Caregivers and web-based health information: An exploratory qualitative study of information seeking, information use, and perspectives

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Abstract (English):

Background: With Canada's aging population, increasing prevalence of chronic disease, and overburdened healthcare systems, there is a growing pressure on family caregivers to manage the care of their family members or friends. The demands of caregiving, however, can be challenging and may result in caregiver distress and an inability for caregivers to continue in their role. To help address this issue, interventions that are developed to support caregivers may contribute to greater confidence, capacity and satisfaction with their role, as well as better outcomes for their care recipient. The Internet is one area that now plays a significant role in information delivery and support services. Offering web-based support to caregivers may assist this population to provide quality care and remain in good health. In particular, online information based upon personal health and illness experiences (PHEx) could be particularly helpful for those populations, such as caregivers, that are isolated and lack support services. In order to provide optimal support and services to caregivers through web-based initiatives, a better understanding for how caregivers search for and use online health information is needed. Furthermore, it will be valuable to explore caregivers' perspectives towards online PHEx information, as this may be an especially appealing and valuable means of information delivery for this population. ***Methods:*** Three focus groups were conducted with a total of 16 people to explore how caregivers retrieve and use health information on the Internet, as well as their perspectives towards the structure, design, and content of an online PHEx website. ***Results:*** 1) In terms of how caregivers retrieve and use online health information, three broad themes were identified: searching for and choosing online health information; empowerment through use of online health information; and concerns with health information on the Internet. 2) In terms of caregivers' perspectives towards the structure, design, and content of a PHEx website, two broad themes were identified: factors important for first impressions of a PHEx website; and perceived needs and expectations for the content presented on a PHEx website. ***Conclusions:*** Caregivers offered key insights regarding online health information retrieval, usage, and other perspectives, which will be helpful for future web-

based initiatives that aim to provide support to caregivers. Two conceptual frameworks are proposed related to: 1) health information website retrieval and usage, and 2) features important for a PHEx website on caregiving.

Abstract (French):

Contexte: Avec la population du Canada qui vieillit, une augmentation du taux de maladies chroniques, et un système de santé surchargé, une pression se développe sur les aidants naturels pour prendre en charge les soins de leurs proches. Ces demandes peuvent être difficiles, résultant en un accumulation de stress pour les aidants et les empêchant de continuer dans leur rôle. Cependant, il existe des preuves qui suggèrent que les interventions qui supportent les aidants peuvent contribuer à augmenter leur confiance, leur capacité de travailler, leur satisfaction dans leur rôle, ainsi que de meilleurs résultats pour les proches qui bénéficient de leurs soins. De nos jours, Internet joue un rôle important dans l'acquisition d'information et dans les services de support. Il est possible que de rendre ces supports disponibles aux aidants naturels peut aider ces derniers à fournir des soins de qualité tout en restant en bonne santé. En particulier, l'information basée sur la santé personnelle et l'expérience des maladies (SPEx) est devenue particulièrement intéressante pour le public, et pourrait être utile pour les populations qui sont isolées et qui manquent de services de support, tels que les aidants naturels. Afin de fournir de meilleurs services et plus de support aux aidants naturels avec des initiatives basées sur Internet, nous devons développer une meilleure compréhension de la façon dont les aidants naturels recherchent et utilisent l'information qui se trouve sur Internet. De plus, il est utile d'explorer le point de vue des aidants naturels par rapport à l'information SPEx sur Internet, car cela peut être un moyen utile de recueillir de l'information pour eux. **Méthodes:** Trois groupes, avec un total de 16 participants chacun, ont été formé pour explorer de quelle façon les aidants naturels recherchent et utilisent l'information sur la santé trouvée sur l'Internet, ainsi que leurs opinions par rapport à la structure, à la disposition, et au contenu d'un site web SPEx. **Résultats**: 1) Trois grands thèmes ont été identifiés en relation à la façon dont les aidants naturels récupèrent et utilisent l'information sur la santé trouvée sur Internet: la recherche et le choix d'informations sur la santé; l'autonomisation grâce à l'utilisation de cette information, et les préoccupations en lien avec l'information sur la santé trouvée sur Internet. 2) Concernant les opinions des aidants naturels par rapport à la structure, la conception et le contenu d'un site web SPEx, deux grands thèmes ont été identifiés: les facteurs qui influencent les premières impressions d'un site web SPEx, et les besoins et attentes envers le contenu présenté sur un site web SPEx. **Conclusions:** Les aidants naturels ont fourni des renseignements importants concernant la recherche et l'utilisation d'information à propos de la santé trouvée sur Internet, ainsi que des perspectives qui seront utiles pour le dévelopement d'initiatives visant à offrir du support aux aidants naturels sur Internet. Deux suggestions sont proposées en rapport avec: 1) la recherche et l'usage de l'information a propos de la santé trouvée sur un site web; et 2) les charactéristiques importantes d'un site web sur les soins SPEx.

