

**iSupport: a WHO global online intervention for informal caregivers of people with dementia.**

Pot A.M.<sup>1</sup>, Gallagher-Thompson D.<sup>2</sup>, Xiao L.D.<sup>3</sup>, Willemse, B.M.<sup>4</sup>, Rosier, I.<sup>4</sup>, Mehta K.M.<sup>2</sup>, Zandi D.<sup>1</sup>, Dua T.<sup>1</sup>, iSupport development team<sup>6</sup>

<sup>1</sup> World Health Organization (WHO), Geneva, Switzerland

<sup>2</sup> Department of Psychiatry and Behavioral Sciences, Stanford University School of Medicine, Stanford, California, United States.

<sup>3</sup> School of Nursing and Health Sciences, Faculty of Medicine, Nursing and Health Sciences, Flinders University, Australia

<sup>4</sup> Netherlands Institute on Mental Health and Addiction, Utrecht, The Netherlands

<sup>6</sup> iSupport development team: Emiliano Albanese, WHO Collaborating Center for Training and Research in Mental Health, University of Geneva, Switzerland; Nicole Batsch, Alzheimer's Disease International, London, UK; Upasana Baruah, National Institute of Mental Health and Neurosciences, Bangalore, India; Kiki Edwards, Rossetti Care, Ibadan, Nigeria; Kieren Egan, WHO Collaborating Center for Training and Research in Mental Health, University of Geneva, Switzerland; Dolores Gallagher-Thompson, Stanford University School of Medicine, Stanford, California, United States; Mariella Guerra, Instituto de la Memoria, Lima, Peru; Jayna Holroyd-Leduc, University of Calgary, Canada; Timothy Kwok, Jockey Club Centre for Positive Ageing, The Chinese University of Hong Kong, Hong Kong; Kala Mehta, Stanford University School of Medicine, Stanford, California, United States; Marleen Prins, WHO Collaborating Centre for Dissemination of Good Practices in Mental Health, Trimbos-Institute, Utrecht, Netherlands; Santosh Loganathan, National Institute of Mental Health and Neurosciences, Bangalore, India; Iris Rosier, WHO Collaborating Centre for Dissemination of Good Practices in Mental Health, Trimbos-Institute, Utrecht, Netherlands; Prafulla Shivakumar, National Institute of Mental Health and Neurosciences, Bangalore, India; Iris van Asch, WHO Collaborating Centre for Dissemination of Good Practices in Mental Health, Trimbos-Institute, Utrecht, Netherlands; Mathew Varghese, National Institute of Mental Health and Neurosciences, Bangalore, India; Huali Wang, Dementia Care & Research Center, Peking University Institute of Mental Health, Beijing, China; Bernadette Willemse, WHO Collaborating Centre for Dissemination of Good Practices in Mental Health, Trimbos-Institute, Utrecht, Netherlands; Marc Wortmann, previously Alzheimer's Disease International, London, UK; Lily Xiao, Flinders University, Adelaide, Australia.

WHO Secretariat: Alison Brunier, Kenneth Carswell, Tarun Dua, Anne Margriet Pot, Dag Rekve, Katrin Seeher, Mark van Ommeren, Shekar Saxena, Diana Zandi.

*Acknowledgement:* The development of iSupport was funded by a grant from the Alzheimer Association U.S., the Ministry of Health, Welfare and Sport in the Netherlands, and Alzheimer Disease International.

The authors declare no conflicts of interest.

The authors alone are responsible for the views expressed in this article and they do not necessarily represent the views, decisions or policies of the institutions with which they are affiliated.

