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Sustainable Caregiving Families: Addressing the Ethno-Cultural-Linguistic Needs of Chinese Immigrant Caregivers for a Web-based Support Portal

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Abstract

Background: Family caregivers are fundamental members of a sustainable health care system. In a multicultural society, family caregivers have different ethnic, cultural, and linguistic support needs. Purpose: To develop and evaluate the design enhancements of a Personalized Support for Family Caregivers (PSFC) web-based portal for Chinese families. Method: Through the portal, 33 participants received caregiver-therapist email support and had access to an information website. After in-depth interviews of 10 users, data were analyzed using qualitative thematic, user profile and requirement analyses to conceptualize the redesign. Results: Traditional family values, information needs, familiarity with English and computer literacy had an impact on the usage of the PSFC. The portal functions was enhanced by: 1) building a sense of presence of the PSFC, 2) engaging more members in a family rather than only a primary caregiver, 3) assisting users with English communication, and 4) delivering information in the form of narratives. Conclusion: Information communication technologies, when well designed and implemented, can meet the ethno-cultural-linguistic needs of caregiving families in a multicultural society.

Keywords:

alzheimer disease, clinical informatics, Canada, Chinese, culture, family caregivers

Introduction

Family caregivers are fundamental members in a sustainable healthcare system. In a multicultural society, the pluralistic ethnic, cultural, and linguistic landscape creates many different caring environments. A number of studies have evaluated the use of communication technologies to support family caregivers [1-4], but few investigated ethno-cultural-linguistic barriers to accessing technology-based support programs. This paper will report on the ethno-cultural-linguistic ehealth needs of Chinese Canadian family caregivers and the design enhancements of a web-based portal that offers Personalized Support for Family Caregivers Support (PSFC) to them.

Methods

This research is a substudy of a larger research being undertaken [5]. The main study provided caregiver support through a web-based portal in both Chinese and English. The portal consisted of 1) a 400-page caregiving information website and 2) a personalized caregiver-therapist email support.

A mixed methods design was used in this substudy. We selected a purposive sample of ten participants from the main study. The sample had varied caregiving characteristics and usage patterns of the caregiver portal. Participants were interviewed by phone or in-person, in a language of their choice (90% in Chinese). The in-depth interviews were audio-taped, translated, and transcribed verbatim. The data were coded, and a thematic analysis conducted [6].

A user-centered design methodology [7] was used to develop the design concept. There were five processes: 1) thematic analysis of the interview data, 2) the construction of user profiles, 3) the stakeholder analysis, 4) the requirement analysis, and 5) the conceptualization of the system enhancements.

Results

The caregiving context and usage experiences

The participants provided care in a caregiving context that had the following salient themes: 1) embracing the traditional family values, 2) living with worries and emotional struggles, 3) seeking external help and reflecting on self, and 4) sharing the care while caring for the family.

Within this caregiving context, the participants had varying usage experiences of the caregiver portal. They 1) talked in Chinese, typed in English, and preferred to hear stories, 2) needed help to access their accounts in an unfamiliar portal, 3) ranged from liking all information in one place to favouring human contacts, and 4) ranged from expressing self freely to not knowing what to say in an email

Enhancement requirement analysis

The requirement analysis [7] focused on the unmet needs of participants who were occasional or non-users. The results showed that these non-adopters typically:

- were not fluent in written English
- did not know what to ask; were unsure which problems were part of the illness
- did not know how to ask; unsure how much to tell
- preferred learning from stories of other caregivers
- preferred notifications and reminders; forgot the user name and password
- felt that they could manage the care on their own
- had difficulty expressing in an email
- felt that going to a support group, asking the doctor, browsing the internet, or reading a book was better

Conceptual design of an enhanced system

The non-adopter characteristics, thematic analysis and requirement analysis were used to conceptualize the redesign. The enhanced system, called PSFC, expanded the original functions to include four new features:

1. Building a sense of presence of the PSFC
2. Expanding from a primary caregiver to a caregiving family
3. Using narratives to inform and educate
4. Addressing multilingual needs with a digital solution

Figure 1 - Screen shots of Short Stories (Chinese version), Family Forum; and Telling More

Conclusion

Ethno-cultural-linguistic needs of family caregivers are complex. Information communication technologies, when well designed and implemented, have the capacity to address the special needs of these caregivers who live in a multicultural society. This study illustrates the iterative design and redesign of such an application based on usage experiences and user preferences. The redesign is currently being evaluated using usability testing and a quantitative analysis of user engagement. The concepts, if proven to be useful, could benefit families from other ethnic or cultural groups that value close family relations, needs assistance in English communication, and prefer narratives to receive information. If caregivers are better supported, caregiving families can be sustained, which in turn can contribute to sustainable health care systems in the 21st century.

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