

Adaptation of an online training and support program for caregivers of people with dementia to Indian cultural setting

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ABSTRACT

Support for caregivers of people with dementia has been identified as an action area in the Global Action Plan on the Public Health Response to Dementia 2017–2025 by the World Health Organization (WHO). As a step towards that, WHO developed iSupport - an online program to provide support and training for caregivers of people with dementia. To address the need of caregivers in India, the iSupport program was adapted to the Indian cultural setting. The process of adaptation consisted of four phases: (a) information gathering (review of literature and focus group discussions), (b) preliminary adaptation design (modifications using an adaptation guide), (c) preliminary adaptation tests (face-to-face interviews and online test run), and (d) adaptation refinement (final modifications to the intervention and study process). The initial adaptation was carried out by effecting changes in words, names, resources, caregiving scenarios and audio files to make the English version of iSupport suitable to the Indian cultural context. The results of the qualitative adaptation tests provided additional recommendations like changing the links to India specific websites, revising the eligibility criterion for caregiving duration, re-wording of e-mail texts, inclusion of a time estimate required to complete the assessments and decreasing the numbers of screens that the caregivers had to navigate in the program, which were incorporated in the final phase. Preliminary data showed that the caregivers who participated in the adaptation process found the changes acceptable. Translation of iSupport to different Indian languages could be undertaken after initial effectiveness of the program is established.

1. Introduction

Globally there are estimated 50 million people with dementia, with nearly 60 % of them living in low- and middle- income countries (LMICs; [Alzheimer's Disease International \[ADI\], 2015](#)). The number of people living with dementia in the world is projected to triple by 2050 with highest projections in Asian nations such as India and China ([Kalaria et al., 2008](#); [World Health Organization \[WHO\], 2017](#)). Caregivers of people with dementia face multiple challenges and the effects of

caregiving can be varied and complicated. It has been extensively documented that caregiving in dementia is associated with higher levels of burden, more serious depressive symptoms, psychological stress and physical ill-health ([Chiao et al., 2015](#); [Gilhooly et al., 2016](#); [Tremont, 2011](#)). The situation is challenging, especially in India, where caregiving is almost entirely family based, with limited resources and few facilities of continued care to meet the complex needs of the persons with dementia and their family caregivers, indicating the need for scaling up dementia education, training and support programs ([Dias and Patel,](#)

Abbreviations: LMIC, low- and middle-income countries; WHO, World Health Organization; ARDSI, Alzheimer's and Related Disorder Society of India; NIMHANS, National Institute of Mental Health & Neurosciences; FGD, focus group discussion.

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2009; Ganesh et al., 2016; Lamech et al., 2017; Prince et al., 2012; Sinha et al., 2017).

Support for dementia caregivers is one of the priority areas under the World Health Organization Global Action Plan on the Public Health Response to Dementia 2017–2025, especially for the LMICs (WHO, 2017). Taking into consideration the promising outcomes of internet based interventions (Egan et al., 2018; Zhao et al., 2019), and the limitations in long-term care funding, infrastructure, including a shortage of trained professionals (Pot et al., 2018), WHO brought together a panel of international experts to develop an online training program called ‘iSupport’ for caregivers of people with dementia. iSupport is an e-program designed to meet the needs of caregivers, especially education and skills training (Pot et al., 2019). iSupport aims to improve knowledge and caregiving skills to reduce stress and improve coping and mental health of caregivers of people with dementia. iSupport can be accessed using a computer or tablet with internet connectivity. The program consists of twenty-three lessons, distributed over five modules, on a range of topics related to self-care, as well as specific to caring for people with dementia.