*Address correspondence to:* Anne Margriet Pot, PhD, Vrije Universiteit Amsterdam, Van der Boechorststraat 7, Office A-534. Email: a.m.pot@vu.nl

In 2015, it was estimated that worldwide 47 million people had dementia, increasing to 75 million in 2030 and 132 million by 2050. Nearly 9.9 million people are expected to develop dementia each year, which translates to one new case every three seconds. While dementia occurs across all levels of socio-economic status, nearly 60% of people with dementia currently live in low- and middle-income countries (LMICs) and most new cases (71%) are expected to occur in those countries.<sup>1</sup> The majority of people with dementia in these countries do not have access to care and support.<sup>2</sup>

To foster a world in which dementia is prevented and people with dementia and their caregivers live well and receive the care and support they need, the World Health Organization (WHO) developed a Global action plan on the public health response to dementia 2017 – 2025.<sup>1</sup> Support for family and other unpaid caregivers is included as one of the seven action areas. Research in countries with different levels of development have shown, that being a caregiver can affect your physical and mental health, well-being and social relationships.<sup>1</sup>

In the Global plan, the target for 2025 is that 75% of WHO's 194 Member States provide support and training programmes for caregivers of people with dementia tailored to their needs. Research in different resource settings around the world has shown that programmes improving knowledge and caregiving skills, such as coping with behavioural changes, have beneficial impact on caregivers' burden, depression and well-being.<sup>3</sup>

Although face-to-face training programmes have shown beneficial impact, to implement these in LMICs is challenging because preconditions for sustainable delivery are lacking. There is limited awareness on dementia and the need for training and support of unpaid caregivers.<sup>1</sup> But even when countries would be aware, limitations in long-term care funding and infrastructure, including a shortage of trained professionals will hamper implementation.<sup>4</sup>

Using the Internet might have advantages to overcome the challenges associated to face-to-face training and support programmes for caregivers of people with dementia in LMICs<sup>5</sup>. It may help to reach more caregivers and increase service coverage, as the number of Internet users and Internet penetration is rapidly increasing worldwide, estimated at over 4.2 billion users and 55% penetration in 2018 by Internet World Stats. As WHO states: eHealth is crucial to achieve Universal Health Coverage.

Although the use of Internet interventions to improve mental health in LMICs is still low, first studies show its potential to improve caregivers' mental health, coping and self-efficacy, at least in high income countries.<sup>6</sup> In order to address the urgent needs for carer support worldwide, WHO has developed iSupport, as a first step to filling this gap. Additionally, a small pilot study was carried out to study its usability and impact in India.<sup>7</sup>

The content of iSupport is based on the ground breaking Kitwood model in which the personhood of someone with dementia is central, and in which care is essentially thought of as interaction, according to each individual's needs, personality and ability. The behaviour of people with dementia, are not only a reflection of the functioning of the brain, but also a result of their personality and coping, life history, health and social and physical environment.<sup>8</sup> In iSupport, these elements are integrated in the exercises.

The techniques that served as the therapeutic foundation for the development of iSupport are based on programmes that showed some beneficial impact, including elements of cognitive behavioural therapy, such as psychoeducation, relaxation, behavioural activation, cognitive reframing, and some problem-solving elements<sup>6</sup>

iSupport is meant for caregivers with feelings of stress or burden or mild to moderate mental health problems, such as symptoms of depression or anxiety. People with severe mental health symptoms are probably better served by a mental health professional. However, when the accessibility of mental health professionals is low, they might still want to participate in iSupport and benefit from it.

The generic version of iSupport is free accessible via [www.SupportForDementia.org](http://www.SupportForDementia.org). The online program contains five themes: (1) What is dementia (1 lesson); (2) Being a caregiver (4 lessons); (3) Caring for me (3 lessons); (4) Providing everyday care (5 lessons); (5) Dealing with changing behaviour (10 lessons). Each lesson presents information about a specific topic and provides engaging, interactive exercises related to this topic. The user is provided with instant feedback.

Since attrition is common in online programs, tailoring components and duration of the lessons to the individual is important, the more so because caregivers often experience time constraints due to their caregiving role.<sup>6</sup> iSupport enables caregivers to choose lessons that are appealing and most relevant to them.

iSupport has been developed as an online or web-based self-help program, but it can also be linked to a caregiver platform (for example a Facebook group), a coach or a face-to-face support group. Contacts with other caregivers or a coach might have added value, however, the human resources that are needed to moderate or guide not always be available, in less developed countries in particular.

