

Web-Based Intervention for Multilingual Family Carers of People with Dementia: Insights from the DrawCare Study

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Abstract. Addressing the needs of ethnically diverse multilingual people can be challenging in environments that are non-native to them. The consequences of this issue become more significant in healthcare contexts. Insights from the DrawCare study—an Australian study that explores the effectiveness of a web-based intervention for multilingual family carers of people with dementia—are presented illustrating the enabling role of digital health.

Keywords. Clinical trial, dementia, e-health, family carers, m-health, multilingual

1. Introduction

Dementia is an umbrella term for neurodegenerative disorders with progressive cognitive impairment that significantly affects daily living activities. Dementia cases across the world are estimated to triple from about 50 million in 2018 to 152 million by 2050 [1]. Caring for people living with dementia can be quite confronting and challenging for informal or family carers who often experience numerous effects such as psychological morbidity, social isolation, physical ill-health, and financial hardship [2]. Therefore, offering adequate support for family carers is vital for improving the quality of care for people with dementia. Multilingual family carers face added challenges as they have few culturally appropriate home and community-based services to access and endure long wait times for support services, which further delay timely care and amplify distress [3]. The DrawCare study [4] explores ways to address this issue, by using animated short films and digital technologies to support Culturally and Linguistically Diverse (CALD) family carers and people living with dementia in Australia. The study is ongoing. In this poster, we summarize our progress and findings from the developed DrawCare website.

2. Methods

The study protocol is provided [4]. The full project was designed to have three studies. The theoretical lens followed by this project along with key milestones is illustrated in

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Figure 1 in page 12 of reference [4]. Covered in 2022 was the first of the three studies. The focus of Study 1 was culturally adapting the World Health Organization (WHO) iSupport Lite program [5] by working with CALD family caregivers, clinicians, service providers, and people living with dementia, as well as partners WHO, Dementia Australia, and the Federation of Ethnic Communities Council of Australia. The objective was to co-produce (using codesign methods) the DrawCare Intervention in nine CALD languages plus English. An integral aspect was codesigning, including six two-hour codesign workshops to cover the six practical support messages of the iSupport Lite program. The workshops focused on three key aspects: (1) Planning and culturally adapting the content as animated short films; (2) Extrapolating key quotes and messages as tip sheets, and (3) Planning a structure for a website for the resources to be presented. Following the workshops, the animated films and the tip sheets were translated into all languages. They were then placed on a website to be carried forward for the subsequent phases including a clinical trial [4].

3. Results

The main outcome of Study 1 was the co-designed DrawCare intervention, including animations, tip sheets, and a website (<https://drawcare.emergetrial.net/>) in ten languages that contains the resources. This website was designed based on identifying and distilling the feedback that emerged from the codesign workshops.

4. Conclusions

The emerged features from the workshops were: Plain language that is appropriately translatable; Less clutter (i.e., static web page design with no moving objects); two-colored design (i.e., white background and a dark color for title bars); contrasting colors for fonts (i.e., black font on white background, and white font on dark backgrounds); a virtual assistant to help find resources; display optimization for different devices; and capability of feedback collection. The website is an attempt to capture the above features. The content is presented in ten languages. Developing such a multilingual website is challenging as the content and message must be both faithfully represented but also culturally responsive to fit with specific cultural nuances. These lessons learned may have relevance and generalizability beyond the subject of focus, dementia. Future work will include assessing the effectiveness of the intervention through a clinical trial.

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