

### **Cultural adaptation of the WHO-iSupport intervention for caregivers of persons with ADRD in Uganda**

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**Background:** Family caregivers of persons with ADRD face major stressful emotional, social and economic burdens, and the negative consequences associated with caregiving are well documented. Given the projected global increase in the number of people with dementia (82 million by 2030 and 152 million by 2050), plus a current Dementia prevalence among persons 60 years and older in Uganda, ranging from 5.5% to 20%, there is paucity of information regarding the psychotherapeutic management of challenges that family caregivers of persons with ADRD go through in many settings in sub-Saharan Africa, including Uganda. This study will contribute to the cultural adaptation of the WHO-iSupport that is an appropriate intervention for caregivers of persons with ADRD in Uganda.

**Objective:** To investigate the current approaches that caregivers use in the support of persons with ADRD, so as to inform the adaptation of the WHO iSupport intervention for Uganda.

**Methods:** This is a cultural adaptation study involving adaptation and pre-test the WHO-iSupport for family caregivers of persons with ADRD in Wakiso, Uganda. We are using a group consensus method that includes a professional translator and independent groups of bilingual experts. Caregivers of patients with ADRD are being recruited into the study. Data will be collected by the researcher and trained research assistants.

**Outcomes:** The primary outcome of this study is the adaptation of the WHO-iSupport psychotherapy. **Analysis:** Primary analyses will be based on Intention to treat (ITT) principle to avoid any biases that may occur by subjective choice of ineligible subjects. Summary statistics like age will be given as a mean (SD) while for categorical data will be given as a proportion and summarized in tables and graphs.

**Utility:** The proposed study is instrumental as it will be the first known study in our setting that provides a step-by-step guide in the cultural adaptation of an intervention for care giving of persons with ADRD. The A-iSupport is a caregiver focused intervention, that promises better health and care outcomes for family caregivers of persons with ADRD, thus reducing the health care load on mental health workers.

### **Preparing for implementing "iSupport" in Tunisia: Experience and needs of caregivers of persons with dementia**

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**Context:** Caregivers of persons with Alzheimer's disease or related dementia (ADRD) are essential for a better quality of life of those they care for. Their role can have a severe impact on their own physical and mental health, as well as on their social and financial situation, according to the current literature. For this reason, WHO has provided the iSupport tool to provide support to caregivers of people with ADRD. Its adaptation and implementation in Tunisia is challenged by the lack of Tunisian data concerning the experience and needs of this population.

**Objectives:** To explore, in cooperation with the WHO, the experience of caregivers of persons with ADRD in Tunisia, and their potential training and support needs.

**Methods:** A qualitative cross-sectional study using individual semi-directive interviews was conducted with caregivers of persons with ADRD in Tunisia. Interviews were recorded and transcribed. A thematic analysis of the interviews was performed by two researchers.

**Results:** Fifteen caregivers (11 women and 4 men) were interviewed on-site, or by telephone. Concerning their overall experience of caregiving, several main themes have emerged: The disruption of the relationship with the close relative (including the role switching, or the impossible mourning), the disruption of the relationship with oneself (including the forgetting of oneself, or the revision of priorities) and the disruption of the relationship with the others and the world (including the isolation and the withdrawal into the dyad caregiver - close relative with an ADRD, the lack of time, or the life as an unending daily struggle). When it comes to training and support needs, content and format preferences were identified.

**Conclusion:** This work helped us to adapt iSupport to the specific needs of caregivers in Tunisia. Data concerning their overall experience should provide an opportunity for a better adaptation of the social and policy context.

### **Adapting the World Health Organisation's 'iSupport' for Young Dementia Carers**

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**Objectives:** The number of children and adolescents who have caring responsibilities for a family member with dementia is rising. They need help to understand the illness, what changes are expected and how it can affect their family member. This presentation reports on the co-design of an adapted version of *iSupport* for young carers.

**Methods:** A theoretically driven co-design approach was followed, drawing on the lived experiences of young dementia carers. Young dementia carers (n=6, age 12-16) and professionals who work with young carers (n=5) took part in three workshops and provided individual contributions. Feedback was analysed and adaptations organized according to the dimensions of the Ecological Validity Model which addressed the structure and design, content, context and language. By focussing on these dimensions, we intended to increase the relevance, acceptability and comprehensibility of *iSupport* to this new target group while keeping the completeness of the theoretical premises underpinning it.

**Results:** Informed by feedback from participants a number of adaptations were carried out. Case scenarios included in the original *iSupport* were edited and other new ones created to place the focus on a young character with caring responsibilities within a family unit. These characters were young people with a parent or grandparent living with dementia. Also, illustrations portraying human characters representing a range of ages and ethnicities were added throughout. These characters emphasised the actions described within the carer case scenarios. Adaptations to the 'design' and 'language' were also carried out. For example, the quantity and complexity of the text was reduced as much as possible without compromising its readability and meaning. Clarity and appeal were increased by changing font size, style and including brighter colour schemes. Adaptations resulted in the creation of *iSupport for Young Carers*.

**Conclusions:** *iSupport for Young Carers* is the first e-health intervention of its kind and aims to support the mental health, knowledge, and skills of young dementia carers. This new adaptation provides opportunities for other countries and demographic groups to translate and adapt *iSupport for Young Carers* to their specific cultural context.