Preface:

This thesis represents a culmination of work and learning experience that has taken place over a period of 20 months at McGill University and St. Mary's Hospital in Montreal, Quebec. The idea for this research project was a collaborative effort between the author (MSc candidate), members of the Health Experiences research team (Principle Investigator: Dr. Susan Law; Project Coordinator: Ilja Ormel), and Dr. Gillian Bartlett. Focus groups were organized and run by the author, along with the assistance of Dr. Susan Law, Ilja Ormel, Brent Hopkins, and Alessandra Miklavcic, as well as Zahoor Chughtai, Claude Savard, Nicole Mike for administrative, technical, and culinary assistance. This work was funded by a St. Mary's Research Center Masters Student Award in MSc Year 1, and a Canadian Institutes of Health Research Frederick Banting and Charles Best Graduate Scholarhip in MSc Year 2.

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Introduction:

This thesis explores how family caregivers seek and use health information on the Internet, and elicits their perspectives relevant to online health information based on people's experiences with health and illness. Family caregivers are those responsible for the unpaid care of a mentally or physically ill, frail, or disabled family member, friend, or other person (Health Canada, 2002). Thus, as defined in the National Profile of Family Caregivers Report (Health Canada, 2002), the term 'family caregiver' is used in a broad sense to include not only family members of the care recipient, but friends and volunteers as well. For the purposes of this thesis, the term 'family caregiver' will be used synonymously with the term 'caregiver'.

Canada's aging population, chronic diseases, and a strained healthcare system has, in part, resulted in a growing pressure on family caregivers to be involved in managing the care of their loved ones (Morgan et al., 2007; CIHI, 2010; CIHI, 2011). The demands of caregiving, however, can be challenging, strenuous, and often untenable, which may result in caregiver distress, negative health outcomes, and an inability for caregivers to continue in their role (CIHI, 2010). To help address this issue, health professionals, researchers, and other agencies recommend that caregivers seek support and assistance from family and friends, organized caregiver support groups, or other means (Health Canada, 2004; Van Mierlo et al., 2012; Perkins & LaMartin, 2012). The Internet is one area that now plays a significant role in information delivery and support services (Murray et al., 2003; Kim & Kim, 2009; Fox & Duggan, 2013), and it is possible that offering cost-effective web-based support to caregivers may assist this population to provide quality care and remain in good health (Lorig et al., 2010; Aalbers et al., 2011; Thinnes & Padilla, 2011). In order to deliver optimal support and services to caregivers through web-based initiatives, service providers need a better understanding for how caregivers search for and use online health information, and should work with the caregivers to determine their expectations of and perspectives on different elements and forms of web-based health information.

Family caregivers

The role of the family caregiver is increasingly being recognized as an integral component of the Canadian healthcare system, as family caregivers typically provide vital physical and emotional support to their care recipient (CIHI, 2010). Caring for someone can be a highly rewarding and enriching experience (Cohen et al., 2002). Caregiving can enhance companionship, improve quality of life, add meaning and importance to people's lives, and also offer enjoyment and fulfill duties and obligations (Cohen et al., 2002). In many cases, however, the responsibilities associated with caregiving can be demanding, stressful, challenging, and burdensome for the person providing care (Wilkinson & Lynn, 2005; Schulz & Sherwood, 2008). In these situations caregivers can become distressed, which can ultimately affect the quality of their care and ability to continue in their caregiving role, with potential consequences for the caregivers' health (CIHI, 2010). This distress may be intensified in caregivers who lack support through family members, friends, health services, or other support resources (CIHI, 2010).

