



journal homepage: www.ijmijournal.com

# Theorizing the health service usage behavior of family caregivers: A qualitative study of an internet-based intervention

# Teresa M.L. Chiu<sup>a,\*</sup>, Gunther Eysenbach<sup>b,c</sup>

- <sup>a</sup> Department of Rehabilitation Sciences, Hong Kong Polytechnic University, Hung Hom, Hong Kong, China
- <sup>b</sup> Centre for Global eHealth Innovation, Canada
- <sup>c</sup> Department of Health Policy, Management, and Evaluation, Canada

#### ARTICLE INFO

Article history: Received 22 July 2010 Received in revised form 27 August 2011 Accepted 27 August 2011

Keywords: Medical informatics Family caregiver Information theory Qualitative research Health services

#### ABSTRACT

Purpose: The purpose of this qualitative study was to improve understanding of family caregivers' use of Web-based intervention support by integrating three theoretical models. The study applied the Anderson's model of health service utilization, Venkatesh's theory of technology acceptance, and Chatman's and Wilson's information behavior theories.

Methods: This qualitative study is part of a larger study. An interpretive grounded theory approach was used to conduct in-depth interviews with Chinese caregivers of family members with dementia. The caregivers received Internet-based information support and personalized e-mail intervention. A purposive sample of fourteen caregivers was selected to participate in the interviews. Constant comparison, analytic memoing, case analysis, and concept mapping were used to conduct theoretical triangulation analysis.

Results: Three main factors influenced the use of the intervention: (a) caregiver needs, which are influenced by personal capacity, social support available, and caregiving belief; (b) information communication technology (ICT) factors, including accessibility barriers and perceived efforts to use the technology; and (c) style of using the technology, such as preference for using e-mail or the customized Website. The personal capacity of caregivers was influenced by many factors, including computer and language proficiency, health service knowledge, caregiving competence and competing roles and responsibilities. Social support available for caregivers included available computer, language or caregiving support and health service knowledge. Caregiving belief included traditional belief of giving care, and health belief of the illness. New caregivers needed a different kind of support intervention compared with experienced caregivers. Caregivers with different amounts of experience tended to have different learning styles, with new caregivers preferring interactive intervention and more experienced caregivers preferring more reflective learning.

<sup>\*</sup> Corresponding author. Tel.: +852 2766 6714.

This study reinforced the findings of the larger quantitative study that it is important to address both care-giving needs and technology factors in Internet-based intervention. The quantitative study found that less competent caregivers with more positive attitudes towards technology tended to use the intervention more frequently. In this qualitative research, the findings revealed that caregiver needs, ICT factors, and style of use explained the pattern of intervention use. This new conceptualization has integrated information acceptance, health service utilization, and information behavior theories. More studies will be needed to confirm if the proposed concept can explain or predict the usage behavior in other Web-based interventions.

© 2011 Elsevier Ireland Ltd. All rights reserved.

#### 1. Introduction

When designing and evaluating Internet-based clinical interventions, program developers can apply knowledge from the fields of healthcare service utilization, such as the Anderson's Behavioral Model of Health Service Utilization (BMHSU) [1,2]; computer sciences, such as Venkatesh's Unified Technology Acceptance and Use of Technology (UTAUT) [3]; or information sciences, such as Wilson's [4] and Chatman's [5,6] information behavior theories. Each of these theoretical concepts provides a useful explanatory model of why and how service recipients continue or discontinue Internet-based services. Motivated to improve understanding of usage behavior using these theoretical models, we conducted a qualitative study of the usage behavior of family caregivers.

This qualitative study is part of a large study, which evaluated an information communication technology (ICT)mediated support service for family caregivers who take care of people with dementia at home. Family caregivers face many challenges that can be stressful [7]; a typical care-giving scenario is illustrated in Appendix A. The support service being studied consisted of an information web site and a personalized e-mail support intervention. The designated web site content consisted of over 400 pages of information on disease diagnosis and progression, caregiving strategies, and a listing of community resources. Caregivers received personalized email support intervention provided by occupational therapists or social worker to manage home safety and difficult behaviors of the care recipients and to improve caregiving burden. The intervention design and study findings of the main study have been reported elsewhere [8,9]. This paper reports on in-depth interviews of the Chinese caregivers. Eighteen participants were recruited to receive the intervention in the study. All participants received the core intervention, which consisted of an information website and personalized, continuous e-mail support for six months. The participants were unpaid, informal caregivers who took care of their family members who lived at home (i.e., not in a nursing home) and received support services from Yee Hong's adult day programs, a not-for-profit community organization in the Greater Toronto Area, Ontario, Canada. The study was approved by the ethics review boards of the University of Toronto and Yee Hong Centre for Geriatric Care.

In this study, a critical inquiry approach was used to theorize usage behavior through an analytic integration of three theoretical models. In our model, the driving question was as follows: What usage behavior can be explained by Andersen's BMHSU, Venkatesh's UTAUT, and Wilson's and Chatman's information behavior theories? We answered this question by constructing a concept map that integrates the theoretical and empirical findings. The concept map and five sub-themes that influence usage and non-usage behavior will be reported.

# 2. Usage behavior and theoretical models

Table 1 presents an overview of the key concepts of the three theoretical models being studied. The focus of usage behavior is different in each model. Common to all three models are the complexity of the explanatory factors that affect behavior. We will briefly explain the core concepts of each model and then explain how we have approached to analyze these models using the qualitative study.

