

How do family caregivers and occupational therapists interact via emails?

《職業治療員》如何跟家庭照護者通過電郵聯絡?

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Background

- Information Communication Technologies (ICT) have been used to design interventions to support family caregivers of people with dementia for more than 10 years.
- E.g., computer network, the Internet, computerized phone system, videoconferencing, etc.
- ICT-mediated interventions benefit some but not all caregivers, and may have moderate effects on improving caregiver stress and depression.

Powell, Chiu, & Eysenbach, 2008; Balle et al., 2006

Background (cont.)

- This study was conducted in Toronto, Canada.
- In Canada, the dominant languages other than English or French are the Chinese languages.
- In 2001, there were 420,000 people who lived in Toronto spoke Chinese as their first language
- The intervention in this study was designed to meet the ethno-cultural

Flanders J. 2005

**TO REPORT ON THE STUDY THAT
EVALUATED A PERSONALIZED EMAIL
SUPPORT SERVICE FOR CHINESE FAMILY
CAREGIVERS,
WITH A FOCUS ON THE EMAIL CONTENTS
AND INTERVENTION PROCESS**

4

Setting

- Toronto, Canada
- A sample of Chinese caregivers
- Recruited from a not-for-profit organization that serves Chinese seniors and their caregivers



5

28 Participants

They were...

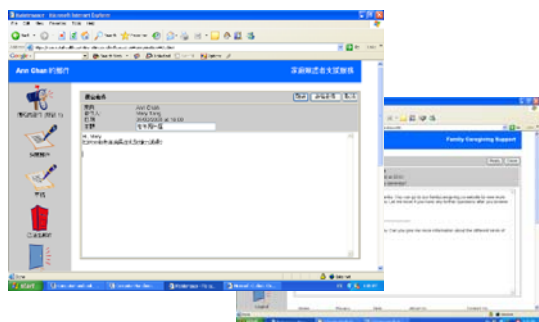
- Female
- 40s to 50s
- Worked full time
- Had college or above education
- Immigrated to Canada 10 to 20 years ago

In addition....

- Most of them cared for their parents who lived with them
- 28% experienced moderate or severe burden
- 51.5% considered themselves as not having the skills or

6

Personalized Email Support



7

Personalized Email Support

- The OTs initiated the service by inviting the caregivers to identify their caregiving concerns
- Upon the receipt of an email, the OTs replied within one working day from Monday to Saturday, at specific hours (e.g., 8:00 to 10:00 pm)
- Throughout the study, the same OT followed a particular caregiver
- The caregivers received the service for 6⁸

Service usage pattern

- The caregivers sent emails both during weekdays and over the weekends
- 61% of the emails were sent outside the 9 to 5 office hours
- Some sent emails as early as 7 am in the morning, and many past midnight
- There were three peak hours:
 - 10–11 pm,
 - 1-2 pm (during lunch hours) and
 - 5-6 pm (after work before going home)

9

Analysis

- The majority of the email messages were written in English. The few Chinese emails were translated.
- An open coding system was used to analyze
 - 1.The caregivers' emails to identify their concerns, feelings and changes over time
 - 2.The OTs' emails to explore the intervention techniques
 - 3.The email exchange processes

10

- 1) CAREGIVER EMAILS
- 2) OT EMAILS
- 3) PROCESS OF EMAIL EXCHANGE

11

Contents of Caregiver Emails

- 1) BELIEF SYSTEM
- 2) QUESTIONS AND RESPONSES TO OTS
- 3) CAREGIVING CONCERNS
- 4) ASSISTANCE THEY HAD RECEIVED
- 5) FEELING ABOUT CAREGIVING

12

1) Belief System

- Chinese beliefs influenced the caregivers
- How they judged the quality of caregiving
- How they identified presenting problems
- How they solved the problems.

"To me, harmony is important for every family member"

"I just couldn't do it [nursing home placement]; ... It will be very bad if she knows we can no longer accompany her."

13

2) Questions and responses to OTs

- General questions
 - "I don't know whether we are overdoing or underdoing things. I'm a bit confused sometimes."*
- Specific questions related to
 - technical (e.g., printing the email)
 - self-care (e.g., bathing, eating, and grooming)
 - safety issues (e.g., falls, kitchen safety)
 - dementia

14

2) Questions and responses to OTs (Cont.)

- Common requests were
 - suggestions for activities
 - coping methods
 - community resources
 - communication techniques with the care-recipients

"She [my mother] sits at home and waits for me to come home, it's not the way I'd like to see she spends her time. Any suggestions you have would be great."

15

"What can I do to lessen the stress and tension"

2) Questions and responses to OTs (Cont.)

