

Original Paper

# Family Caregivers' Needs of Internet-Based Services: A Survey of Caregivers of Brain Injury Survivors in Ontario

Teresa Chiu<sup>1,2,3</sup>, PhD (Candidate); Angela Colantonio<sup>2,4</sup>, PhD; Michelle Keightley<sup>2,4</sup>, PhD; Alice Bellavance<sup>5</sup>; Zahid Naseer<sup>1</sup>; Analia Barroetavena<sup>6</sup>

<sup>1</sup>COTA Health, Toronto, ON, Canada

<sup>2</sup>Department of Occupational Science and Occupational Therapy, University of Toronto, Toronto, ON, Canada

<sup>3</sup>Department of Health Policy, University of Toronto, Management, and Evaluation, Toronto, ON, Canada

<sup>4</sup>Toronto Rehabilitation Institute, Toronto, ON, Canada

<sup>5</sup>Brain Injury Services of Northern Ontario, Thunder Bay, ON, Canada

## Corresponding Author:

Teresa Chiu, PhD (Candidate)

Department of Research and Development

COTA Health

700 Lawrence Avenue West, Suite 362

Toronto, ON, M6A 3B4, Canada

Phone: +1 416 785 9230 ext 1109

Fax: +1 416 785 9358

Email: [chiu\\_t@cotahealth.ca](mailto:chiu_t@cotahealth.ca)

## Abstract

**Background:** Brain injuries often result in long term disabling consequences. Family members who take care of brain injury survivors have expressed an interest to access caregiver services supported by information communication technologies.

**Objectives:** To investigate the needs of internet-based support services by family caregivers of brain injury survivors in the province of Ontario, Canada.

**Methods:** Family members of one provincial and one regional brain injury organizations participated in a mail survey.

**Results:** A total of 157 internet users participated. The response rate was 39%. A typical internet user was female, aged 41-60, provided moderate to heavy care for a family member in a post-acute long-term recovery stage. Most caregivers preferred information about programs (73.9%), brain injury (67.5%), and caregiving (64.3%). Approximately half preferred to email health professionals (56.7%) and to obtain website lists (55.4%). They were less interested in email exchanges with other caregivers (35.7%), a message board (22.9%), or a chat group (19.7%). Logistic regression analyses showed that caregivers' preferences were affected by their prior experiences of internet, email, and chat group uses ( $P < 0.01$ ). If caregivers had experiences in searching brain injury information on the internet, they were more likely to prefer information-based support. If they had experiences in emailing someone about brain injury, they were more likely to prefer email-based support.

**Conclusions:** In Ontario, family caregivers of brain injury survivors have accepted to use the internet as a medium to receive support services. When designing ehealth services for family caregivers of brain injury survivors in Ontario, an easy-to-use information website can serve as the basic resource. The base service can be expanded to include email services and message board at a later stage for subgroups of caregivers who are ready to use the services.

## KEYWORDS

Family caregivers; ehealth services; internet; information systems; brain injuries

## Introduction

Traumatic brain injury is the leading cause of death and disability in persons under 45 years of age in Canada. Brain injuries often result in long term disabling consequences [1]. Family caregivers need accessible and flexible support systems during the long-term post-acute period, particularly for those individuals living in a rural or remote area where traditional

support systems and services are limited. Among other traditional support services, caregivers have expressed an interest to access services supported by information communication technologies [2].

The purpose of the survey was to examine the needs of Internet-based support services for family caregivers who take care of a brain injury survivor in the province of Ontario, Canada. Specific objectives were to (1) describe the profiles of

family caregivers who have internet access, (2) examine usage and experience of use of existing brain injury internet resources by family caregivers, and (3) identify preferences for Internet services of family caregivers and factors affecting their preferences.

## Methods

A cross-sectional mail survey was conducted in 2004 and 2005. All family caregiver members, including internet users and non-users, of one provincial and one regional brain injury organizations were invited to participate in a mail survey. The regional brain injury organization covers remote areas in Northern Ontario.

The caregiver members received a package that included an invitation letter, a questionnaire and a stamped addressed envelope. A 27-item questionnaire was used with 18 core questions that asked the caregivers about internet usage, concerns and barriers of internet use, and specific knowledge of brain injury information websites. We used a combination of open-ended and close-ended questions. Most closed-ended questions were modified from the Household Internet Use Survey Questionnaire, a survey used nationally by Statistics Canada [3]. Nine questions were used to establish the demographics of the sample group.

Descriptive statistics of the responses were analyzed using SPSS statistical software. Answers to open-ended questions were analyzed using theme identification method. Participants' preferences of internet-based resources were analyzed. First, in each preference, a univariate analysis was used to select statistically significant variables in the areas of demographics, caregiving characteristics, general internet use, and brain-injury specific internet use. Second, significant variables identified were further analyzed using logistic regression to identify which factors contributed to caregivers' preferences. Multiple comparison adjustments were made.

## Results

### Caregiver and Caregiving Characteristics

A total of 157 internet users participated in the survey. They included internet users and non-users from both organizations. The response rate was 39%. According to the statistics of the local organization, the response rate was representative of the caregivers who had access to the internet in their membership list.

