

Cultural adaptation of the iSupport for Dementia psychoeducation programme for care partners

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This article examines the cultural adaptation of iSupport for Dementia, an online platform developed by the WHO for dementia caregivers. It emphasises research findings that demonstrate the program's effectiveness and benefits for Chinese care partners

Care partners of people with dementia often face significant challenges and need more support in acquiring caregiving knowledge and skills. An online self-learning platform is a viable choice because it suits their busy lives, allowing them to learn at their own pace and convenience. This article illustrates the cultural adaptation of iSupport for Dementia, an online self-learning platform developed by the World Health Organization (WHO) for care partners of people with dementia. It also documents the research findings of the adaptation process, highlighting the effectiveness and benefits of the programme for Chinese care partners.

The WHO estimates that care partners have contributed approximately 89 billion hours towards supporting people with dementia in their daily living activities as of 2019. ⁽¹⁾ This extensive commitment poses numerous challenges to care partners, including alterations in familial roles, insufficient understanding of dementia, increasing responsibilities as the condition progresses, and social isolation. These factors can significantly detriment care partners' physical and psychological wellbeing. ⁽²⁻⁴⁾

The benefits of psychoeducation programmes for care partners

Psychoeducation programmes, designed to provide care partners with essential knowledge and skills in dementia care, have been proven effective in alleviating caregiving distress and managing the changing behaviours of people with dementia. Participants in these programmes have shown improvements in their quality of life and self-efficacy for caregiving. ^(5,6) They experienced reduced depression and relief from the burdens of supporting people with dementia. However, attending physical psychoeducation programmes could be challenging for care partners due to caregiving responsibilities, travel restrictions, and time constraints. Online psychoeducation programmes offer a flexible learning approach, allowing care partners to learn at their own pace, from any location, and at any time. This saves on travel costs and enables them to select content based on their specific needs. ⁽⁷⁾

iSupport for Dementia

iSupport for Dementia is an online psychoeducation programme for care partners developed by the WHO. It consists of 23 learning units covering five key aspects: (1) introduction to dementia, (2) being a carer, (3) caring for me, (4) providing everyday care, and (5) dealing with behaviour changes. Each unit includes a brief introduction to the topic, case studies, and exercises. iSupport for Dementia has been translated into various languages. Funded by the National Foundation for Australia-China Relations, an Australian Government initiative, Flinders University in Australia started a multi-country trial to adapt the programme for Chinese care partners in Australia and the Greater China Region. Jockey Club Centre for Positive Ageing (JCCPA) was responsible for the localisation trial in Hong Kong.

The first phase of the study focused on adapting the contents for Chinese care partners in Hong Kong. Care partners and healthcare professionals with diverse backgrounds and experience in dementia care were interviewed individually or in focus groups about the adapted version of the iSupport for Dementia programme. Several themes were identified: (1) adapting case studies to the local culture to align with the everyday experiences of Chinese care partners in Hong Kong; (2) adding content to address the learning needs of care partners with different backgrounds; (3) incorporating the management of distressed behaviours and relaxation exercises as key learning components; (4) addressing the importance and difficulty of discussing future care arrangements; (5) including up-to-date and comprehensive community resources and skills for care partners to seek external help; (6) incorporating interactive forums and multimedia materials to increase motivation in using the online platform; (7) using technology to tailor the needs of users; and (8) providing guidance during the utilisation of the iSupport for Dementia platform. The results were presented at the 36th Global Conference of the Alzheimer's Disease International and the 27th Asia-Pacific Regional Conference of Alzheimer's Disease International as knowledge transfer.

Phase 2 of the study was a multi-centre randomized controlled trial to measure the effectiveness of the Chinese iSupport for Dementia. Participants in the intervention group accessed the iSupport Programme over six months, with the support of trained facilitators in the format of monthly online support meetings. Control group participants received monthly educational messages over the same period. Two hundred and sixty-six care partners participated in the study. Research results showed that intervention group participants demonstrated improvement in mental health-related quality of life, caregiving self-efficacy in controlling upsetting thoughts, and reduced reaction to the distressed behaviours of people with dementia. ⁽⁸⁾

The promising results of Phase 2 led to the promotion of the online iSupport for Dementia Programme in the local community across the study sites in Phase 3. JCCPA adopted a train-the-trainer approach to train facilitators to assist more Chinese care partners in Hong Kong in using the online psychoeducation programme in a three-month intervention. In response to the suggestion to include multimedia materials from the previous phase, audiobooks, animations, and posters covering different caregiving skills

and knowledge, along with brief introductions to the relevant learning units of the online Chinese iSupport for Dementia platform, were introduced in this phase to further increase the effectiveness of self-learning for care partners.

Online psychoeducation programmes can offer flexible learning options that cater to the particular needs of care partners. The cultural adaptation of iSupport for Dementia adds valuable resources and support to Hong Kong care partners, enabling them to equip themselves with indispensable knowledge and skills in a culturally relevant and engaging setting. This approach helps alleviate the physical and psychological impacts of dementia care, ultimately enhancing self-efficacy in caregiving and thus improving the quality of life for both care partners and those they care for.

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