Chapter 11

Internet-based interventions for family carers of people with dementia

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Introduction

Globally, families represent the cornerstone of care and support for people living with dementia, especially in low- and middle-income countries (LMICs) where resources and access to services are scarce (WHO, 2017; WHO, 2021; Wimo et al., 2018). This comes often at a high personal and financial cost to carers, who may feel stressed or report significant health issues. Providing evidence-based training to family or informal carers will not only lead to better outcomes for carers but also benefit the over 55 million people currently living with dementia worldwide (WHO, 2021).

In response to the growing challenge posed by dementia, the Member States of the World Health Organization (WHO) adopted the global action plan on the public health response to dementia 2017–2025 in May 2017 (WHO, 2017). The plan recognises the important role that informal carers play and calls on Member States to provide carers with training and support in order to reduce the burden and negative toll that caregiving can have on carers' physical health and well-being. The global dementia action plan aims to ensure that 75% of countries provide support and training for dementia carers by 2025.

For over three decades, research has been conducted into personal interventions for carers of people with dementia, delivered either face-to-face or by telephone. The approach of such interventions varies widely and originally focused on one or more of the following: coping strategies, behavioural management techniques and the provision of social support. The theoretical basis for such interventions predominantly builds on stress models such as Pearlin's stress process model (Pearlin et al., 1990; Raina et al., 2004).

Early systematic review work (Selwood et al., 2007) identified that not all face-to-face studies with carers demonstrated improvements (such as group behavioural therapy and supportive therapy). However, the authors identified that higher dose interventions, delivering six or more sessions, demonstrated efficacy for individual behavioural management therapy. In addition, individual and group interventions focused on coping strategies established good evidence for improving distress and depression.

Nowadays, interventions are commonly designed as 'multi-component interventions' (Schulz et al., 2020). This means that 'one' intervention includes a range of components such as information sharing, coping and communication skills training, alongside social supports (e.g. balancing theoretical material with practical and 'actionable' insights or interactive elements, including human supports such as a 'coach'). Different techniques are often integrated within interventions such as Cognitive Behavioural Therapy (CBT) or meditation. Such approaches have been shown to independently improve depression, anxiety, burden, stress and dysfunctional thoughts among carers (Collins & Kishita, 2019; Kwon et al., 2017; Schulz et al., 2020).

There is a strong and increasing research interest to develop more accessible interventions to support carers of people living with dementia (Wiegelmann et al., 2021), particularly in LMICs. While technology-focused efforts began with a dependency on specific hardware (e.g. specialised computer networks/ CD-ROM based solutions), over time such innovations have become web-based, and this is an increasingly popular approach for training and support programmes for carers of people living with dementia (Blom et al., 2015; Egan et al., 2018; Kajiyama et al., 2013).

From the perspective of carers, web-based training programmes may have several advantages when compared with face-to-face interventions. For example, they may reach carers in remote areas that cannot be reached otherwise. They will save time for carers who are often already time constrained due to the care they provide and other roles and tasks in life. Carers do not have to leave the person living with dementia unattended. Moreover, not needing to attend a mental health institution in person may be perceived as less stigmatising. Where carers have continued access to web-based support, they also have the freedom to revisit materials at a time of their convenience/need, which holds value considering the progressive nature of dementia. Further, since the global COVID-19 pandemic has exerted more pressure on carers (Altieri & Santangelo, 2021; Budnick et al., 2021), an added value of web-based training is to deliver support when critically needed and avoid the unnecessary risk of contracting infections outside the home.

From a system's perspective, self-help interventions present a universal advantage in that face-to-face interventions are often resource intense, with respect to human and financial resources. In lower income settings, health professionals often lack the knowledge and abilities to provide face-to-face skills training and support programmes for carers. In addition, in high- and low-resource settings alike, economic pressures favour financially sustainable models of delivery (Winblad et al., 2016).

There are now many published systematic reviews that echo the plausibility of web-based or online skills training and support programmes for carers of people living with dementia (Egan et al., 2018; Etxeberria et al., 2021). Such programmes and interventions, that have been tested across many high-income countries but rarely in LMICs, have the potential to reduce carers' psychological distress, improve mental health, and be cost-effective.

Studies demonstrate a wide variety of intervention programmes for carers of people with dementia. However, unfortunately, the quality of these studies is often poor. For example, there is a lack of sufficiently powered randomised controlled trials and details about interventions are often lacking. In one review, only half of the online programmes were described in enough detail to understand which components they included (Egan et al., 2018). Of the programmes that provided at least some description of the content, the following themes were covered: understanding dementia, improving communication skills, arranging help and support, coping with carer stress, dealing with functional decline and with behaviour changes of the person with dementia, and preparation for the future.