# 2.1. Andersen's Behavioral Model of Health Service Utilization (BMHSU)

Andersen's Behavioral Model of Health Service Utilization (BMHSU) [1,2] is the most frequently used theoretical model for predicting and explaining health services use. The model consists of three determinant factors (Table 1): predisposing, enabling, and needs factors. Predisposing factors are exogenous factors. Enabling factors are necessary but not sufficient conditions for service use. Needs factors must be present for service use to happen.

# 2.2. Venkatesh's Unified Theory of Acceptance and Use of Technology (UTAUT)

Venkatesh's Unified Theory of Acceptance and Use of Technology (UTAUT) explains the intention to adopt or use information technology [3]. There are four core constructs: (1) Performance expectancy, which is a person's belief that a new technology will improve task performance. (2) Effort expectancy, which is the degree of ease associated with the use of the new technology. (3) Social influence, and (4) Facilitating conditions. These four constructs affect intention to use, which in turn predicts technology usage. Performance expectancy and effort expectancy explain a greater proportion of the variance than the other factors [3].

Table 1 – Definitions of usage behavior in three theoretical models.		
Theoretical models	Focus of usage behavior	Key explanatory factors
Andersen's BMHSU	Use of health services to meet health needs	<ul> <li>Predisposing factors – demographics, social structure, and health beliefs.</li> <li>Enabling factors – community and personal enabling resources.</li> <li>Needs factors – evaluated needs and perceived needs.</li> </ul>
Venkatesh's UTAUT	Adopt new information technology to complete task at hand	<ul> <li>Performance expectancy – perceived usefulness</li> <li>Effort expectancy – perceived ease of use</li> <li>Social influence</li> <li>Facilitating conditions</li> </ul>
Information behavior	Use of information system to meet the information needs of users	• User – reference group, user's life world
		• Information systems – mediators and
		technologies  • Information resources – to meet the
		<ul> <li>Information resources – to meet the information needs</li> </ul>

# 2.3. Wilson's and Chatman's Models of Information Behavior (IB)

Wilson [4] describes the context of information seeking as a dynamic relation among the user, information system, and information resources. User is surrounded by his or her reference group (e.g. colleagues) and embedded within the user's life world. Chatman further conceptualizes information small world that explains information behavior [5,6]. Each information system consists of two subsystems: the mediator and technology. Mediators are people who help users seek information. Technologies are techniques, tools, and machines that can be used to help users with the search. The information system serves as a bridge between users and information resources to meet the information needs of users.

In this qualitative study, we deliberately explored usage behavior through different theoretical lenses. Usage behavior has a different meaning in each theoretical model, so as the meaning of user needs and usefulness. For example, when we applied BMHSU to analyze the usage behavior, we focused on the use of the intervention (i.e., e-mail communication) and the needs factors that explain the behavior of intervention use. When we examined UTAUT, we analyzed the use of the technology (i.e., the e-mail program and Internet) and the perceived usefulness and other explanatory factors. When we explored the IB models, we focused on the use of information system (i.e., the e-mail as information technology and the therapist as the mediator of information) and explored how the user's life world and reference group affected information needs. The deliberate shifting of the lenses is a qualitative analysis technique called theoretical triangulation [10]. The triangulation technique is an interpretive grounded theory approach [11] in qualitative research.

# 3. Methods

The interpretative grounded theory approach is one of many methodological approaches in qualitative study. This approach takes a reflexive stance to theoretically analyze the data from prior interpretive frames. Researchers using this approach select the sample, develop the interview questions, conduct the interviews, and interpret the data with the prior interpretive frameworks in mind. In this study, the prior interpretive frameworks are the three theoretical models.

We used a purposive sampling strategy to identify fourteen caregivers from the larger study. We included in the sample both users and non-users of the Internet-based support intervention. Caregivers with the following characteristics were sought: (a) those with moderate to severe perceived burden based on the scores of the Burden Scale for Family Caregivers [12], (b) participants who had reported e-mail or Internet usage issues, and (c) those whose preferred language of online communication was Chinese. Fourteen caregivers participated in an indepth interview, with most (N=13) interviewed in person and one by phone. The interviews lasted for approximately one hour to one and a half hours. All interviews were conducted in Cantonese and were audio-taped.

An interview guide (Appendix B) was developed based on the three theoretical models. A total of 18 open-ended questions were constructed to explore the reasons for usage and non-usage behavior within prior interpretive frameworks. For example, caregivers were facilitated to describe their experience of communicating via e-mail with the therapist and were prompted to give examples of when they did not send e-mails and when they did so. This question was framed based on the BMHSU. Another example is that the caregivers were asked to express their experience of using computers and elaborate on situations when they encountered barriers to access service due to technology-related issues. This question is structured based on the UTAUT. During the interviews, methodical decisions were made to determine the choice and order of the questions listed in the interview guide [13,14].

The first author (TC) conducted all the interviews, transcribed and translated them verbatim and coded the data line-by-line using the software ATLAS.ti [15]. The findings arise through the researchers' interpretations of data using prior frameworks rather than emanating from them or from the methodological procedures (the traditional grounded theory approach) [14]. Constant comparison, analytic memoing, case analysis, and concept mapping were used to identify recurring or competing themes, patterns and linkages between

sub-themes, and plausible explanations through inductive analysis [10,11,14]. The same set of data was analyzed through the three theoretical lenses to explore different possibilities for organizing and interpreting the data. For instance, if a caregiver reported not sending e-mails to a therapist, would the explanatory factors be similar using different lenses? Or would there be alternative explanations from different theoretical lenses? This theoretical triangulation approach strengthened the credibility of the analysis [11]. The approach we used was a substantive approach [16], and data analysis quality was ensured through an audit trail and reflexivity [17].