A typical internet user was female (87.6%), aged 41-60 (66.9%), and had given care for more than 10 years (46.4%). Most caregivers were giving care to either their spouse (31.0%) or child (54.8%). The care-recipients in our sample needed moderate to heavy care, and the caregivers needed longer term support. Most caregivers spent more than 20 hours giving care per week (36.8%), followed by between 5 to 20 hours per week (34.0%). The participants felt competent in their caregiving skills and knowledge (87.3%) and had a handle on the care situation (83.4%). Yet, approximately one in six (16.6%) caregivers felt that they did not have a handle of the caregiving

situation and one in eight felt they were not competent (12.7%). Two out of five felt less content with their life since assuming this role (40.0%).

### General Internet Use and Brain Injury Internet Resources Use

Most participants used the internet at least 7 times per month (83.1%). The most popular location for accessing the internet was at home (91.7%). Those with a computer at home reported to have connection primarily through telephone line (54.1%) or cable line (28.0%).

With respect to general internet uses (ie, not specific to brain injury), the participants mainly used the internet to access email accounts (91.9%), to find medical/health related information (68.9%), and less so to participate in chat groups (9.4%). The main barrier for not using the internet at home was due to lack of time (8.9%). Many caregivers had concerns about internet privacy and security (73.2%).

The pattern of general internet use was quite different from their usage of the internet to access brain injury services. Caregivers accessed brain injury services mostly through searching brain injury information sites (74.2%), followed by email services (25.3%) to discuss brain injury issues, and participated in chat groups (7.2%) about brain injury.

In the open-ended questions, the participants commented on their experiences of accessing brain injury resources on the internet. With respect to searching brain injury information, two major categories were identified: positive and negative experiences. The positive experiences of use were that caregivers found the sites helpful, useful, and informative. The negative experiences showed that the caregivers found the information to be hard to find, too general, and too technical or academic; and they were concerned about the quality of the information. In terms of the experience of using email to talk about brain injury, a main theme was "no problem or fine". Caregivers found that it was useful to email other caregivers with similar situations and receive mutual support. With respect to taking part in a chat group, caregivers were not comfortable or unsure if they would join a chat group.

### Preferences and Contributing Factors of Internet-Based Resources

Participants were asked to select which types of online services they prefer to receive from a list of 9 online services (Table 1). The majority of them preferred to access information about programs, brain injury, and caregiving suggestions. Approximately half wanted to email health professionals or obtain website lists. Communicating with other caregivers was the least preferred internet-based service.

Overall, participants' preferences were affected by their prior experiences of internet use (Table 2). If caregivers had experiences in searching brain injury information on the internet, they were more likely to prefer to receive information-based support. If they had emailed someone to talk about brain injury, they were more likely to prefer email-based support. A similar trend was noted in the use of message board.

**Table .** Preferences of internet-based resources for family caregivers

Type of Services	Number of Participants (%)
To access information about programs	116 (73.9)
To access information brain injury	106 (67.5)
To access information about practical caregiving suggestions	101 (64.3)
To talk to a health professional through emails	89 (56.7)
To obtain lists of websites	87 (55.4)
To talk to other family caregivers through emails	56 (35.7)
To talk to other caregivers through a message board	36 (22.9)
To talk to other caregivers through a chat group	31 (19.7)

**Table .** Logistic regressions of factors affecting the preferences of internet-based resource

Dependent Variables	Independent Variables	Odds Ratio*
To access information about programs	Had searched brain injury information	3.13
To access information about brain injury	Had searched brain injury information	4.35
	Care made life less content	0.37
To access information about practical caregiving suggestions	Had searched brain injury information	2.63
To talk to a health professional through emails	Had emailed someone to talk about brain injury	3.81
To obtain lists of websites	Had searched brain injury information	2.39
To talk to other family caregivers through emails	Had emailed someone to talk about brain injury	4.78
To talk to other caregivers through a message board	Had participated in general chat groups	10.66
To talk to other caregivers through a chat group	-	-

\*P < 0.01, adjusted for multiple comparison

In Ontario, family caregivers of brain injury survivors have accepted to use the internet as a medium to receive support services. A typical family caregiver who is an internet user is female, aged 41 to 60, and has provided moderate to heavy care for a family member who is in a post-acute long-term stage of recovery. Most caregivers use the internet frequently and have searched brain injury information. Some have difficulties accessing the information they need because the information is hard to find, too technical, or too general. The user profile can be used to determine the design requirements of the internet-based caregiver support services. For instance, certain assumptions of internet design that are based on young male populations may not be applicable to this user group. Such assumptions should be tested through usability studies. Also, studies that examine the language literacy and health literacy of the users can help to ensure information is presented in formats that are easy to use, find, and understand for them.

With respect to the caregivers' preferences of internet-based resources, most of them want information about brain injury, program, or caregiving suggestions. They are somewhat

comfortable with emailing the professionals or obtaining website lists, and less interested in emailing other family caregivers, a message board, or a chat group. Their preferences are affected by their prior experiences of internet and email uses. Participants with prior search experiences of brain injury information are more likely to prefer information-based resources. Similar trends are noted in email and chat group experiences. The findings are consistent with studies about technology readiness: people are not always ready to make too great a jump in information communication technologies. Failure of adoption is more likely to occur when the users' readiness is ignored in the system design [4]. Also, the extent to which users perceive a system as useful predicts how they eventually accept and use the system [5].

Therefore, when designing ehealth services for family caregivers of brain injury survivors in Ontario, an easy-to-use information website can serve as the basic resource. The base service can be expanded to include email services and message board at a later stage for subgroups of caregivers who are ready to use the services.

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### **Conflicts of Interest**

None declared

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