

WHO's iSupport model for dementia care: why the mode and measures matter

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In the mid-2000's, the World Health Organization convened a global panel of experts to create iSupport, a skills and training programme for carers of people with dementia.¹ The aim of the program is to prevent and/or decrease mental and physical health problems associated with care and to improve the quality of life of those caring for people with dementia.²

Since its release in 2019, iSupport has been culturally adapted and implemented across 40 countries. However, the evidence on its efficacy is scant. In Windle et al.'s robust trial³—published in this issue of *The Lancet Regional Health—Europe*—performed across England, Wales, and Scotland and involving 262 carers of people living with dementia living in communities, the mean distress scores at six-months were 20.0 (SD = 8.3) for usual care and 20.6 (SD = 8.6) for the iSupport carer group. Correspondingly, the mean depression scores at six-months were 9.5 (SD = 7.0) for usual care and 9.8 (SD = 6.5) for the iSupport carer group. Furthermore, no significant differences were identified for anxiety, resilience, quality of the carer-patient relationship, dementia knowledge, and quality of life (secondary outcomes). These results match pilot trial results from India⁴ and Portugal,⁵ involving 55 and 44 participants respectively, which also showed no significant differences regarding the primary outcomes (distress and depression).

For those of us involved in different iterations of iSupport across the world, these results are thought provoking. Are we wasting time and money implementing a program that doesn't achieve its aims?

Maybe.

But a closer reading of Windle et al.'s³ article also reveals a broader cautionary tale about mode and measure in dementia care trials.

First: the mode. Windle et al.'s³ results show that their participants engagement with iSupport online was low, averaging four visits in six months, and that human contact, beyond technical support, is crucial to meaningful change. For policymakers, eager to find cost-effective ways to support unpaid carers the message is

clear: Do not be seduced by the cost-saving that a pure digital solution may offer. Instead, embed the technology in human relationships, and use it to augment existing services such as through online peer support groups or live chat Q&A about aspects of care.

This message is also borne out in Xiao et al.'s⁶ Chinese adaptation of iSupport, which included 266 Chinese family carers across Greater China and Australia. Xiao et al.'s⁶ is the only iSupport trial that showed improvements in the intervention groups' mental health-related quality of life, control over upsetting thoughts, and reduced distress reactions to changed behaviours of people with dementia. The main difference between the two trials^{3,6} was that the Chinese version included a carer peer support group with monthly facilitator led meetings.

Second, the salience of the measures. Distress and depression are common among carers of people with dementia and hence ubiquitous outcome measures in dementia care trials. But distress and depression are complex, multidimensional, and transformational affective states. Numerous studies document carers suffering in witnessing a loved one's decline, sacrificing life opportunities to care, and learning through trial and error. But carers also report experiencing personal growth, family cohesion, and accomplishment through caring.⁷ Can information alone, in an online manual, really change these myriad emotions?

Additionally, dogmatic adherence to longstanding measurements of distress and depression, limits researchers' capacity to consider how emotions and care intersect cross-culturally. In our codesign work⁸ adapting iSupport Lite to animations, our participants were irritated by the 'niceness' of the original messaging, the overemphasis on informal support, and how 'easy' help-seeking appeared. Instead, they wanted messages to dispel notions of carers as 'superheroes', show that caring and help-seeking are stressful and time-consuming, and that poor decision-making and relationship breakdown do occur.

Incorporating these ideas into intervention development and measurement instruments is necessary to advancing the care literature and improving care outcomes. This area needs more research, not least because the latest dementia drugs remain inaccessible for those in low-and-middle income countries due to financial constraints and limited health infrastructure.⁹ Yet, these communities are disproportionately affected by the



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condition; the World Alzheimer's Report¹⁰ estimates over 55 million people live with dementia, most in countries like China, India, and their South Asian and Western Pacific neighbours. In these settings, care may be the only option.

Therefore, we must develop, test, and refine more programmes like iSupport to build a stronger evidence base, which helps families and people with dementia lead a better quality of life. To that end, we must also include more ethnically diverse populations in dementia trials (in Windle et al.'s³ study 93.2% of participants identified as 'White') to ensure that the evidence-base reflects real-world patients and families affected by dementia, who are the designated end-users of programmes such as iSupport.

Contributors

BB drafted the first version of this commentary, JA provided feedback and input, and both authors approved the final version.

Declaration of interests

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