Multi-component interventions that are sensitive to the needs and cultural distinctions are needed to improve accessibility, acceptability and utilization of services and have been found to be effective in improving coping skills and the quality of life of caregivers (Cheng et al., 2019; Napoles et al., 2010). Cultural adaptation of any intervention targeting enhancement of mental health should incorporate aspects of the local culture into its content, which has the potential to improve both client engagement in treatment and outcomes (Barrera et al., 2013; Lau, 2006). WHO has, thus, strongly recommended that different countries and cultures should further adapt the iSupport program, suitable to their way of life and ethnicity to ensure delivery of the key features of iSupport.

To address the need for culturally competent training and support programs for caregivers of persons with dementia in India, the generic iSupport developed by WHO, was adapted to Indian cultural setting. The adaptation was done to ensure relevance and ease of use keeping in consideration the cultural context and technical challenges in India, such as infrastructure and low bandwidth. The current manuscript is a description of the process of adaptation of the generic iSupport program to the Indian cultural setting.

2. Methods

2.1. Study setting

The study was carried out at the National Institute of Mental Health and Neurosciences (NIMHANS), Bengaluru, India and was approved by the NIMHANS Ethics Committee (NIMHANS/88th IEC/2014 and NIMHANS/3rd IEC/(BEH.SC.DIV.)/2016) and the Ethical Review Committee of WHO (WHO RPC628).

2.2. Procedure

In the recent past, several models to guide cultural adaptations have been proposed (Barrera and Castro, 2006; Kumpfer et al., 2008; McKleroy et al., 2006; Wingood and DiClemente, 2008). Although these models appear to have been developed independently, they exhibit considerable consensus in terms of the processes involved (Castro et al., 2010) and also content strategies like incorporation of cultural values in intervention design or implementation, involvement of the family in interventions, adjustment of materials to literacy level of participants, use of social support and networks (Mier et al., 2010; Resnicow et al., 1999).

The adaptation process in this study followed the framework proposed by Barrera and Castro to guide cultural adaptations, which contains the essential elements of comprehensive adaptation models (Barrera and Castro, 2006). It presents four phases, consisting of (a)

information gathering, (b) preliminary adaptation design, (c) preliminary adaptation tests, and (d) adaptation refinement. These four phases of adaptation of the generic iSupport program to Indian cultural setting are described below. A flow chart of the phases is summarized in Fig. 1.

2.3. Phase 1: information gathering

This phase consisted of review of existing literature to understand common and unique factors of the intervention and conducting focus groups to assess perceptions about the intervention. The review of literature established that the components included in iSupport addressed the needs of caregivers of people with dementia in India to a considerable extent (Dhikav and Anand, 2012; Dias et al., 2008; Narayan et al., 2015; Srivastava et al., 2016). To further explore the perspectives of stakeholders, three focus group discussions (FGDs) were conducted - two with family caregivers and one with professionals from various disciplines involved in dementia care (Baruah et al., 2020). Thirteen primary caregivers (seven in the first FGD and six in the second FGD) and ten health professionals (third FGD) participated in the study. The health professionals who participated in the study were actively involved in dementia care in their professional capacity and the group comprised of two psychologists, two social workers, one psychiatrist,

