home-based care was hindered by financial strain, caregiver exhaustion, safety risks, gaps in weekend coverage, and lack of guidance at diagnosis, while family support, respite, home-care services and a day-by-day coping approach acted as facilitators. Institutionalization was rarely planned in advance - it was typically triggered by an acute crisis or caregiver exhaustion and accompanied by guilt, ambivalence, and, at times, deception to secure the relative's acceptance, with access further limited by long waits, high costs, and pressure for hospital discharge. Caregivers of PLWD in residential care described intense guilt and loss of identity, but most reported improved wellbeing for both parties after an adjustment period, reframing institutionalization as a redefinition rather than an abandonment of their caregiving role. Across both groups, participants expressed a clear need for structured training and information - on communication, behavioral symptoms, and the institutionalization process, largely unmet by support services.

Table 2. Summary of content analysis categories identified in the module-design focus groups.

| Category                                                     | Main ideas (codes)                                                                                                                                                                                                                                                    |
|--------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 1. Barriers to continued home-based care                     | Financial strain; caregiver physical/emotional exhaustion; safety risks (falls, wandering, gas/stove, poor nutrition and hygiene); lack of weekend/holiday coverage for care; challenging behavioral symptoms; lack of guidance at diagnosis; loss of a co-caregiver. |
| 2. Facilitators of continued home-based care                 | Family/social support; opportunities for respite and self-care; professional day-care services; financial resources; coping by not projecting into the future.                                                                                                        |
| 3. Deciding to institutionalize: triggers and process        | Crisis-triggered decisions (hospitalization, infection, exhaustion); difficulty managing multiple roles; long waits and high private-facility costs; discharge pressure from hospitals/social services; need for one family decision-maker.                           |
| 4. Emotional experience: guilt, grief and caregiver identity | Feelings of abandonment and self-blame; exhaustion; caregiver identity; grief over the changing relationship with the person cared for.                                                                                                                               |
| 5. Post-institutionalization adaptation                      | Initial adjustment difficulty for both parties; gradual acceptance; improved wellbeing/safety for the person cared for; relief and restored routine for the caregiver; redefining visiting as continued care, not abandonment; improved relationship with the PLWD.   |
| 6. Support, information and training needs                   | Lack of guidance from health services at diagnosis; desire for practical training (communication strategies, managing delusions/agitation); peer support networks; emotional support for caregivers; information on facilities, costs and waiting lists.              |

*"I'm feeling like a terrible daughter for resorting to a nursing home. I know my mother would not have wanted it at all, but I couldn't support her anymore."*

— O, caregiver of a PLWD in residential care

## THE MODULE

From the triangulation of the literature review and focus group findings, Module 6, *Changes in the Caregiving Role*, was developed as an additional module for iSupport-Portugal. It comprises five sessions addressing the transition from home care to residential care:

- (1) Considering the Move: From Home Care to Residential Care;
- (2) Preparing for the Move: Choosing a Residential Care Home;
- (3) Preparing for the Transition;
- (4) Adaptation of the Person with Dementia to the Move;
- (5) Adaptation of the Caregiver to the Move.

Each session includes interactive exercises, caregiving stories, self-assessments, links to relevant websites, legislation and support services, and downloadable resources (e.g., residential care home visit checklist, biography booklet, packing checklist, visitors' book).