Interventions aimed at supporting caregivers can be a powerful means to reduce caregiver distress and help improve quality of care (Van Mierlo et al., 2012). While a variety of proven effective services exist for caregiver support, these may not be sufficient to meet individual caregivers' needs, and are often not accessible because of a lack of free time, cultural expectations, scheduling conflicts, geographic isolation, or other obstacles (Roberto & Jarrott, 2008; Tanis et al., 2011; Van Mierlo et al., 2012).

Health information on the Internet

One area that is making a profound impact on availability of healthcare resources and information use, for both caregivers and the general public, is the Internet (Hesse et al., 2005; Statistics Canada, 2005; Statistics Canada, 2007; Statistics Canada, 2010; Hesse et al., 2010). Searching for and using online health information can improve knowledge, competence, and increase engagement in health decision-making (Murray et al., 2003; Kim & Kim, 2009; Ziebland & Wyke, 2012). People now have the ability to search health related questions and explore sensitive or embarrassing topics in the comfort and privacy of their own home. Online health information, if provided in a valid, evidence-based and trustworthy setting, represents a cost-effective and powerful means of education and support (Murray et al., 2003; Griffiths et al., 2006; Kim & Kim, 2009). While it is possible for the Internet to contribute to increased knowledge about health and healthcare, which may lead to improvements in a person's health and wellbeing (Lewis, 1999; Wantland et al., 2004; Cutler & Lleras-Muney, 2006), questions remain about how different populations or groups interact with web-based health information.

With Internet usage rates climbing rapidly each year (Statistics Canada, 2009), and health information availability being one of the primary reasons people use the Internet (Fox & Duggan, 2013), health services researchers are attempting to understand more about how people search for and use online health information. While the content of a health website is one factor that weighs in on why people will choose a certain website, this is secondary to superficial structural and design elements of the web page (Sillence et al., 2007). With a plethora of health websites emerging on the Internet - serving private and public interests - people often make quick decisions about whether they wish to explore a website further or not. This is usually accomplished by a swift appraisal of the more superficial aspects of the website (Sillence et al., 2007). Thus, legitimate and evidence-based websites may be hastily skipped over due to poor graphic design, while unreliable sites may be explored further because of catchy, attractive, and engaging images, font, and colours. Given that people appear to base important health decisions on information gleaned from the Internet, health service providers who are developing valid and trustworthy websites need to ensure they give considerable effort to web design.

Online health information based on personal experiences

In addition to seeking an attractive website design, many people also wish to access content they can relate to, is easy to process, and is relevant to their health condition or query (Ziebland et al., 2004; Sillence et al., 2007; van Uden-Kraan, 2008). Websites that showcase personal experiences with health and illness are becoming popular in the public domain, where people often seek insights and reflections from others who are experiencing a similar situation (Sillence et al., 2004; Sillence et al., 2007; van Uden-Kraan, 2008). Online personal health and illness experience information contains patients' accounts of their experiences with anything related to health and healthcare (Ziebland & Wyke, 2012). People can either contribute information to patient experience websites (e.g., through blogging or joining a discussion group on a social networking health website), or they can simply visit and read information posted by other people on such websites, without contributing themselves. Appendix 1, modified from Ziebland & Wyke (2012), presents nine primary ways that personal health and illness experience information currently appears on the Internet.

Retrieving and using personal experience health information, in contrast to information based on traditional facts and figures, can help people become better informed and also reduces feelings of loneliness and isolation, which are commonly seen in caregivers who experience distress (Gabriel, 2004; van Uden-Kraan, 2008). However, this information is often presented through unfiltered and non-moderated patient experience blogs, chat rooms, or testimonials. These venues may sometimes be used as a platform for sensationalized and emotionally charged stories, hoaxes, spam, marketing efforts, or to promote health practices that are not evidence-based (Houghton et al., 2001; Kelly et al., 2002; Walji et al., 2004; Scanfeld et al., 2010). People looking for health information may be in a vulnerable position, and many are willing to accept any – albeit potentially spurious – information that provides a sense of hope and control. In order to help combat this issue, health services researchers, service providers, and targeted end-users should work together to develop websites that present trustworthy patient experience information to the public.