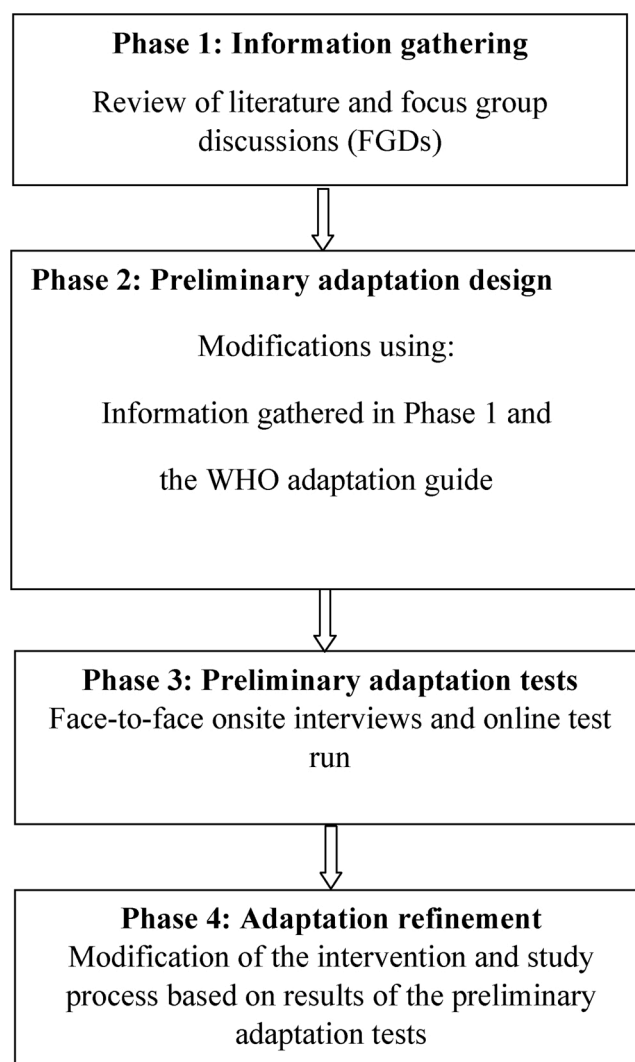


Fig. 1. Flow chart of the adaptation process. The flow chart shows the four phases of the process of adaptation of iSupport to Indian cultural setting, based on the framework proposed by Barrera and Castro, 2006.

one geriatrician, one mental health educator, one nursing professional working in a mental health institute and two rehabilitation professionals. Adaptation of the online training and support program to Indian setting was one of the major themes that emerged from the FGDs pertaining to factors that would encourage use of the program. Recommendations for adaptations included the need to highlight family-based caregiving, Indian culture specific caregiving scenarios, resources available in India, translation of the program into various Indian languages, and consideration for the quality of internet connectivity in India.

2.4. Phase 2: preliminary adaptation design

Information gathered in the first phase was consolidated to prepare the preliminary modifications to the iSupport program. Care was taken not to alter the core components of the original intervention (Card et al., 2011; McKleroy et al., 2006). The World Health Organization (WHO) provides a standardized guide for translation and adaptation (available upon request from whodementia@who.int) 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.

Changes required for adaptation to the Indian setting, based on the information gathered in Phase 1, were documented by the research associates (UB and PS) involved in the study in separate templates developed for each module of the program. In the templates, the proposed changes or modification were described in terms of design, content, flow for each lesson of the specific modules of the program. The proposed changes were then reviewed by the two senior investigators (MV and SL) of the study and finalised after detailed discussion with the research team including inputs from the WHO team. The adaptations were then incorporated in the online program with the help of the content management system manual developed by WHO to facilitate the process of adaptation. Details of the preliminary adaptations that were done at this phase are described in Table 1. Translation to local language was not done as it was difficult to identify specific regional language for an online intervention catering to a nationwide population and the process of translation can be time and cost intensive. The iSupport program was delivered in English as it has been used as a medium of instruction and communication for caregiver interventions in India (Kaur et al., 2018).

2.5. Phase 3: preliminary adaptation tests

A test run was conducted to assess the acceptability of the adapted version of the iSupport program and the assessment procedure for the planned effectiveness trial (Mehta et al., 2018). This also provided an opportunity to examine the appropriateness of the measures and the clarity of instructions (Barrera et al., 2013). The test run was conducted in two parts. The first part involved initial face to face interviews with caregivers during which they were asked to evaluate the assessment tools and the adapted Indian version of the iSupport program onsite, i.e., at NIMHANS. In the second part, online test run of the whole process was conducted and qualitative feedback was obtained through e-mails from the caregivers.

