Adapting iSupport program around the world: a cross-cultural study

Fiordelli M., Messina A., Magelli A., Amati R. & Albanese E.
Faculty of Biomedical Sciences, Institute of Public Health, Università della Svizzera Italiana
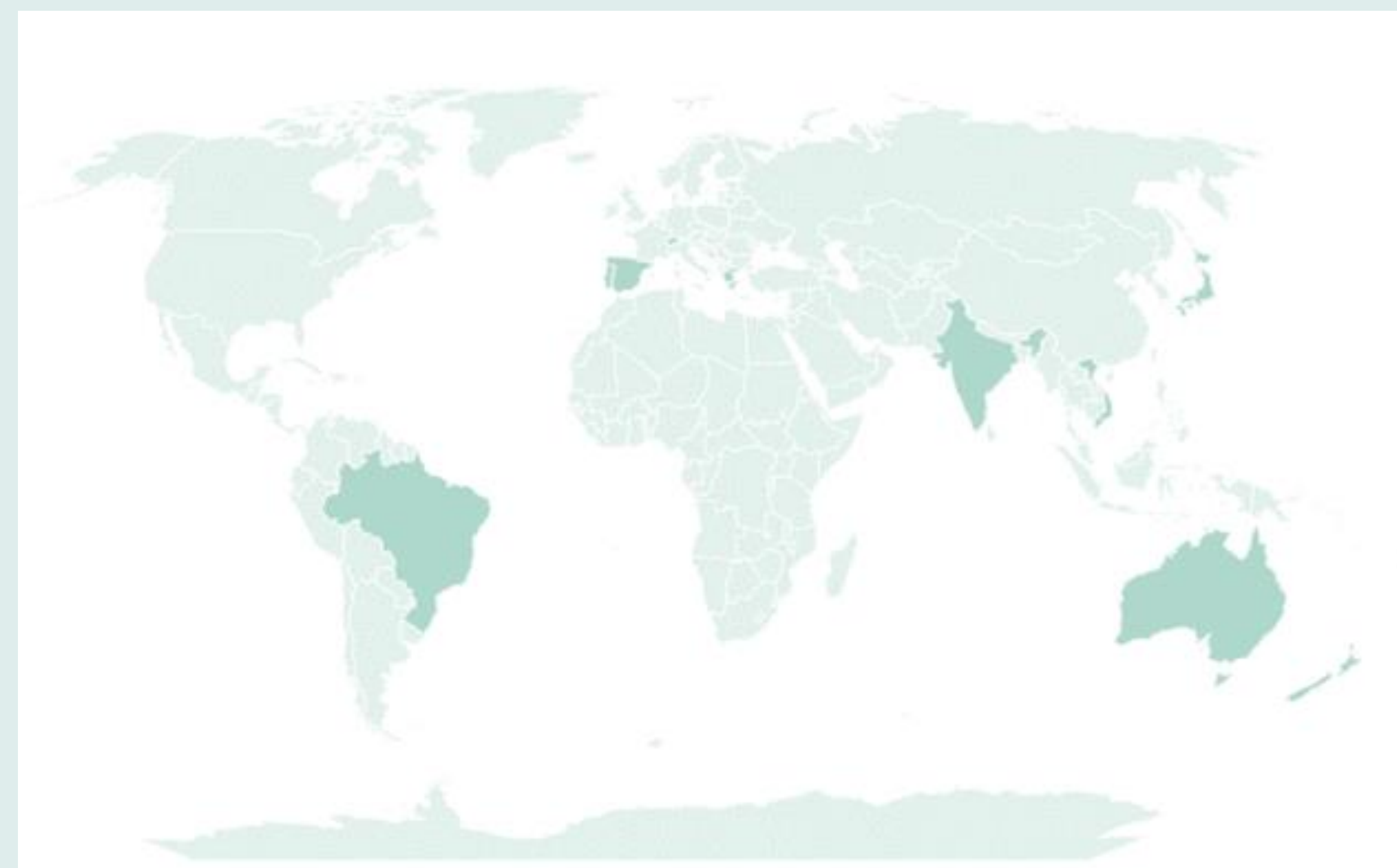
Background

iSupport is an online evidence-based intervention developed by the World Health Organization (WHO) targeting informal caregivers of people with dementia (Pot et al.2019). iSupport is being adapted in over 30 countries composing an international network. Cultural adaptation of interventions has the potential to increase their effectiveness, usability, and scalability (Theobald et al., 2018). **This cross-cultural investigation aims to collect experiences and synthesize methodologies used for the cultural adaptation of iSupport worldwide.**