Most programmes (with sufficient information) use a variety of techniques ranging from psychoeducation, behavioural analysis, relaxation, behavioural activation, cognitive reframing and improvement of communication skills, problem-solving/decision-making skills, to time-management. The programmes also vary in the delivery approach, for example through written text, videos, (interactive) exercises and quizzes/assessments, a forum and/or videoconferencing. Moreover, there are different ways in which the programmes are personalised, for example by involving a therapist/psychologist, nurse or peer carer (Egan et al., 2018).

Benefits are not universal. It remains unclear whether specific subgroups of carers may benefit more than others. There is a drive to undertake studies with larger sample sizes and longer intervention exposures. There is also a need to move from efficacy research towards implementation research. For example, a recent systematic review suggests that despite much research being undertaken, implementation readiness remains low and existing work has not been delivered in terms of accessible solutions to carers (Christie et al., 2019). In addition, programmes often are not described in sufficient detail: information is lacking on the underlying theoretical model, the content, the psychological techniques used and the way in which personalisation has (or has not) been integrated in the programme. As a result, less scientific progress has been made than hoped for.

iSupport: WHO training and support programme for carers of people living with dementia

Since skills training and support for carers of people living with dementia are urgently needed worldwide, WHO has developed iSupport (WHO, 2019). iSupport aims to teach carers to provide better care, for a longer period of time, thus allowing the person living with dementia to live in the community for longer, while at the same time preventing or reducing detrimental consequences on carers' health and well-being.

iSupport is based on the latest evidence, described in detail, freely accessible and available for scaling worldwide, online, in hardcopy and shortened poster

format. There is an opportunity to co-ordinate excellence in research in multiple country settings, for example to: improve the overall reporting, share the background theory and components of the intervention, and better understand the differential impact of iSupport for example in subgroups of carers. iSupport has been developed in collaboration with an international expert group and Alzheimer's Disease International and reflects the needs of carers of people living with dementia.

The following describes iSupport in detail, the translation and adaptation process to tailor iSupport to a specific cultural setting or group of carers, and findings from preliminary research on its effectiveness.

iSupport consists of 23 sessions in total, covering five modules: (a) what is dementia (one session); (b) being a carer (four sessions); (c) caring for me (three sessions); (d) providing everyday care (five sessions) and (e) dealing with changing behaviour (ten sessions). All sessions follow the same structure. They start with a summary of why the specific session is important, how it will help and what the carer will learn. The summary is followed by new information, examples and activities with instant feedback to internalise knowledge and develop carer skills. Carers can take all sessions from start to finish or choose the sessions that are most relevant to their own situation. For more information on iSupport, see www.iSupportforDementia.org.

The iSupport content is deeply grounded in Kitwood's model of personhood. It conceptualises care provision as an interaction between the person with dementia and the carer based on the individual's needs, personality and ability. Behaviour changes that occur in dementia are not only a reflection of deteriorating brain functioning but also the result of a person's personality, coping mechanisms, personal history, health status and the social/physical environment. iSupport integrates all these elements into interactive exercises for carers that are grounded in therapeutic techniques that have proven beneficial in the context of dementia caregiving, such as CBT, psychoeducation, relaxation, behavioural activation, cognitive reframing and some problem-solving elements (Pot et al., 2019).

WHO is promoting a broad use of iSupport. The programme has been developed initially as a self-help tool because face-to-face training programmes might be difficult to implement in LMICs where prerequisites for sustainable delivery are often lacking. In addition, iSupport might be used by groups of carers, with or without the guidance of a volunteer or healthcare worker, or by healthcare workers themselves (WHO, 2019). Although iSupport is originally developed as an online tool, there is also a hardcopy manual available for areas challenged with aspects of the digital divide (e.g. limited Internet bandwidth or low digital literacy) (Pot et al., 2019; WHO, 2019). In response to the breakdown of carer support services during the COVID-19 pandemic, an additional Lite version has been developed. This Lite version consists of posters with easy read tips based on, and referring to iSupport, covering topics such as Reaching out to others for help and Ensuring that the person with dementia continues to receive care (WHO, 2020).

Translation, adaptation and implementation of iSupport worldwide

To implement iSupport in a specific setting, the programme needs to be translated and adapted to the context and culture of that setting and the specific group of carers, for ecological validity (Gearing et al., 2013). Currently, implementations of iSupport at various states are ongoing in over 30 countries worldwide. This ranges from initial planning stages to the completion of pilot Randomised Controlled Trials (RCTs) with published results (Baruah et al., 2021; Mehta et al., 2018; Teles et al., 2020; Teles et al., 2021; Xiao et al., 2021). Together, these implementation projects cover over 30 different languages, including all official WHO languages (i.e. Arabic, Chinese, English, French, Russian and Spanish). WHO provides a standardised guide for translation and adaptation to ensure that local versions of iSupport are accurate and in line with the generic version, while at the same time appropriate for local target groups of carers. The guide describes the actual changes that might be (in)appropriate, such as specific words, names and links to local Alzheimer's organisations and care and support services. Translations and adaptations for different settings have been described (Baruah et al., 2021; Oliveira et al., 2020; Teles et al., 2021; Teles et al., 2021; Xiao et al., 2021).