#### 4. Results

Fig. 1 is a concept map constructed to represent the theorization of what factors influence the usage behavior of family caregivers who receive Internet-based intervention. The concept map consists of five themes: (a) caregiver needs, (b) beliefs, (c) personal capacity and family support, (d) ICT factors, and (e) styles of using the ICT-mediated support.

### 4.1. Caregiver needs

The core theme was caregiver needs, which was categorized into new caregivers' and experienced caregivers' needs. This theme was identified through the lens of service utilization needs suggested by the BMHSU [1,2]. Andersen argued that the needs factor must be present for service use to happen. The usage behavior in this theme focused on the use of e-mail intervention to meet the caregiver needs. The caregivers must have a need for service before they would use the Internet-based support intervention. Hence, a thorough understanding of the perceived needs of the caregivers is a fundamental knowledge required to explain usage behavior.

## 4.1.1. Needs of new caregivers

The perceived needs of new caregivers explained why they needed the service. The analysis found that new caregivers' needs changed over time. As a result, their use of the intervention also changed over the course of intervention.

4.1.1.1. First reaction – desperate for more information. A caregiver who recently heard of the diagnosis said, "My mother has this condition. I want very much to find more information about the illness. See if there is anything that can help her." A caregiver recalled when she first heard of the diagnosis and said, "At that time you really know nothing. I didn't know how to find that out. That is why I was determined...to search for the information." Their first reaction was that they must find out more information about the illness. The strong need motivated them to actively seek and use support intervention. In other words, they have a strong intention to use the service.

4.1.1.2. Being confused by the overwhelming information. New caregivers often got lots of information from different sources. For example, a caregiver during the interview asked, "Is it due to genetic or because there is a lack of stimulation, or because of the food we eat?" She was confused when she got

conflicting information for these questions from different sources. The use of the information at this stage is characteristized by a cognitive overload of information and psychological distress. The caregivers still could not resolve the problems in daily care. For example, a caregiver described the difficulty she had in digesting and remembering what she had read. "I have looked for information about dementia and found that there are many types. Then I forget... Is it deterioration of the brain [or something else?]...I forget." At this stage, the caregivers expected the service to help them make sense of the confusion and to alleviate the anxiety. The expectation explained the type of support intervention they would use.

4.1.1.3. Don't understand why and don't know how to help. Other than sorting out problems related to the diagnosis, new caregivers also struggled with how to provide daily care. They were also concerned about the psychological reaction of the family member and other behavioral problems that they did not understand and were puzzled about. One caregiver wanted to know "Why is that…once in a while she has emotional problems?…Is it right the others are like that too?" Another caregiver described what puzzled her most. "She does not do what I want her to do but always does what I don't want her to do!" The caregivers needed an explanation of the strange behavior and the knowledge to manage them. At this stage, they expected support intervention for practical solutions in daily care. Service use occurred if the service could address the practical needs.

4.1.1.4. Learning one thing at a time. After finding the information, new caregivers learned it one step at a time. A caregiver recalled how she learned and accepted her grandmother's strange behaviors. She explained that she had to accept the fact that the strange behavior was caused by the illness and psychologically change her reactions when facing the situation. The process took time and energy. That is why caregivers needed to learn one thing at a time. What they have learned may be meaningless until they encounter the situation in real life, as one new caregiver explained,

"You search the website and review a lot of information...But understanding the fact does not mean that you can really picture what it looks like when it happens. For example, she is a bit short temper. That is fine. When the time came that she scolded you out of the blue at your face, you didn't know that...you need to use this mindset to handle the situation. The first time I was not used to [doing this]."

When the service matched their learning needs, the caregivers would apply what they had learned in real life situation. Usage behavior means more than reviewing the information; it encompasses the processes of active learning, problem solving, and real-life practice.

#### 4.1.2. Needs of experienced caregivers

Different from new caregivers, experienced caregivers encountered two types of needs: (a) episodic deteriorations of family members with dementia or the care-giving support network and (b) latent needs caused by suppressed, unresolved issues.

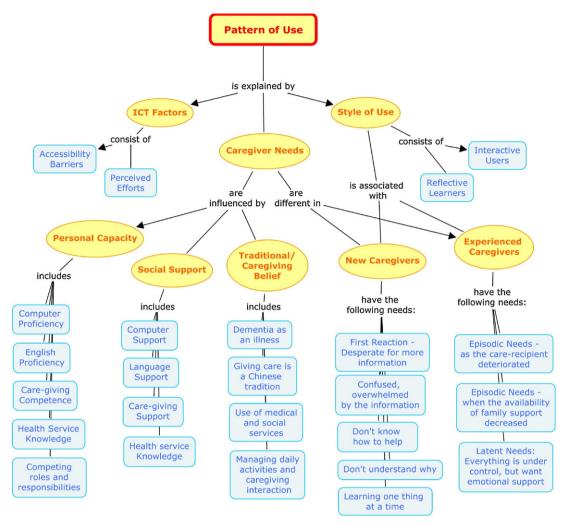


Fig. 1 - Concept mapping of usage behavior of family caregivers.