Method

We conducted this qualitative study in collaboration with the WHO Brain Health Unit. In 2022, we carried on online semi-structured interviews with local study coordinators and implementers. We explored **cultural adaptation approaches, methods used, stakeholders' and caregivers' involvement, and measures used to ensure and monitor external validity.** Interviews were transcribed verbatim and followed by thematic analysis of transcripts.

Results

26 participants
11 countries
14 online interviews (~1h)

Process length = **variable**
Caregivers' associations = **always involved**
Implementer = **mainly research and/or governmental institutions**
Method = **focus groups and a constant exchange with WHO**
Facilitators = **active listening and flexibility essential; multi-disciplinarity added value**
Barriers = **caregivers recruitment, limited economic and time resources, cultural diversity**

Active listening of caregivers experience

"The lesson learned is that it's **really important to hear** what the carers think about this, because they are the ones who are going to use it."
(New Zealand)

"And because some of them said that they didn't like certain things, but they didn't give any suggestions as to why or how I could make it better. And so **going more in depth**, I think, in the question and get very explicit answers from your participants from what they want and why. I think that's important."
(Wales)

Centrality of stakeholders involvement

"And really try to be **as much flexible as possible**, and to do that you should of course again engage as much as possible the Community and all the people that are involved in this area in particular."
(Switzerland)

Importance of different formats

"So having a **mobile based application**, that would definitely have been helpful and also say.. **inclusion of more interactive components** because even in the feedback that we got, they really enjoyed the exercises they used to get some inputs like whether they correctly or what they could have done differently. **Maybe including videos**, because now everything is video based, more interactive. So even if we do not include live action figures, animated video or something would have been helpful." (India)

Lessons learned

Challenging caregivers involvement

"…but tapping into Carers is difficult just because of the nature of what they're doing, they're not going to come and find the researchers to be part of research. It's you…To be able to engage them and interview them **because they're really busy**, then they've got a lot going on and it's difficult."
(Australia)

Complexity and richness of multifaceted national cultures

"And there are lots of things, even though we did quite a careful job of trying to adapt, and that maybe has a bit to do with **regional differences** as well. Like, you know your area, but you don't know other areas."
(Brazil)

Need for harmonization of adaptation and monitoring

"They say to use focus groups. But what do you do with that data once you've got it? And how do you base your decisions on something that one participant has said? Do you need a majority? And how to make my decision based on these two conflicting ideas that **it doesn't seem to be much guidance out there so**."
(Wales)

Discussion

The results of this investigation provide insights and information that can be shared among individuals and groups within the iSupport international network. **Knowledge exchange in this context involves sharing best practices, challenges, lessons learned, and successful strategies for cultural adaptation.** The knowledge exchange should extend not only within the iSupport network but also to external parties or broader communities.

Conclusion

Knowledge exchange is an essential step of implementation research, which can inform not only a specific health intervention but more broadly global public health.

References

Pot, A. M., Gallagher-Thompson, D., Xiao, L. D., Willemse, B. M., Rosier, I., Mehta, K. M., Zandi, D., Dua, T. & iSupport Development Team. (2019). iSupport: a WHO global online intervention for informal caregivers of people with dementia. *World Psychiatry*, *18*(3), 365-366.

Theobald, S., Brandes, N., Gyapong, M., El-Saharty, S., Proctor, E., Diaz, T., Wanji, S., Elloker, S., Raven, J., Elsey, H., Bharal, S., Pelletier, D. & Peters, D. H. (2018). Implementation research: new imperatives and opportunities in global health. *The Lancet*, *392*(10160), 2214-2228.