When countries want to implement iSupport, translation and adaptation of the program is needed. We assume that iSupport can be useful in different cultural contexts for different groups of caregivers, if appropriate adaptations to context and culture are made for ecological validity.<sup>26</sup> For example, for caregivers of people with dementia generational differences within cultures should be examined.

WHO provides a standardized guide<sup>1</sup> for translation and adaptation to ensure that the local version of iSupport is accurate and in line with the generic version, but at the same time appropriate for the local target group of family caregivers. It describes the process to translate and adapt the generic English version and actual changes that might be (in)appropriate in the program, such as specific words, names, and links to local Alzheimer's organizations and care and support services.

Several countries are currently adapting and implementing iSupport, for example India, China, Japan, Portugal, Brazil, Australia and the Netherlands. In a next step the usability and effectiveness of iSupport will be studied and will guide the further improvement of this global course. On request of some countries, a generic hardcopy manual of iSupport for adaptation and implementation to local contexts will become available in 2019.

## REFERENCES

1. WHO. Global action plan on the public health response to dementia 2017 – 2025. Geneva: World Health Organization; 2017 (ISBN 978-92-4-151348-7).
2. Aboderin, I., & JA. Epping-Jordan. Towards long-term care systems in sub-Saharan Africa. Geneva: WHO; 2017. In A.M. Pot, & J. Beard (Eds.): WHO series on long-term care (ISBN 978-92-4-151338-8).
3. Gilhooly KJ, Gilhooly ML, Sullivan MP, McIntyre A, Wilson L, Harding E, Woodbridge R, Crutch S. A meta-review of stress, coping and interventions in dementia and dementia caregiving. *BMC Geriatr*. 2016 May 18;16:106. doi: 10.1186/s12877-016-0280-8.
4. Pot AM, Briggs AM, Beard JR. The Sustainable Development Agenda Needs to Include Long-term Care. *J Am Med Dir Assoc*. 2018 Sep;19(9):725-727. doi:10.1016/j.jamda.2018.04.009.
5. Arjadi R, Nauta MH, Chowdhary N, Bockting CLH. A systematic review of online interventions for mental health in low and middle income countries: a neglected field. *Glob Ment Health (Camb)*. 2015 Jul 14;2:e12. doi: 10.1017/gmh.2015.10.
6. Egan KJ, Pinto-Bruno AC, Bighelli I, Berg-Weger M, van Straten A, Albanese E, Pot AM. Online Training and Support Programs Designed to Improve Mental Health and Reduce Burden Among Caregivers of People With Dementia: A Systematic Review. *J Am Med Dir Assoc*. 2018 Mar;19(3):200-206.e1. doi: 10.1016/j.jamda.2017.10.023.
7. Mehta KM, Gallagher-Thompson D, Varghese M, Loganathan S, Baruah U, Seeher K, Zandi D, Dua T, Pot AM. iSupport, an online training and support program for caregivers of people with dementia: study protocol for a randomized controlled trial in India. *Trials*. 2018 May 8;19(1):271. doi: 10.1186/s13063-018-2604-9.
8. Kitwood, T. Dementia reconsidered. He person comes first. Berkshire: Open University Press, 1997.
9. Gearing, R.E., Schwalbe, C.S., MacKenzie, M.J., Brewer, K.B., Ibrahim, R.W., Olimat, H.S., Al-Makhamreh, S.S., Mian, I. and Al-Krenawi, A., 2013. Adaptation and translation of mental health interventions in Middle Eastern Arab countries: a systematic review of barriers to and strategies for effective treatment implementation. *International Journal of Social Psychiatry*, 59(7), pp.671-681.

---

<sup>a</sup> The iSupport adaptation and implementation is on request available: [whodementia@who.int](mailto:whodementia@who.int)