4.1.2.1. Episodic needs – when the care recipient deteriorated. The deterioration of the family member with dementia triggered the experienced caregivers to adjust the way in which they gave care. For example, an experienced caregiver who had given care to her grandmother for more than ten years described how she has constantly learned new care-giving skills in response to her grandmother's changing condition. After a fall and a hospital stay, her grandmother became totally dependent upon returning home. "How to take her down to have a shower? How can we help her to take a bath?" The kinds of support experienced caregivers expected would change over time as the status of the care recipients deteriorated.

4.1.2.2. Episodic needs – when the availability of family support decreased. An episodic need can be triggered by a decrease in available family support, even if the condition of the family member being cared for does not deteriorate. The participants in this study were mostly the son or daughter of the person receiving care, but the primary caregivers were most often the mother or father of the person receiving care. The son or daughter caregivers were concerned about the health of their parents who were giving care. One said, "My daddy is

his 80s...I am worried that one day if he could not take care of her anymore". Other than a gradual decrease in family support, a drastic change unfortunately occurred in two families. In a family, the daughter caregiver who was the primary caregiver passed away. Her younger sister took over the primary caregiver role with reduced family support after the sudden change.

4.1.2.3. Latent needs — everything is under control, but.... Experienced caregivers dealt with episodic needs as they occurred and tolerated some of the issues that they faced in daily care. When the issues remained unresolved, the experienced caregivers felt that "everything is under control, but I want to know more about..." These situations represented latent needs. Caregivers' latent needs were suppressed when their energy was used to address episodic needs. When they said, "Everything is under control," they meant they could manage the daily care fine. When the episodes were over, the latent needs began to surface. A caregiver when reflecting on her situation said, "Really, it is very tiring. Facing her is very tiring...The problem is not just feeling physically exhausted but also mentally stressed out. Mental distress is more difficult to face."

# 4.1.3. Beliefs

The themes concerning beliefs were identified through two frameworks: the BMHSU [1,2] and Chatman's IB theories [6]. The usage behavior in BMHSU focused on the e-mail intervention use to meet health needs, which is affected by a person's attitudes, values, and knowledge about health and about health services. On the other hand, the usage behavior in IB focused on the use of information system to address knowledge gap, and the information seeking is affected by the beliefs and values within the socio-cultural norms of the information user [4]. Four salient sub-themes about beliefs were identified: (a) care-giving as a Chinese tradition, (b) the belief that dementia is an illness, (c) the need to take care of daily activities and interaction, and (d) the use of medical services and wanting more home help and an adult day program.

4.1.3.1. Giving care is a Chinese tradition. Caregivers explained that they felt that giving care is more than a responsibility; it is a way of life. One caregiver said, "Since childhood, you are being taught...to give care to our parents...Seeing mom took care of her last generation, you then know that you would take care of them in a similar way." Traditional family values motivated the caregivers to try their best. As one caregiver said, "I would try my best to make her happy."

4.1.3.2. Believing that dementia is an illness. Although some literature has shown that Chinese men and women are more likely to consider dementia as a normal part of aging [18], most participants in this study believed that dementia is an illness congruent with the Western medical model. The most frequently mentioned problem of their family member was memory loss. Other symptoms and problems were typical of those who have dementia, such as home safety, delusions, reduced activity level, change of personality, and being "uncooperative". The caregivers understood the course of the illness and judged its progress by assessing how fast their family member deteriorated. They believed there was a medical reason why their family member became forgetful and acted abnormally. In search of a medical solution, caregivers relied on doctors and medications. A caregiver said, "I would ask the doctor. Then she can explain to me." After their family member had taken the medication, the caregivers noticed that "It seems that it is getting better." They also believed that more activities would help prevent deterioration. When it came to behavioral issues, some caregivers did not feel that these were due to the illness.

4.1.3.3. Taking care of daily activities and maintaining harmonious interactions. Other than assisting with daily activities, such as bathing, dressing, and preparing meals, caregivers also had to solve problems due to memory loss in everyday activities. For example, a caregiver said, "Knowing that she can't manage taking medication...I have thought of many methods...I bought a machine that is a pill dispenser." Also, caregivers made an effort to help their family members to be more active. They either tried to accompany their family members, find someone to accompany them, or arrange for them to attend the Adult Day Program. They wanted their family member to be happy. Daily care also meant taking good care of their emotions and maintaining harmonious

interactions. They tried to avoid arguing when their family member could not comprehend what was going on because of memory loss or delusional ideations. The experience of one caregiver illustrated this belief. "There was no such incident, but she [his mother] insisted that there was. Do you confront her?...I have found that it is absolutely useless" After realizing that he could not change his mother's thinking and that doing so would upset her, he decided to stop correcting his mother and not to upset her by doing so. "Hope that she is generally happy...that is if she is in a good mood or generally is happy." Maintaining a harmonious interaction was the most important for him.

4.1.3.4. Using medical services and wanting more home help and an adult day program. Caregivers were familiar with medical services and sought help from their family doctors or geriatricians. Most believed the adult day program was useful. Many said they had applied for one, but the waiting list was long. They wanted to have more home help for personal care from the government. If there was no help available, they would try their best to give care. Some talked about applying for a nursing home. They believed that because the waiting list was long, they should apply now just in case they would need it later. In addition, caregivers were familiar with the medical models of dementia. They preferred day programs and home help to nursing home placement. Mutual support from other caregivers or emotional support from health professionals was indicated.