The first adaptation was made for the Indian context (Baruah et al., 2021; Baruah et al., 2020). The adaptation process was guided by a heuristic framework (Barrera & Castro, 2006), and included a literature review and focus group discussions with family carers and health professionals, content modifications based on WHO's adaptation guide, online user testing with face-to-face interviews followed by final modifications to the intervention. The modifications ranged from words, names, references to resources and case descriptions to audio files. Overall, the online programme was developed in a way to cater particularly for low Internet bandwidth in India. Preliminary data showed that carers who participated in the adaptation process were satisfied with the changes, although the translation to different Indian languages was suggested.

The second country adaptation has been documented for Portugal (Teles et al., 2021). In collaboration with the national Alzheimer Association, the adaptation process was carried out in five steps, including a needs assessment, content translation and technical accuracy check, cultural adaptation, expert panel appraisal and fidelity check. The study revealed the complexity of translating and adapting a generic training programme such as iSupport to a specific cultural setting, including the involvement of a multidisciplinary team, which comprised a translator, professionals and experts in ageing, dementia and caregiver support. Translations were carried out in a 'sense to sense', rather than in a 'word to word' (literal) approach, requiring a solid understanding of idioms, grammar and conventions in the cultural context of the source language. The translation and adaptation process also resulted in small improvements of the generic English version of iSupport. On the basis of the initial findings of a mixed-methods study (Teles et al., 2021), involving two focus groups ($n = 15$)

and 15 usability test sessions with carers and health professionals, the usability of iSupport was rated as excellent. Participants perceived iSupport as trustworthy, and were satisfied with the content, 'look and feel' and easiness of use. The feedback and personalisation features of the programme were valued.

The third country adaptation explored the best way to adapt and deliver iSupport to the Australian context (Xiao et al., 2021). Two focus groups with family and other unpaid carers ($n = 16$) and two focus groups with care staff ($n = 20$) were conducted using semi-structured interviews. Prior to participation, participants were given access to iSupport, and asked to review the programme. Topics covered in the interviews were accessibility, appropriateness, acceptability, user-friendliness, and barriers and enablers for using the programme. Thematic data analysis (Xiao et al., 2021) revealed that participants perceived iSupport as an opportunity for an online one-stop shop to meet their needs for education and managing care services. They wanted an integrated carer network attached to iSupport, to share and translate dementia care knowledge into everyday care and socialise with others. Discussions showed the need to have a systematic approach to promote the programme among family carers, in rural and remote regions in particular. Lastly, challenges regarding time constraints using a programme such as iSupport were discussed. Suggestions were made to facilitate the feasibility of the programme, for example by enabling searching of sessions based on carers' needs.

Adaptation of iSupport has also been reported for the Brazilian context (Oliveira et al., 2020). After professional translation of the programme, the Brazilian-Portuguese content was discussed and checked for relevance, clarity and accuracy by a multidisciplinary team of researchers. In the next step, the translation was discussed and checked within 16 focus groups ($n = 48$) with family carers of people living with dementia and health and social care professionals from different geographic regions in Brazil. Representatives of the Brazilian Ministry of Health and Alzheimer's Associations also contributed to this assessment. In general, participants were positive about the programme in terms of content and relevance to the Brazilian context. They helped to refine the text and examples and suggested a few changes. Thus, with the input from the different groups of participants, iSupport was successfully culturally adapted for the Brazilian setting. Meanwhile, adaptation of iSupport is continuing, for carers in other countries, such as Greece (Efthymiou et al., 2022), and subpopulations, such as Chinese-Australian carers (Xiao et al., 2022).

Research on the feasibility and effectiveness of iSupport

Although a beneficial impact of Internet-based interventions has been found in Western countries, it cannot be assumed that Internet-based interventions are equally feasible and effective in LMICs settings. For this reason, the feasibility and effectiveness of iSupport were tested in a pilot RCT in India (Baruah et al., 2021), recruiting carers nationwide over a period of 15 months (2017–2018) who were

aged 18 years and older, caring for a family member with dementia for at least six months, living in India and had regular access to the Internet. To confirm the dementia diagnosis, the AD8 Dementia Screening Interview (AD8 ≥ 2) was used.

