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

Upasana Baruah, Santosh Loganathan, Prafulla Shivakumar, Anne Margriet Pot, Kala M. Mehta, Dolores Gallagher-Thompson, Tarun Dua, Mathew Varghese

Geriatric Clinic and Services, Department of Psychiatry, National Institute of Mental Health and Neurosciences (NIMHANS), Bangalore, India
Department of Mental Health and Substance Use, World Health Organization (WHO), Geneva, Switzerland
Department of Epidemiology and Biostatistics, University of California, San Francisco, San Francisco, CA, United States
Department of Psychiatry and Behavioral Sciences, Stanford University School of Medicine, Stanford, CA, United States
Betty Irene Moore School of Nursing, University of California, Davis, CA, United States

ARTICLE INFO

Keywords:
Cultural adaptation
Online caregiver training and support program
Dementia
Family caregivers
India

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, 2000).
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 ‘Support’ 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/(BEHSC.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,
Informal feedback from caregivers suggested a need for contextual modifications. For example, names such as Diana and Dan were changed to family members such as daughter, son, husband, wife, relative, or neighbour. Other words and phrases such as 'trousers' were changed to 'dhoti', 'skirt', 'saree', etc. were added. Names of characters mentioned in the examples were changed according to common Indian local names. For example, names such as Diana and Dan were changed to Rekhla and Prasad and Oliver and Ella were changed to Iqbal and Noor.

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.

#### 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; McLeroy 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.

“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>
<thead>
<tr>
<th>Table 2</th>
<th>Socio-demographic profile of the participants in the preliminary adaptation tests:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver characteristics</td>
<td>Face to face interviews</td>
</tr>
<tr>
<td>(N = 4)</td>
<td>(N = 11)</td>
</tr>
<tr>
<td>Age in years (Mean ± S.D)</td>
<td>35.75 ± 3.30</td>
</tr>
<tr>
<td>Sex: Male N(%)</td>
<td>3(75 %)</td>
</tr>
<tr>
<td>Female N(%)</td>
<td>1(25 %)</td>
</tr>
<tr>
<td>Education: Bachelors degree</td>
<td>1(25 %)</td>
</tr>
<tr>
<td>Masters degree</td>
<td>1(25 %)</td>
</tr>
<tr>
<td>Professional degree (including B. E./B.Tech/ M.B.B.S)</td>
<td>2(50 %)</td>
</tr>
<tr>
<td>Education in Years (Mean ± S.D)</td>
<td>16.50 ± 1.00</td>
</tr>
<tr>
<td>Relationship to Patient: Son N(%)</td>
<td>3(75 %)</td>
</tr>
<tr>
<td>Daughter N(%)</td>
<td>1(25 %)</td>
</tr>
<tr>
<td>Spouse N(%)</td>
<td>–</td>
</tr>
<tr>
<td>Duration of caregiving in months (Mean ± S.D)</td>
<td>30.50 ± 10.24</td>
</tr>
<tr>
<td>Place of residence in India:</td>
<td></td>
</tr>
<tr>
<td>Bengaluru</td>
<td>4 (100 %)</td>
</tr>
<tr>
<td>Mysuru</td>
<td>–</td>
</tr>
<tr>
<td>New Delhi</td>
<td>–</td>
</tr>
<tr>
<td>Vadodara</td>
<td>–</td>
</tr>
<tr>
<td>Kolkata</td>
<td>–</td>
</tr>
<tr>
<td>Hyderabad</td>
<td>–</td>
</tr>
<tr>
<td>Access to internet through:</td>
<td></td>
</tr>
<tr>
<td>Computers</td>
<td>–</td>
</tr>
<tr>
<td>Computers and smartphones</td>
<td>4(100 %)</td>
</tr>
</tbody>
</table>
Notes: ADI - Alzheimer’s Disease International; ARDSI - Alzheimer’s and Related disorders Society of India.

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

<table>
<thead>
<tr>
<th>Area where modification was required</th>
<th>Findings from the interviews and online test run</th>
<th>Corresponding modification made</th>
<th>Reasons for modification</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intervention program</td>
<td>The resource links were mostly links to international websites.</td>
<td>The links were changed to India specific websites (if available). For example, links to ADI website were changed to local Alzheimer association (ARDSI) website.</td>
<td>To provide relevant information about local resources and information specific to the Indian context.</td>
</tr>
<tr>
<td>Methodology</td>
<td>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.</td>
<td>Eligibility criterion for caregiving duration was changed from 1 year to 6 months.</td>
<td>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.</td>
</tr>
<tr>
<td>Content of email to participants</td>
<td>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 reword the content of the email.</td>
<td>The email was reworded to be more sensitive and empathetic to the caregiver’s distress.</td>
<td></td>
</tr>
<tr>
<td>Assessment process</td>
<td>There was a need for additional information about the approximate time required to fill out the screening questions and initial assessments.</td>
<td>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.</td>
<td>To help the participants make an informed decision about participating in the study and also to help them plan their time accordingly.</td>
</tr>
<tr>
<td>Presentation</td>
<td>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’.</td>
<td>The numbers of screens were decreased without compromising on the size of the font, keeping in consideration ease of use for elderly caregivers.</td>
<td>To help make the presentation and process of the study more user friendly.</td>
</tr>
</tbody>
</table>

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 content and final approval of the version to be submitted.
content and final approval of the version to be submitted

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

Taran 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

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.

Funding

This work was supported by a grant from the US National office of the Alzheimer’s Association [Grant# ETAC 13-280725].

Role of funding agency

The funders had no role in the study design, data collection, management, analysis, interpretation of data, writing of the report, and the decision to submit the report for publication. The funders do not have ultimate authority over any of these activities.

Declaration of Competing Interest

The authors report no conflict of interest.

Acknowledgments

The authors would like to thank Katrin Seeher from World Health Organization for her thoughtful comments on the manuscript. The authors would also like to thank the caregivers who participated in the study. The ideas and opinions expressed herein are those of the authors alone, and endorsement by the authors’ institutions or the funding agency is not intended and should not be inferred.

References


Barrera Jr., M., Castro, F.G., 2006. A heuristic framework for the cultural adaptation of data, revising article critically for important intellectual content and final approval of the version to be submitted

Barrera Jr, M., Castro, F.G., 2006. A heuristic framework for the cultural adaptation of data, revising article critically for important intellectual content and final approval of the version to be submitted