# 4.1.4. Personal capacity, social support, and competing

This theme was identified through the BMHSU and IB frameworks. In Andersen's model, social structure predicts utilization of service and consists of two components: (a) the personal capacity of the individual to address health issues and to seek help and (b) the support available from the family or social network. Similar to the BMHSU, use of information system is explained by the reference group in IB models, i.e., people surrounding them. A user would seek information first within his or her information small world from people who shared the same social norms before seeking outside help. Although different terminologies were used in the two models, the usage behavior (use of the e-mail intervention) of the caregivers was found to be explained by their personal capacity, family support, and competing roles and responsibilities defined by their social norm.

4.1.4.1. Personal capacity and family support. In this study, usage behavior was found to be affected by the caregiver's knowledge concerning giving care and the availability of family support. If a person has been a caregiver before, their knowledge of care-giving and local service was better than that of another person who did not have such experience. In the interview, a caregiver explained, "Now I am OK because I have the experience with my mom. That is why I get to know." Participants also learned from their relatives who had the illness. One said, "Dementia is not something new...My grand aunt also had a similar illness." For some caregivers who did not have personal experience, they gained the knowledge through their family and friends. One said, "I have many

friends who are doctors and social workers. I called them when this happened." Through these supports, the caregivers learned about the illness and how to give care.

4.1.4.2. Competing roles and responsibilities. Many caregivers have to balance competing responsibilities while fulfilling their care-giving role. Some worked full time, while having other roles and responsibilities, such as being a mother, homemaker, daughter, and so on. Only caregivers who could juggle these various roles could spare time to access and use the services. For instance, one caregiver was unable to find time to access the service when her job demands increased substantially. For several months because she had to work overtime and take work home, she did not have the time to use the service until the job situation returned to normal. Another caregiver described that it was not easy to manage her time when she had full-time work, was a homemaker and a mother of two teenage children, and took care of her parents who both have health needs (her mother has dementia). She said she had a supportive husband who took primary responsibility for taking care of the children. She hired a helper for the household chores and to help take care of her mother. She coordinated the care for her mother among the helper, her father, and her brother. Because this particular caregiver was able to juggle her competing roles, she managed to find time in the late evenings to use the support intervention.

# 4.2. Style of using ICT-mediated support

Reflective learner and interactive user were two different styles of use identified in this study. This concept was constructed through the lens of IB theories. In Wilson's model, a person may access the information through an information system or a mediator (the therapist). If a person prefers to interact with the information site, he or she shows a reflective learning style. On the other hand, if a person chooses to interact with the therapist via e-mail, he or she adopts a style of an interactive user.

# 4.2.1. Reflective learner

Reflective learners were caregivers who did not use e-mail support but actively used the information site. A caregiver who was a frequent visitor of the information site described how she engaged in active learning.

"At the beginning after finished reading it, [you] remembered it. Then, after a while, you would forget what you have read. Then you read it again and it stays in your mind more. It is like reading a storybook many times. What you get out of it is different every time."

Another reflective learner illustrated why he preferred to regularly receive newsletters with stories and strategies about care-giving instead of direct contacts with the therapist. "Because sometimes I don't feel that there is a need to contact me directly. If you continue to tell people what is happening out there...it will be very good." He described that he felt he was hiding himself in an enclosed environment at times when the burden of care became intense. Reading the newsletter helped him to learn how to look at the

situation from a different angle. He explained, "I don't need to hide in my own room. The frequent contacts can be refreshing to me – like having fresh air. It is a feeling like this. 'Ah! Every month you can read something new. That feels good."

#### 4.2.2. Interactive learner

The second style of use is the interactive user who sent e-mails to the online therapists and replied to emails from them. The interactive process of a caregiver illustrates this style of use. After receiving the replies from the therapist, the caregiver described how she processed the information. "I have already done my research on the Internet. What is said and what I have found out seem to have no difference." The therapist's replies gave her the confidence to handle the care situation. "I feel that the information was useful...I learned how to deal with the behavior...and to try my best to let her do what she used to do daily." The caregiver described how she applied what she had learned in daily care and obtained encouragements from the therapists to change the caregiving strategies. She actively communicated with the therapist to obtain suggestions and receive emotional support while trying new ways to interact with her mother to improve the caring situation.

#### 4.3. ICT factors

The UTAUT focuses on the adoption behavior of new technology. The technology issue related to usage was technology acceptance. The acceptance and use of the e-mail intervention was affected by the perceived effort to use technology and access barriers to Internet use.

# 4.3.1. Perceived efforts

Caregivers felt that the perceived efforts to use the technology seemed to be greater when they were under stress, which made them more reluctant to use the support intervention. One caregiver explained, "That means when a person is very frustrated, she may not have the mood to sit in front of the computer to ask others a question." However, when caregivers were asked if they had difficulty using the web-based software program during the usability testing in a laboratory setting, most said that using the software program was easy. In real-life situations, the amount of effort required to use the intervention explains the attrition behavior. Another stressful caregiver recalled why he did not reply to more e-mails after sending it once. His broken speech and the description of what happened reflected the struggles of trying to access the service under distress.

