Sustainable Caregiving Families:

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

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Purpose

- This paper will report on
  - the ethno-cultural-linguistic ehealth needs of Chinese Canadian family caregivers
  - the design enhancements of a web-based portal that offers Personalized Support for Family Caregivers Support (PSFC) to them

Background

- 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

A Mixed Methods Evaluative Study

- A substudy of a larger research that provides caregiver support through a web-based portal [5].
- The portal
  - Offers in both Chinese and English
  - Is consisted of 1) a 400-page caregiving information website and 2) a personalized caregiver-therapist email support.
- A mixed methods evaluative design
  - In-depth interview
  - User-centered design

In-depth Interview

- A purposive sample of 10 participants from the main study was selected
- 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]

User-centered design

- The portal redesign was conceptualized using a user-centred design method [7]:

1. thematic analysis of the interview data
2. the construction of user profiles
3. the stakeholder analysis
4. the requirement analysis
5. the conceptualization of the system enhancements

Results:
Caregiving Context & Usage Experiences

- Caregiving context:
  - embracing the traditional family values
  - living with worries and emotional struggles
  - seeking external help and reflecting on self
  - sharing the care while caring for the family.
- Usage experiences of the caregiver portal:
  - talked in Chinese, typed in English, and preferred to hear stories
  - needed help to access their accounts in an unfamiliar portal
  - ranged from liking all information in one place to favouring human contacts
  - ranged from expressing self freely to not knowing what to say in an email

Results:
Enhancement Requirement Analysis

Participants who were occasional or non-users 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

Results:

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

Screenshots of the Enhanced Features

照護者資訊網站

處理無奈的感覺

本週的五個簡短故事，內容是敘述照顧老年癡呆病患者的家屬，在日常照顧時感到的無奈。

無暇做自己的事情

李太的先生想她時常陪伴他，她不能把李先生單獨留在家中、以出外做點自己的事情，她因此而感到很無奈。

快要失去耐性

王先生的媽媽重覆地問他同樣的問題，他每次都回答她，他感到快要失去他的耐性了，但他卻不想發他媽媽的脾氣。

太多責任了

麗珍一面工作、一面要照顧自己的家庭，同時亦要照顧患有老人癡呆症的爸爸，麗珍感到她所承擔的責任太多了。她不能給她的家人一切所需的照顧，她因而感到無奈。

不知怎樣幫助

美芬的媽媽以前能應付自如的事，現在已不能做到，美芬不知怎樣可以幫助她媽媽，這樣的改變令到美芬很無奈。

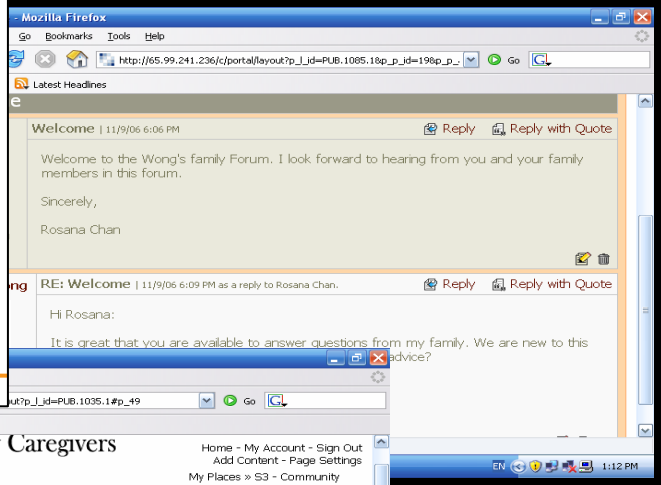
無理的指責

志文發覺他的祖母時常忘記放了東西在甚麼地方，有時還指責志文偷了她的東西，他祖母對志文的不信任令志文很生氣，可是、志文又不想跟他祖母爭執，他不知如何是好。

COTA Health

當你照顧你的家人時，如有相似的經歷和感受，你可能想跟你的網上治療師談談。若要發放電郵給網上治療師，請按 https://icss.cotahealth.ca.

2006年11月



Mozilla Firefox

Go Bookmarks Tools Help

http://65.99.241.236/c/portal/layout?p_l_id=PUB.1085.1&p_p_id=19&p_p_...

Latest Headlines

Welcome | 11/9/06 6:06 PM — Reply — Reply with Quote

Welcome to the Wong's family Forum. I look forward to hearing from you and your family members in this forum.

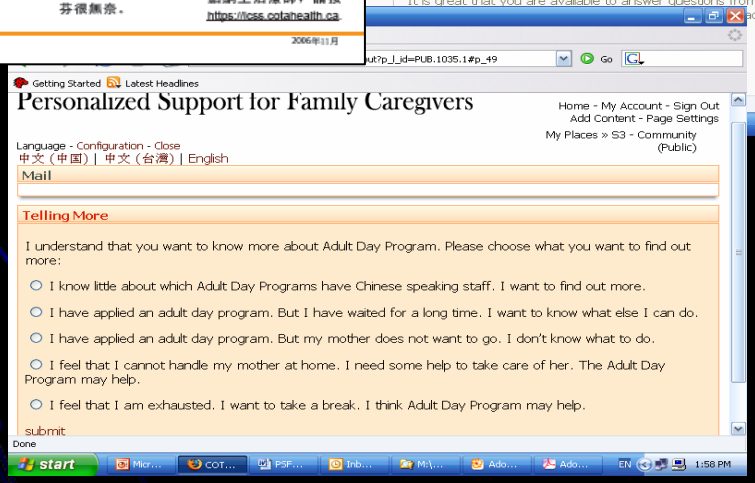
Sincerely,

Rosana Chan

RE: Welcome | 11/9/06 6:09 PM as a reply to Rosana Chan. — Reply — Reply with Quote

Hi Rosana:

It is great that you are available to answer questions from my family. We are new to this ... advice?



Getting Started Latest Headlines

Personalized Support for Family Caregivers

Home - My Account - Sign Out
Add Content - Page Settings
My Places » S3 - Community (Public)

Language - Configuration - Close
中文（中国）| 中文（台灣）| English

Mail

Telling More

I understand that you want to know more about Adult Day Program. Please choose what you want to find out more:

- I know little about which Adult Day Programs have Chinese speaking staff. I want to find out more.
- I have applied an adult day program. But I have waited for a long time. I want to know what else I can do.
- I have applied an adult day program. But my mother does not want to go. I don't know what to do.
- I feel that I cannot handle my mother at home. I need some help to take care of her. The Adult Day Program may help.
- I feel that I am exhausted. I want to take a break. I think Adult Day Program may help.

submit

Done

Conclusion

- Ethno-cultural-linguistic needs of family caregivers are complex
- ICT has the capacity to address the special needs of these caregivers
- This study illustrates the redesign process of a caregiver portal based on user preferences and usage experiences
- The redesign is currently being evaluated using usability testing and a quantitative analysis of user engagement
- The design concepts may 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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