- From time to time, caregivers also expressed appreciation of the OT service
 - "We are very fortunate to have you ... as our support."*

16

3) Caregiving concerns

- Repetitive behaviours of the care-recipients
- Problem in taking medications
- Forgetfulness
- Irritability
- Loss of interests
- Refusal to get help
- Verbal aggression
- Physical health problems not directly caused by dementia, e.g., knee pains

17

4) Assistance to caregivers

Informal

- Immediate family members, e.g., siblings, parents, spouse, children
- Extended family members, e.g., nephews, nieces, aunt

Formal

- Personal support workers
- Adult day program
- Health care professionals:
 - family doctor, neurologist, geriatrician, audiologist and

18

5) Feelings about caregiving

Negative

- Exhausted, worried, and frustrated
- Helplessness and difficulty to cope
- Guilty as they felt they were not doing enough for the care recipients
- Torn between various

Positive

- Positive attitude.
"I try to be as positive and upbeat as I can"
- Coping strategies that reflected
 - their creativity in their problem-solving strategies
 - their dedication to

19

Contents of OT emails

- 1) VALIDATION, EMPATHY & CLARIFICATION
- 2) INFORMATION, SUGGESTIONS & EDUCATION
- 3) PROVIDE INFORMATION

20

1) Validation, empathy, & clarification techniques

- Validated the caregivers by addressing the efforts made by the caregivers when providing care.
"I can tell that you are doing such a great job in caring for your mom."
- Empathized with the caregivers feelings.
"I can sense your unease regarding placement issues."
- Asked questions for clarification

21

2) Suggestions, education & encouragements

- Practical suggestions in how to take care of the ADL of the care recipients
- Suggestions in how to facilitate communication with the care recipients
- Behavioral management strategies to deal with the problem behaviours
- Use of culturally-appropriate recreational activities
- Education on safety concerns and competency issues
- Stress the importance of taking good care of themselves and employing positive stress

22

3) Provide information

- To resolve technical issues of the email service
- Dementia and community resources
- Non-dementia eldercare issues

23

Process of email exchange

- 1) CAREGIVER CENTREDNESS
- 2) LENGTH OF MESSAGE
- 3) CHANGES OVER TIME

24

1) Caregiver centredness

- The caregivers took control of the process, the timing of response, what to say and how to say it.
- They used the email support anytime they felt necessary.

"Have not written to you for some time. Everything is stable for the moment. Nothing to report, which is a blessing."

25

1) Caregiver centredness (Cont.)

- The caregivers used different styles to express themselves
- Some described an event and talked about the difficulties they came across. They expected the OTs to analyze the situation and suggested a solution for them.
- Others raised specific questions and wanted an immediate, direct answer.
- Some wrote moving stories,
- Others listed factual information.

26

2) Length of message

- When caregivers wrote long emails, the OTs might respond with short replies
- Whereas when caregivers wrote short ones, the OTs had to write longer messages in the reply.
- In long accounts of the caregiving situations, the OTs could have a comprehensive assessment of the problems, feelings, and needs for support.
- Otherwise, the OTs had to ask several questions in the reply to clarify the

27

3) Changes over time

- At the beginning,
 - caregivers started with general descriptions of their caregiving situations
 - The OTs' messages involved many questions to clarify the concerns and caregiving situations
- At the middle phase,
 - caregivers brought up specific concerns
 - The OTs provided direct answers to the concerns.
- At a later phase
 - The caregivers expressed more positive feelings about their caregiving, demonstrating their sense of humor.

28

Compared with traditional services

Similarities

- The OTs developed rapport
- Provided information, emotional support, and education
- Employed conventional techniques

Differences

- The caregivers determined when, why, and where to use the service.

30

29

Challenges

- Miscommunication was a concern
 - The email support was text-based and asynchronous, limited non-verbal cues were available in the communication process
- Both the caregivers and OTs compensated by using more explicit expressions and more frequent validation.
- OTs needed to spend more time to “read between the lines” to understand the subtle emotions embedded in the emails
- A lack of immediate response from the

31

Conclusion

- Providing support to family caregivers via emails can be helpful to the caregivers.
- It allows the caregivers to access professional services at a time and location convenient to them.
- The contents of information and help sought by caregivers were similar to those in traditional services.
- Yet, compared with the traditional support, the service showed a stronger caregiver-

32

Conclusion (cont.)

- Challenges due to a lack of non-verbal cues could be compensated by more explicit descriptions and constant validation.
- OTs require new skills
 - to “read between the lines”
 - to adapt to the delayed response
 - To develop innovative strategies to evaluate effectiveness when there is a lack of feedback from some caregivers
- More studies can help to refine this

33

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34

QUESTIONS AND COMMENTS?

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35