"because you do not use...I use Yahoo and you do not use Yahoo...You have your own, your own email...Then I will need to go back to...have to return there so I can get that [the reply email]...This is not too convenient. I have to do one more thing, and have to remember [the user name and password], then it becomes difficult at times."

### 4.3.2. Access to barriers to Internet Use

The caregivers could not use the service even if they wanted to do so if access to the Internet was not available in the home or in the workplace or if there was no technical support.

In the workplace, some caregivers had problems accessing the intervention due to policies that forbid personal use of the Internet at work. One caregiver explained, "Actually I do not always check emails [sent by the therapist]. That is because when I am at work, I am sure I can't browse these."

Internet access barriers in the home were different from those in workplace. A caregiver explained why she did not have a "workstation" at home. "We have only one computer that can access the Internet. Then I have a teenage son — he is there and occupies it around the clock." Not all caregivers who faced technical problems knew how to resolve them. When caregivers had insufficient technical support or hardware at home, they had barriers to accessing the support intervention. For example, a caregiver said, "...I was wondering: how to send it. I don't have the writing pad [an input device for writing Chinese]. My English, I have to think about it slowly in how to ask." Another caregiver could not access the Internet at home even though she had more than one computer at home, as she did not know how to resolve the wireless modem problem.

# 4.4. Concept map

The theorization of the usage behavior was represented in a concept map that consists of three main themes: (a) caregiver needs, (b) style of use, and (c) ICT factors (Fig. 1).

In the center of the map was caregiver needs, which has five dense and rich sub-themes. The first cluster consists of three factors that directly influence usage behavior: personal capacity, social support, and traditional/care-giving beliefs. A caregiver's capacity includes language and computer proficiency, caregiving competence, health service knowledge, and the ability to handle competing roles and responsibilities. The social support of the caregivers includes computer and care-giving support and resources to access health service knowledge. The traditional/care-giving beliefs consist of the belief in dementia as an illness, the value of giving care as a Chinese tradition, the perception of medical and social services and the practice of managing daily activities and interaction while providing care. The second cluster differentiates the needs of new and experienced caregivers who show different styles of use. Being desperate for information is the first reaction of new caregivers, who later become confused, uncertain why things happen and what they can do, and adopt a learning method characterized by learning one thing at a time. On the other hand, the needs of experienced caregivers can be episodic or latent in nature. Episodes of increased need for support occur when the care-recipient deteriorates or when the available family support decreases. Experienced caregivers attend to their latent needs when their suppressed emotion gradually surfaces after the episodic needs are addressed.

Style of use and ICT factors are situated on two sides of the concept map. Style of use consists of reflective learners and interactive users and is associated with care-giving experience. New caregivers are more likely to be interactive users, while experienced caregivers are more likely to be reflective learners. ICT factors explain the non-usage behavior of caregivers, even if the caregivers have clinical needs. Caregivers do not use the intervention due to access barriers to the Internet and the perceived efforts required to use the technology.

### 5. Discussion

This in-depth study was based on a sample of Chinese caregivers living in Canada. Their usage behavior may not represent that of the caregivers who have different sociocultural backgrounds. Despite the limitation, this paper has improved our understanding of usage behavior through the theoretical models in health service utilization, technology acceptance, and information behavior. An analytic integration of these theories has resulted in a conceptualization of usage behavior that contributes to three important findings.

First, caregiver needs are multi-faceted and complex in nature. New and experienced caregivers have different needs. The differing needs based on care-giving experience have been well documented [19,20]. The notion of cultural variations in health beliefs found in this study is supported by reported studies [18,21]. The information and support intervention needs found in this study are similar to those identified in systematic reviews [22,23]. However, relatively few studies have examined the impact of Internet literacy and attitude towards technology on usage behavior [24,25]. Given the diverse and complicated nature of caregiver needs, understanding and addressing their needs should be the focus of the design and evaluation of e-health interventions.

Second, studies of technology acceptance have been conducted mainly in work situations. Although the theoretical concept of intention to use has helped to explain the usage behavior of family caregivers, the nature of the access barrier is presented differently in the family caregiver user group. In particular, if there was inadequate technological support when the caregivers faced a technical problem at home, the technology became a barrier to service access. Also, arrangements concerning who will use the computer for how long in a family are very different from sharing the work space in an office setting. Even though technical support is available in a workplace, policies that forbid the personal use of the Internet can become an access barrier. The context or place in which the support intervention is received by the caregivers requires further research to identify solutions that can improve service access.

Third, the styles of using Internet-based intervention were found to be different among the participants. Some preferred to learn quietly on their own as reflective learners, while others preferred to interact with the therapist. Different learning and cognitive styles of learning have also been identified in web-based learning among health professionals. Active learners have been found to do better with interactive learning, while reflective learners do better with strategies that promote reflection [26]. A study that applied learning theory to describe online information-seeking found that the learning styles of the searcher, i.e., abstract, concrete, reflective and active learning styles, have some moderating effect on the searching characteristics [27]. The authors argued that learning theory can be a useful concept in understanding online information-seeking behavior.

This qualitative study reinforced the quantitative findings of the main study [8]. Caregiver needs and technology factors were found to predict frequency of use. Caregivers who had greater care-giving burden and more positive

attitudes towards technology tended to use the intervention more frequently. The main study, however, did not explicitly measure style of use. Future research questions can focus on the type of intervention design that would best match the different learning styles of individual caregivers and whether addressing learning style would improve usage and outcomes. Another research direction is the identification of intervention strategies to mobilize support resources and modify the environment at home and at work to improve service access. Theoretical models in health promotion, occupation therapy, [28] and chronic condition self management can provide useful conceptual frameworks for future research.