2.5.1. Participants

Caregivers who met the following criteria were contacted: a) self-reported caregiver of a person with dementia, b) aged 18 years and older, c) read and spoke English, d) were regular users of computers/ the Internet. The caregiver had to be Indian residents and for the face to face interviews, they had to reside in Bengaluru city region. Four caregivers consented for the face to face interviews at NIMHANS and eleven caregivers consented for the online evaluation of the assessment process and intervention program. The participants for the onsite interviews provided written informed consent and the participants for the online test run provided online informed consent.

Table 1
Preliminary adaptations to iSupport intervention at Phase 2.

Areas in which adaptation was done	Details of the modifications/adaptations done
Words	Words/expressions were changed according to local standards/habits. For example words for food choices such as 'pasta', 'mashed potatoes', 'noodles' etc. were changed to Indian food items such as 'idli' 'khichdi' 'dal' etc. For words denoting attire such 'trousers' and 'skirts', additional words pertaining to Indian attire such as 'dhoti', 'kurta', 'saree' etc. were added.
Names	Names of characters mentioned in the examples were changed according to common Indian local names. Keeping in mind the religious and cultural diversity of India, names representing major religions were used. For example, names such as Diana and Dan were changed to <i>Rekha</i> and <i>Prasad</i> and Oliver and Ella were changed to <i>Iqbal</i> and <i>Noor</i> .
Resources	In India, caregiving of persons with dementia is mostly family based. Hence, the resources available for care as mentioned in the generic iSupport program such as 'nurses' and 'paid help' were changed to family caregivers – daughter, son, husband, wife, relative, neighbour.
Caregiving scenario	Caregiving situations and scenarios given in the generic iSupport program were changed to make it relevant to Indian context. For example, one of the activities suggested in the generic iSupport program to keep the person with dementia occupied for some part of the day, was baking of cookies and cakes. As baking is not a very common family activity in most Indian households, this scenario was changed by suggesting activities such as, making Indian snacks and sweets that the person with dementia might enjoy.
Other	In the iSupport program, there are relaxation exercises at the end of each lesson for the caregivers to practice. Some these exercises are guided with audio instructions. As the voice in the audio files has a western accent, the instructions were re-recorded in an Indian voice.

2.5.2. Procedure for the onsite face to face interviews

Caregivers who met the above mentioned inclusion criteria and resided in Bengaluru, were identified from those who accompanied the persons with dementia to the Geriatric Clinic & Services, NIMHANS and were contacted over telephone. A total of fifteen caregivers were contacted and information about the study was provided. Four caregivers consented for the interviews. The other caregivers cited lack of time due to job related or caregiving responsibilities and other inconveniences as reasons for decline of consent. Over the course of two days, the four caregivers were invited to view the adapted iSupport program at the NIMHANS hospital. After a brief introduction, the caregivers were asked to complete the screening questionnaires and the outcome assessments. The screening questionnaires included the following measures: the AD8 Dementia Screening Interview (Galvin et al., 2005), a 1-item burden scale ranging from 1 to 10 (Blom et al., 2013), the Generalized Anxiety Disorder scale (GAD7; Spitzer et al., 2006) and the Center for Epidemiologic Study-Depression scale (CES-D10; Radloff, 1977). The outcome assessments included the Zarit Burden Interview (ZBI; Zarit et al., 1985), the Approaches to Dementia Questionnaire - Person-centered attitude subscale (ADQ; Lintern et al., 2000), the RIS Eldercare Self-efficacy Scale (Gottlieb and Rooney, 2003), the Mastery Scale and the EuroQol - Visual Analog Scale (EQ-VAS; the EuroQol Group, 1990). After completion of the assessments, each caregiver was asked to log in to the adapted iSupport program. They were then guided to read and complete the lessons in the program along with the interactive exercises that were provided in all but the first lesson. The caregivers were asked to complete at least five lessons out of the 23 lessons available. Qualitative feedback from the caregivers regarding the adapted program was obtained using open ended questions which covered the following aspects of the program – content, appropriateness to cultural context, assessment measures used, technical aspects and overall feedback. Duration of

the interviews varied from two to three hours. Detailed notes were taken by the study personnel during the whole process.