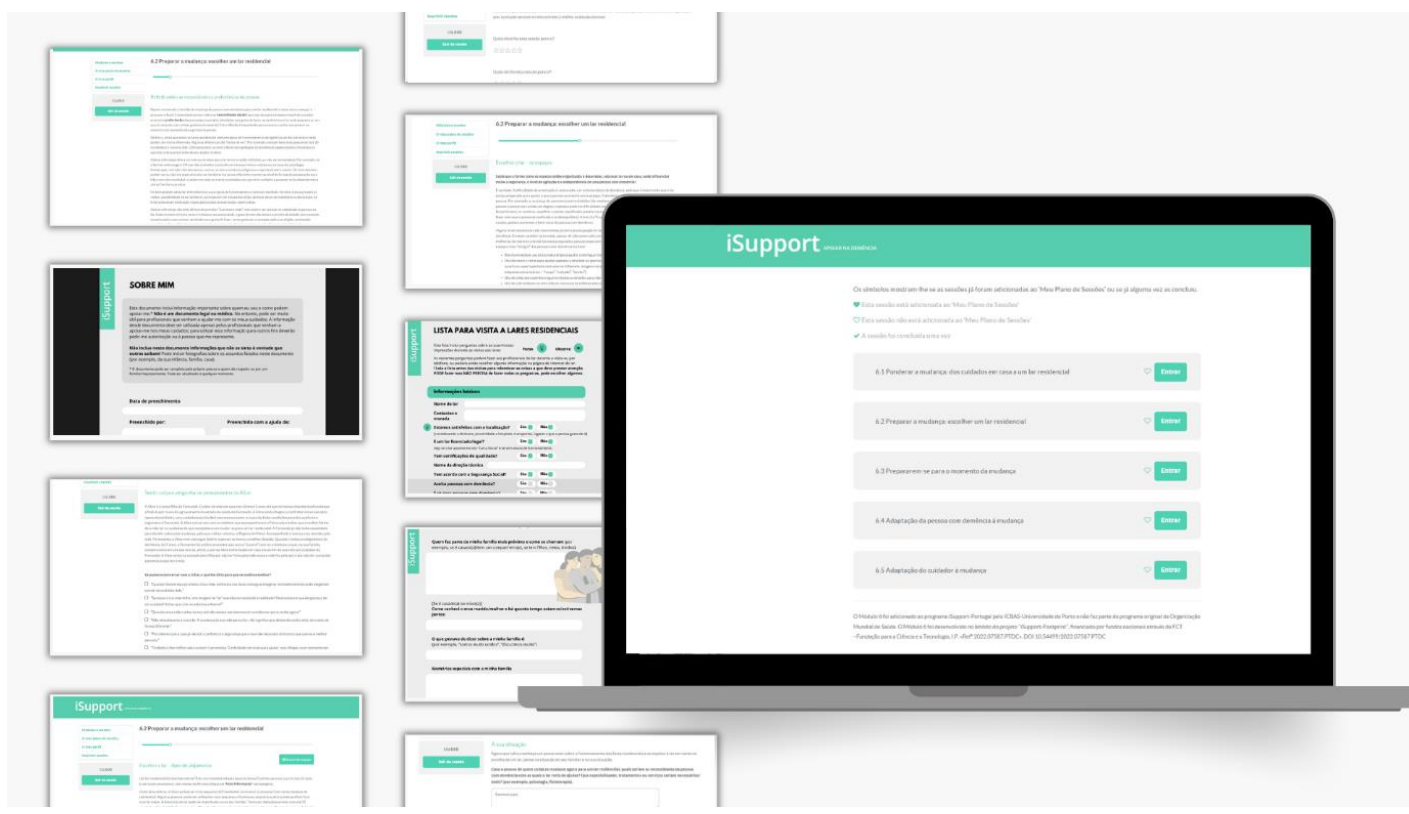


Figure 2. iSupport-Portugal add-on module addressing the transition of the person living with dementia (PLWD) to residential care.

### Module Validation

Both caregivers and professionals perceived the add-on module as useful for providing information and support. Language was considered clear and accessible, and content was regarded as informative, comprehensive, and effective in addressing gaps in existing resources. Visuals and interactive exercises, consistent with the original iSupport modules, were well integrated. Suggested improvements focused on platform-wide enhancements, particularly incorporating multimodal content (audio or video) to increase accessibility and engagement.

## CONCLUSION

iSupport-Portugal continues to gather evidence supporting its acceptability and usefulness as a resource for carers in Portugal, a high-prevalence dementia context (an estimated 238,401 PLWD, 2.29% of the population; Alzheimer Europe, 2025). The new add-on module was similarly well evaluated by carers and professionals for its usefulness, comprehensibility, and overall quality. Future research should examine use of the new module among the iSupport-Portugal user base (currently over 1,200 users) through platform logs, alongside further qualitative work.