#### 6. Conclusion

Caregiver needs, ICT factors and style of use are the three factors that influence the usage pattern of Internet-based support intervention. Caregiver needs are influenced by personal capacity, social support, traditional beliefs and experience in care-giving. ICT factors include Internet access barriers and perceived ease of use of the technology. Caregivers show two styles of use, being a reflective learner or an interactive user. New and experienced caregivers preferred different styles. Our study has contributed to the conceptualization of usage behavior among family caregivers by integrating health service utilization, information behavior, and technology acceptance theories. Further studies will be needed to confirm if the proposed concept can explain or predict the usage behavior in other web-based interventions.

#### **Author contributions**

TC contributed to the study design and implementation, analysis and interpretation of the findings, and preparation of the manuscript. GE contributed to the study concept, interpretation of findings and revision of manuscript.

# **Conflict of interest**

There is no conflict of interest.

# Acknowledgements

Special thanks go to Dr. Rhonda Cockerill and Dr. Mark Chignell for their guidance to the first author when completing this study as part of her PhD thesis. We thank the family caregivers who participated in the study. This study was supported in part by the Alzheimer Society of Canada, Toronto, Ontario, and by a fellowship award from the Canadian Institutes of Health Research, Ottawa, Ontario (Dr. Chiu).

# Appendix A. Betty's caregiving scenario

Betty (42) has taken care of her mother who has dementia for five years. As a mother of two teenage children who works part-time at home as an accountant, Betty changes her roles depending on the time of the day and the day of a week. She gives medications to her mother and helps her arrange medical appointments, adult day programs, transportation, meals, finance, and so on. Betty also spends time listening to her mother when she feels miserable. Betty's brother comes over for dinner at times, and they talk about their mother's condition. Like other homemakers, Betty takes care of household chores and her teenage children. At times, she explains her mother's memory loss to her children, telling them what they can and cannot do to help. She sets aside a specific time in the day for her accounting job. Betty has learned she needs to take care of her own health to provide good care for her mother. She attends a weekly line-dance program. Betty talks to her friends about the everyday juggling of her many tasks and roles. She feels her friends understand her situation and are willing to listen to her.

Two weeks ago, Betty discovered that her mother got up in the middle of the night to boil some water for a cup of tea. Betty was concerned because her mother might forget to turn off the stove, and her mother seemed to have confused day with night, which might be a sign of deterioration. Betty was not sure what to do. She talked to her husband, James, who suggested that they might consider nursing home placement again, although he understood Betty was most unwilling to go this route. Betty called her friends and her brother to discuss the problem. It seemed everybody around her suggested that she should take her mother to see the doctor. Betty then made an appointment. She also searched for information to find suitable nursing homes in the area, in case her mother would need one soon. The uncertainties of the situation and Betty's inability to fulfill her role as a daughter caregiver made her realize she needed help.

A week later, Betty was relieved to notice that her mother did not get up in the middle of the night anymore. The problem seemed to have disappeared. Betty then cancelled the doctor's appointment and stopped the search for nursing homes. Life continued as usual.

# Appendix B. Interview guide

## Opening questions

- 1. Can you tell me why you are interested in participating in this study? What do you expect? Tell me why you wanted to receive the service when you heard about it?
- Please tell me what is happening to you and your family now in general.
- 3. What is going on in the way you give care now?

### Main questions

- 1. Could you describe your experience of using the service? Is there anything you like about the service? Anything you dislike about the service?
- Have you received our caregiving information in your email account? A new message is sent to you every two weeks. Tell me more what you have received.
- 3. Have you used the email service? If so, what do you think about it? If not, why is that you have not used it?

#### Summary points

What was known before the study?

 The usage behavior of internet-based interventions can be separately explained by Anderson's model of health service utilization, Venkatesh's theory of technology acceptance, or Chatman's or Wilson's information behavior theories.

What the study has added to the body of knowledge?

- The integration of the health service utilization, information behavior, and technology acceptance theories has contributed to a comprehensive model that explains how family caregivers used Internet-based support intervention.
- The findings showed the importance of addressing both care-giving needs and technology factors which should be addressed when designing and evaluating Internet interventions.
- 4. How would you compare the way Chinese take care of their family to the way Westerners do? Some participants feel there is no difference. Some feel they are different. What do you think?
- 5. Tell me what other caregiver services you have used. Are they useful? What is most useful for you? What services have you received that you think would be good for other caregivers to know?
- 6. Who do you go to when you have a problem about caregiving or dementia? Who is helping you to give care?
- 7. Would you consider yourself as a knowledgeable caregiver? What knowledge is important to give care? How have you learned how to give care?
- 8. What do you think you need to learn more or know more? What kind of support do you feel you need the most?
- 9. Caregivers are very busy. Some have told me that they get through their days and weeks with very tight schedules. Do you have a similar feeling? Maybe you have a different feeling. Tell me more about it.

### **Ending questions**

- 1. If you have a friend who had just become a caregiver, how would you advise him/her?
- 2. Is there anything you would like to ask me?
- 3. Is there anything I have not asked you that you would like to tell me about that you think I should know?
- 4. What is the most important thing that you have told me today?