2.5.3. Procedure for the online test run

Fifteen caregivers, who accompanied the persons with dementia to the Geriatric Clinic & Services, NIMHANS and met the inclusion criteria (as mentioned in section 2.5.1), were selected using purposive sampling. Caregivers who had participated in the onsite face to face interviews were excluded. All the fifteen caregivers were contacted over telephone and explained about the study. Eleven caregivers consented for the study, while four caregivers declined consent due to constraint of time. After initial verbal consent over telephone, it was communicated to them that they would receive an e-mail link to participate in the test run. The participants were given one week to complete the assessments and go through the intervention program that they were assigned to. One week after the first e-mail, the participants received another e-mail requesting their feedback on the process and intervention. The qualitative feedback questionnaire included open-ended questions on the following aspects: process of online consent and online assessment; automated e-mails that the participants received; content and presentation of the intervention; cultural appropriateness of the adapted version of iSupport and its relevance to the Indian context. The participants were requested to send their feedback via e-mail and were encouraged to contact the research team over telephone for any additional comments.

2.5.4. Analysis

The notes taken by study personnel during the face to face interviews were reviewed for convergence. Items that were consistently mentioned in at least 3 of the 4 interviews were reviewed by study personnel using a roundtable format and decisions regarding follow up action were noted following each convergent issue. In addition, some lower level 'easy fixes' such as typographical errors were highlighted for immediate action. For the online test run, the email feedback received from the participants was analysed manually by the research associate (UB). The final data were prepared by organizing the feedback received from both the onsite interviews and the online test run. A summary of the convergent issues was prepared and areas that required amendments were finalised after consensus by all members of the research team.

2.6. Phase 4: adaptation refinement

Changes were made to the preliminary adaptation based on the results of the test run (Barrera and Castro, 2006; McKleroy et al., 2006). As in phase two, the core components of the original intervention were not modified or deviated from. Modifications made at this phase incorporated informed decisions from the research team including the developers of the program, investigators and research staff.

3. Results

Demographic characteristics of the caregivers who participated in the preliminary adaptation tests (onsite interviews and the online test run) are described in Table 2. The results of the qualitative feedback showed that development of the online training and support program was appreciated and acknowledged by the participants as an important intervention for caregivers of people with dementia. Some of the aspects which garnered positive response from the participants include - content and information provided in the program, relaxation exercises provided at the end of each lesson, interactive format of the program. The participants found the content to be culturally appropriate and relevant to the Indian context. There were a few areas where modifications were required. A detailed description of the changes and modifications incorporated in the intervention and study process based on the results of the test run is summarized in Table 3. A few verbatim quotes from the qualitative feedback are mentioned below.

Table 2

Socio-demographic profile of the participants in the preliminary adaptation tests:

Caregiver characteristics	Face to face interviews (N = 4)	Online test run (N = 11)
Age in years (Mean \pm S.D)	35.75 \pm 3.30	40.64 \pm 13.99
Sex: Male N(%)	3(75 %)	6 (54.5 %)
Female N(%)	1(25 %)	5 (45.5 %)
Education:		
Bachelors degree	1(25 %)	3 (27.3 %)
Masters degree	1(25 %)	4 (36.4 %)
Professional degree (including B. E./B.Tech/ M.B.B.S)	2(50 %)	4 (36.4 %)
Education in Years (Mean \pm S.D)	16.50 \pm 1.00	16.54 \pm 1.03
Relationship to Patient: Son N(%)	3(75 %)	5 (45.5 %)
Daughter N(%)	1(25 %)	5 (45.5 %)
Spouse N(%)	–	1 (9.1 %)
Duration of caregiving in months (Mean \pm S.D)	30.50 \pm 10.24	13.63 \pm 7.72
Place of residence in India:		
Bengaluru	4 (100 %)	4 (36.4 %)
Mysuru	–	2 (18.2 %)
New Delhi	–	1 (9.1 %)
Vadodara	–	1 (9.1 %)
Kolkata	–	2 (18.2 %)
Hyderabad	–	1 (9.1 %)
Accessed internet through:		
Computers	–	1 (9.1 %)
Computers and smartphones	4(100 %)	10 (90.9 %)