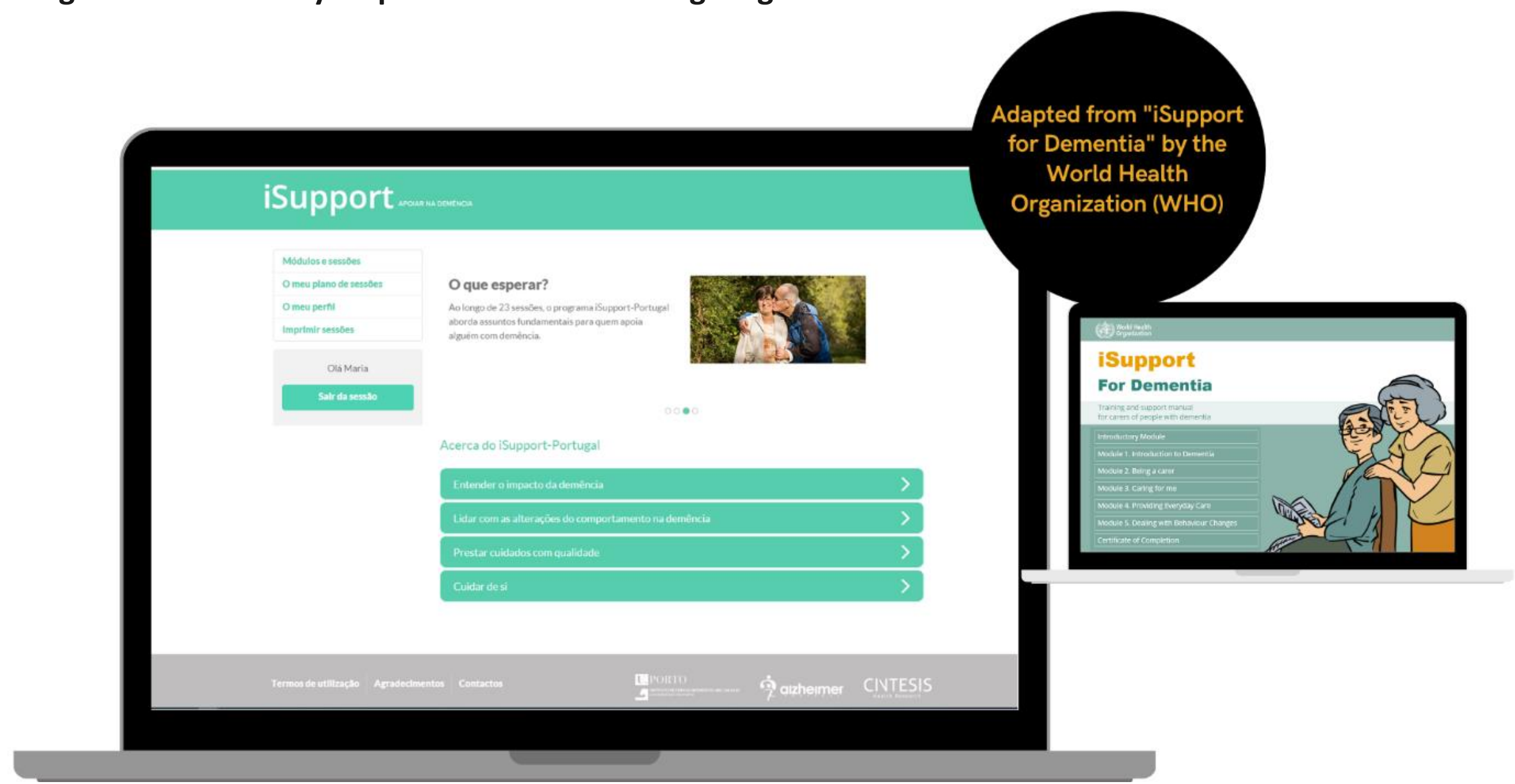


Figure 1. iSupport-Portugal landing page, adapted from "iSupport for Dementia," originally developed by the World Health Organization (WHO).

### Learn More



Scan me

### Acknowledgements

World Health Organization (special thanks to Katrin Seeher and Laura Diaz). Partners: Associação Alzheimer Portugal (special thanks to Maria do Rosário Zincke); CIDIFAD – Centro de Investigação, Diagnóstico, Formação e Acompanhamento das Demências, SCM de Riba de Ave; Santa Casa da Misericórdia de Vila do Conde. Other contributors to iSupport-Portugal: Maria João Azevedo (ESE-IPVC), Alberto Freitas (RISE-Health, FMUP), Ana Ferreira (RISE-Health, FMUP), Milaydis Sosa Napolskij (FMUP, specialized translation), Rui Chilro (development), Pedro Lima (design).

Author Disclosure Information: None.

### Funding

This work was funded by national funds through FCT – Fundação para a Ciência e a Tecnologia, I.P., under project "2022.07587.PTDC" (DOI 10.54499/2022.07587.PTDC) and 2023.06494.CEECIND/CP2871/CT0001 (DOI 10.54499/2023.06494.CEECIND/CP2871/CT0001).



### References

Alzheimer Europe. (2025). Dementia prevalence in Europe. <https://www.alzheimer-europe.org/dementia/prevalence-dementia-europe>

Barca, M. L., Engedal, K., Laks, J., & Selbaek, G. (2011). Quality of life among elderly patients with dementia in institutions. *Dementia and Geriatric Cognitive Disorders*, 31(6), 435–442. <https://doi.org/10.1159/000328969>

Luppá, M., Luck, T., Brähler, E., König, H.-H., & Riedel-Heller, S. G. (2008). Prediction of institutionalisation in dementia. *Dementia and Geriatric Cognitive Disorders*, 26(1), 65–78. <https://doi.org/10.1159/000144027>

Teles, S., Napolskij, M. S., Paúl, C., Ferreira, A., & Seeher, K. (2020). Training and support for caregivers of people with dementia: The process of culturally adapting the WHO iSupport programme to Portugal. *Dementia*, 20, 672–697. <https://doi.org/10.1177/1471301220910333>

Teles, S., Paúl, C., Lima, P., Chilro, R., & Ferreira, A. (2021). User feedback and usability testing of an online training and support program for dementia carers. *Internet Interventions*, 25, 100412. <https://doi.org/10.1016/j.invent.2021.100412>

Teles, S., Ferreira, A., & Paúl, C. (2022a). Feasibility of an online training and support program for dementia carers: Results from a mixed-methods pilot RCT. *BMC Geriatrics*, 22, 173. <https://doi.org/10.1186/s12877-022-02831-z>

Teles, S., Paúl, C., Sosa Napolskij, M., & Ferreira, A. (2022b). Dementia caregivers training needs and preferences for online interventions: A mixed-methods study. *Journal of Clinical Nursing*, 31(13–14), 2036–2054. <https://doi.org/10.1111/jocn.15445>