## REFERENCES

 R. Andersen, J.F. Newman, Societal and individual determinants of medical care utilization in the United States, Milbank Memfd Quarterly 51 (1973) 95–124.

- [2] R.M. Andersen, Revisiting the behavioral model and access to medical care: does it matter? Journal of Health and Social Behavior 36 (1995) 1–10.
- [3] V. Venkatesh, M.G. Morris, G.B. Davis, F.D. Davis, User acceptance of information technology: toward a unified view, MIS Quarterly: Management Information Systems 27 (2003) 425–478.
- [4] T.D. Wilson, On user studies and information needs, Journal of Librarianship 37 (1981) 3–15, http://informationr.net/tdw/publ/papers/1981infoneeds.html.
- [5] E.A. Chatman, The impoverished life-world of outsiders, Journal of the American Society for Information Science 47 (1996) 193–206.
- [6] E.A. Chatman, A theory of life in the round, Journal of the American Society for Information Science 50 (1999) 207–217.
- [7] S. Sörensen, P. Duberstein, D. Gill, M. Pinquart, Dementia care: mental health effects, intervention strategies, and clinical implications, Lancet Neurology 5 (2006) 961–973.
- [8] T.M. Chiu, G. Eysenbach, Stages of use: consideration, initiation, utilization, and outcomes of an internet-mediated intervention, BMC Medical Informatics and Decision Making 10 (2010) 73.
- [9] T. Chiu, E. Marziali, A. Colantono, A. Carswell, M. Gruneir, M. Tang, G. Eysenbach, Internet-based caregiver support for Chinese Canadians taking care of a family member with Alzheimer disease and related dementia, Canadian Journal on Aging 28 (2009) 323–336.
- [10] M.Q. Patton, Qualitative Evaluation and Research Methods, 2nd ed., Sage Publications, Newbury Park, CA, 1990.
- [11] M.Q. Patton, Enhancing the quality and credibility of qualitative analysis, Health Services Research 34 (1999) 1189–1208.
- [12] E. Gräsel, T. Chiu, R. Oliver, Development and Validation of the Burden Scale for Family Caregivers, COTA Comprehensive Rehabilitation and Mental Health Services, Toronto, ON, 2003.
- [13] S. Kvale, InterViews: An Introduction to Qualitative Research Interviewing, Sage Publications, Thousand Oaks, CA, 1996.
- [14] K. Charmaz, Qualitative interviewing and grounded theory analysis, in: J.F. Gubrium, J.A. Holstein (Eds.), Inside Interviewing New Lenses New Concerns, Sage Publications, Thousand Oaks, CA, 2003, pp. 311–330.
- [15] GmBH At., ATLAS.ti: Visual Qualitative Data Analysis, 5.2nd ed., 2006.
- [16] J.M. Eakin, E. Mykhalovskiy, Reframing the evaluation of qualitative health research: reflections on a review of appraisal guidelines in the health sciences, Journal of Evaluation in Clinical Practice 9 (2003) 187–194.
- [17] G.A. Tobin, C.M. Begley, Methodological rigour within a qualitative framework, Journal of Advanced Nursing 48 (2004) 388–396.
- [18] H.L. Gray, D.E. Jimenez, M.A. Cucciare, H.Q. Tong, D. Gallagher-Thompson, Ethnic differences in beliefs regarding Alzheimer disease among dementia family caregivers, American Journal of Geriatric Psychiatry 17 (2009) 925–933.
- [19] J.I. Cameron, M.A.M. Gignac, Timing It Right": a conceptual framework for addressing the support needs of family caregivers to stroke survivors from the hospital to the home, Patient Education and Counseling 70 (2008) 305–314.
- [20] S.B. Wackerbarth, M.M.S. Johnson, Essential information and support needs of family caregivers, Patient Education and Counseling 47 (2002) 95–100.
- [21] P. Dilworth-Anderson, I.C. Williams, B.E. Gibson, Issues of race, ethnicity, and culture in caregiving research: a 20-year review (1980–2000), Gerontologist 42 (2002) 237–272.
- [22] K.T. Washington, S.E. Meadows, S.G. Elliott, R.J. Koopman, Information needs of informal caregivers of older adults

- with chronic health conditions, Patient Education and Counseling (2010).
- [23] C.A. Thompson, K. Spilsbury, J. Hall, Y. Birks, C. Barnes, J. Adamson, Systematic review of information and support interventions for caregivers of people with dementia, BMC Geriatrics 7 (2007).
- [24] C.D. Norman, H.A. Skinner, eHealth literacy: essential skills for consumer health in a networked world, Journal of Medical Internet Research 8 (2006).
- [25] E.Z. Kontos, G.G. Bennett, K. Viswanath, Barriers and facilitators to home computer and Internet use among urban novice computer users of low socioeconomic position, Journal of medical Internet research 9 (2007).
- [26] D.A. Cook, Learning and cognitive styles in Web-based learning: theory, evidence, and application, Academic Medicine 80 (2005) 266–278.
- [27] B.J. Jansen, D. Booth, B. Smith, Using the taxonomy of cognitive learning to model online searching, Information Processing & Management 45 (2009) 643–663.
- [28] T.M.L. Chiu, E. Marziali, M. Tang, A. Colantonio, A. Carswell, Client-centred concepts in a personalized e-mail support intervention designed for Chinese caregivers of family members with dementia: a qualitative study. Hong Kong, Journal of Occupational Therapy 20 (2010) 87–93.