“The information included in the program is good, clear and in simple language. I liked the interactive part where feedback was given about the options we chose.” - a 30 year old woman caring for her mother (participated in the online test run)

“I could relate very well to some of the situations mentioned in the interactive exercises as those are situations that we actually went through with my mother.” – a 36 year old man caring for his mother (participated in the face-to-face onsite interviews)

“The content of the program is informative and relevant, but the numbers of screens I had to navigate in the beginning of the process was tedious.” – a 32 year old woman caring for her father (participated in the online test run)

4. Discussion

The need for training and support services for people with dementia and their caregivers, especially in LMICs, is well established (WHO, 2015, 2017; Hinton et al., 2019). It is also important that the services or interventions developed are culturally sensitive when they are implemented in real world settings (Lau, 2006; Marsiglia and Booth, 2015). This study was an attempt to adapt the iSupport program to Indian cultural setting by preserving the core features that are integral to the intervention while being responsive to the context and situation of caregivers of people with dementia in India. Based on a four phase conceptual framework for cultural adaptation by Barrera and Castro (2006), the generic iSupport program was evaluated for cultural adaptation in the areas of content, design and flow; changes were made accordingly in words, names, resources, caregiving scenarios and audio files. Care was taken to include non-data-intensive applications in the program considering the relatively slow internet connection speed in India. These elements were included to boost program appeal, appropriateness, and efficacy (Barrera et al., 2011; Kreuter et al., 2003). The online test run was conducted to ensure that the study methods would work in practice and to assess the acceptability and understandability of the proposed research process, including its cultural context (Perry, 2001; van Teijlingen and Hundley, 2002). The test run proved to be instrumental in making some of the important changes to the intervention and study process. Involvement of the stakeholders from the

Table 3
Changes and modifications incorporated during adaptation refinement phase (Phase 4):

Area where modification was required	Findings from the interviews and online test run	Corresponding modification made	Reasons for modification
Intervention program	The resource links provided in the iSupport program for additional information were mostly links to international websites	The links were changed to India specific websites (if available). For example, links to ADI website were changed to local Alzheimer association (ARDSI) website.	To provide relevant information about local resources and information specific to the Indian context
Methodology	The eligibility criterion for caregiving duration was 1 year. This excluded many caregivers, who needed information about caregiving but had been caregivers for less than 1 year, from taking part in the study	Eligibility criterion for caregiving duration was changed from 1 year to 6 months	To accommodate caregivers who were relatively new to the caregiving role and needed support and guidance, and also had some caregiving experience to be able to respond to the screening and outcome questionnaires
Content of email to participants	After the screening questionnaires, the caregivers who scored higher than the cut-off score for the study received an email explaining their non-eligibility to take part in the study and asking them to consult a mental health professional. There was a need to re-word the content of the email.	The email was re-worded to be more sensitive and empathetic to the caregiver's distress.	Having a higher score on the screening instruments indicated that the respondent might be experiencing clinical depression or anxiety or severe burden. This aspect was kept in mind while drafting the e-mail response, so that non-eligibility to take part in the study was not perceived as a rejection, which might further increase their distress.
Assessment process	There was a need for additional information about the approximate time required to fill out the screening questions and initial assessments.	An estimate of the time required to complete the assessments was added in the informed consent form and also at the start of the assessments	To help the participants make an informed decision about participating in the study and also to help them plan their time accordingly
Presentation	The participants had to navigate many screens to complete the online assessments as there were only two questions per screen. The process was reported to be 'tedious'	The numbers of screens were decreased without compromising on the size of the font, keeping in consideration ease of use for elderly caregivers	To help make the presentation and process of the study more user friendly

Notes: ADI - Alzheimer's Disease International; ARDSI - Alzheimer's and Related disorders Society of India.

beginning and throughout the process was an important aspect of this study which contributed to its strength and credibility (Williams et al., 2013). The need for the intervention, characteristics of the population, the cultural context, and other factors that might affect the effectiveness study were taken into consideration.