In total, 151 carers were recruited and split into two groups to test whether those completing iSupport online (i.e. intervention group) would feel less burdened and less depressed compared to carers reading a control caregiving e-book (i.e. control group). For those who completed the study ($n = 55$), no significant difference between both groups regarding carer burden and depression was found. Carers in the iSupport group did have more positive attitudes towards people with dementia at the end of the study.

Several challenges likely influenced the outcomes of the study and also had implications for future work in this area. For example, recruitment for the study proved challenging, leading to smaller than expected samples. In addition, the study faced very high attrition rates in both study arms, which reduced samples further. Small samples make it statistically difficult to detect differences between groups. In addition, a lot of carers did not complete the recommended minimum number of online iSupport sessions. This suggests that for the involved carers in India, completing an online carer training and participating in a research study in addition to their normal daily workload and carer responsibilities may be very challenging.

Interestingly, the study attracted an unusual group of carers. Compared to more typical carer populations for whom iSupport was originally developed and later culturally adapted in India, there were more men, more non-spousal carers in this efficacy study. Furthermore, almost all carers in this study had completed college or university. This could mean that the content needed to be more contextualised for the needs of this particular group of carers. In addition, very stressed carers who might have benefitted the most from completing an online carer training and support programme might have dropped out or chosen not to participate in the first place due to time constraints, workload and feelings of being overwhelmed.

Meanwhile, in other countries and regions studies on the impact of iSupport on the mental health and well-being of carers of people with dementia have been initiated. Results from a pilot RCT in Portugal (N = 42) suggest a beneficial impact on carers' symptoms of anxiety and their satisfaction with access to information or health services (Teles et al., 2022). No impact was found on other outcomes, including burden, depression and self-efficacy. In addition, the user satisfaction of people completing the generic online iSupport course available on www.iSupportforDementia.org is being monitored. For the first 51 people who completed the online course (as of August 2022), overall user satisfaction with the online training was high: 82% of users strongly agreed that the content was relevant for building their skills as carers; 72% of users strongly agreed that the lessons were useful and suitable; 69% of users strongly agreed that the included exercises are interesting and useful. The majority of users access iSupport on their laptop (63%) and from home (67%). Perceived barriers to accessing iSupport include time required to complete all lessons

(61% of users), internet bandwidth/speed (26% of users) and complexity of the intervention (7%). Users of iSupport reported self-rated improvements for the following symptoms: depression (18%), anxiety (31%), relationship with the care recipient (54%), stress (61%) and confidence (69%). These findings are preliminary and do not reflect the views or feedback of users who have not completed the online training (yet).

Ongoing iSupport work shows that web-based interventions for carers of people with dementia especially in LMICs require further consideration. Recruitment challenges as well as low uptake of, and adherence to, the intervention limit the evidence. Yet, studies like the ones presented here help us better understand which barriers carers face and as a result how future studies can tailor iSupport better to carers' needs. For example, carers might still be less familiar with receiving training and support via the Internet and less computer- and Internet-savvy than the general population. They might be using smartphones rather than computers or tablets and might have less stable Internet connectivity. Additional research is required to further improve translation, adaptation and implementation of the iSupport programme in India.

Conclusion

There is an urgent global need for accessible, usable, effective and scalable skills training and support programmes for carers of people with dementia, particularly in LMICs. WHO's iSupport is filling this gap by providing such a programme, accessible for translation and cultural adaptation worldwide. First steps have been undertaken to support the systematic and culturally fair translation and adaptation of the programme in several countries.

However, while web-based or online programmes for dementia carers such as iSupport seem to be promising, the scaling of these programmes remains challenging and is a common issue for digital health solutions (Greenhalgh et al., 2017). In fact, the findings of a first efficacy study from India highlight the need to understand carers' individual situation better and tailor support programmes even more to their specific needs. Going forward, iSupport could be improved by adding a mobile phone application to offer more flexibility to users, including an interactive or moderated chat function or more audio-visual materials to the online programme to increase its appeal. To assist carers who wish to use more traditional ways of learning, WHO has released the iSupport hardcopy manual, which presents the entire iSupport content in book format. Further robust cultural adaptations and high-quality research investigating the effectiveness of iSupport across different settings and for different groups of carers are required.

Finally, in the context of the ongoing COVID-19 pandemic, digital support services such as iSupport are more important than ever and present a real opportunity to build back better, which will help to reach the global target set by WHO that 75% of countries will provide support and training programmes for carers and families of people with dementia by 2025.

Acknowledgements/Conflicts of interest

List of abbreviations

CBT   Cognitive Behavioural Therapy
LMICs   Low- and middle-income countries
RCT   Randomised controlled trial
WHO   World Health Organization

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