In India there exists a considerable heterogeneity within and between different geographical areas, communities, ethnic groups and within each of these broad groups, there exist many homogeneous sub-cultural groups and hidden subpopulations with their own beliefs, values, customs, traditions, and lifestyles. An important limitation of the study was the small sample size, primarily from urban Bengaluru, which makes it difficult to generalize the findings to the larger population of India with its vast cultural diversity. However, as the iSupport intervention was developed and targeted for the English speaking, educated and computer/Internet savvy caregivers, addressing the insurmountable beliefs, values, customs, traditions, and lifestyle existing in the cultural melting pot that is India was not within the purview of the study from the outset. The focus of the adaptation was to enhance caregiver responsiveness and participation for the intervention. So, efforts were made to make the intervention comprehensible by matching the content to the educational, and/or developmental needs of the caregivers (Castro et al., 2004). Efforts were also made to enhance motivation by making the content interesting and important to the caregivers and by including relevant content and materials that were applicable to the everyday lives of the caregivers (Castro et al., 2004).

A study to examine the effectiveness of the adapted iSupport program was designed (Mehta et al., 2018). The process of translation of the iSupport program to Indian languages and further adaptation could be undertaken based on the results of the randomized controlled trial which examined the feasibility and preliminary effectiveness of the intervention (Baruah et al., 2021).

This study was a preliminary attempt to adapt an online training and support program for caregivers of persons with dementia to Indian setting. From the first phase of information gathering and preliminary revisions, all approaches aimed to learn directly from the people who represented the intended beneficiaries of the proposed intervention (Castro et al., 2010). These phases of adaptation lead to a refined intervention that has the potential to be implemented in larger-scale outcome research after incorporation of the learnings from the preliminary effectiveness trial (Baruah et al., 2021). Any attempt at adapting behavioural or cognitive interventions to the cultural milieu of India is a mammoth task. The Indian culture varies like its vast geography - people speak in different languages, dress differently, follow different religions, have different food habits. Thus, any intervention that has to be implemented in such culturally diverse communities need to be adapted to each cultural community, ethnic and other minority groups to address the cultural norms that may be impacting their behaviors or decision-making process. This study has adapted an English version of iSupport for India and further work is necessary to adapt iSupport in other languages and cultural subsets.

Authors' contributions

Upasana Baruah: conception and design of the study, data acquisition, analysis and interpretation of data, drafting the article, revising article critically for important intellectual content and final approval of the version to be submitted

Santosh Loganathan: conception and design of the study, interpretation of data, revising article critically for important intellectual content and final approval of the version to be submitted

Prafulla Shivakumar: conception and design of the study, data acquisition, analysis and interpretation of data, revising article critically for important intellectual content and final approval of the version to be submitted

Anne Margriet Pot: conception and design of the study, interpretation of data, revising article critically for important intellectual

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Kala M. Mehta: conception and design of the study, interpretation of data, revising article critically for important intellectual content and final approval of the version to be submitted

Dolores Gallagher-Thompson: conception and design of the study, interpretation of data, revising article critically for important intellectual content and final approval of the version to be submitted

Tarun Dua: conception and design of the study, interpretation of data, revising article critically for important intellectual content and final approval of the version to be submitted

Mathew Varghese: conception and design of the study, interpretation of data, revising article critically for important intellectual content and final approval of the version to be submitted

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Declaration of Competing Interest

The authors report no conflict of interest.

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