One evidence-based personal health and illness experience web-based initiative that has come out of the University of Oxford in the United Kingdom is healthtalkonline.org (DIPEx, 2012). Healthtalkonline contains audio, video, and text clips of people's experiences with over 70 types of health and illness related conditions and experiences. This resource is considered a trusted site, featuring evidence-based information and resources, and is popular both within the UK and around the world (DIPEx, 2012). The feedback from users of this website has been overwhelmingly positive (Sillence et al., 2004; Newman et al., 2009; DIPEx, 2012). Many health websites require people to possess high literacy levels in order to comprehend the information presented on them (Berland et al., 2001). Healthtalkonline circumvents this issue by supplying experiential information told through individual stories, in a variety of formats including audio, video and text (Herxheimer et al., 2000). Healthtalkonline has also published several modules on experiences of caregiving, which provide practical advice, important reassurance, and other caregiver-driven information (DIPEx, 2012). It is thought that caregivers and other people in Canada may also benefit from this form of information delivery and support, and thus a Canadian arm of the Healthtalkonline initiative (called www.healthexperiences.ca, with the first module on caregiving) is now in development with collaboration between St. Mary's Hospital and McGill University researchers in Montreal, Quebec.

When people use reliable online health information, in addition to increasing their own knowledge, this also has the potential to improve health outcomes, enhance the doctor-patient relationship, and promote healthy behaviors (Murray et al., 2003; Kim & Kim, 2009), and caregivers are likely to be no exception. There is some evidence that suggests caregivers who use the Internet as a means of accessing social support and health information experience improved wellbeing and other positive lifestyle changes (Perkins & LaMartin, 2012). Understanding how caregivers search for and subsequently use web-based health information may help to develop online interventions and support resources for this population. While some research has explored this area in other populations (Quintana et al., 2001; Stanford, et al., 2002; Sillence et al., 2007), there is little information on how caregivers interact with web-based health information (Perkins & LaMartin 2012). Understanding this will be the first step towards developing attractive and useful online support services for caregivers. Given that personal health and illness experience information seems to be particularly appealing and useful to the public, it will also be useful to explore caregivers' needs and perspectives towards this style of health information. Evidence-based personal experience information is a promising avenue for information delivery and health support for the general public; however, it is not clear what caregivers in particular would want from such a website.

Thesis objectives

This thesis has two primary objectives. The first is to explore how caregivers retrieve and use health information from the Internet. This objective involves two of the three main research areas on information behavior: information seeking and information use (Case, 2002). Notably, seeking itself does not necessarily lead one to find relevant information, and irrelevant information is usually not used. The use of relevant information is typically defined as a better understanding of something (e.g., a problematic health situation), the application of information as a resource in a process (e.g., writing a thesis), or resulting human interactions with information (e.g., in a consultation with health professionals) (Case, 2002). The second objective is to explore caregivers' needs, expectations, and perspectives towards online health and support information delivered through personal experiences.

Literature Review:

With these objectives in mind, this literature review will present what is known about (1) family caregivers in a Canadian context, including their increasing need for health related support and resources; (2) the current status of the Internet as a tool for health information and support; (3) how people search for and use online health information; (4) various forms of online health information delivery; and (5) current evidence about the use of e-health initiatives to assist caregivers.

Burden of chronic disease in Canada

Canadians are living longer and are healthier than ever before, but with this longevity has also come a significant increase in the number of people living with chronic health conditions (Morgan et al., 2007). Advances in healthcare and medical technologies allow many people to live with what were once debilitating and deadly diseases, but have become chronic and manageable conditions (Morgan et al., 2007). The majority of patients seeking healthcare in North America today have at least one chronic condition (Morgan et al., 2007). Over half of adults in North America have at least one chronic disease, and over three quarters of family doctor visits are related to diagnosing, treating, or managing chronic illness (Rapoport et al., 2004). The economic impact of chronic disease alone is estimated to comprise over two thirds of all healthcare costs (Rapoport et al., 2004). To add to these issues, the first baby boomer generation turned 65 in the year 2011, and this demographic shift means that seniors will account for an increasingly greater percentage of the Canadian population (25% by the year 2036) (CIHI, 2011). While these seniors will be healthier and live longer than previous generations, many of them will develop chronic health conditions and experience difficulties carrying out various activities of daily living (CIHI, 2011). Furthermore, the impact of chronic illness extends beyond the elderly. The progress that has been made in medicine and healthcare offers children and younger adults, living with an array of medical conditions, the opportunity to live longer, more independent lives by preventing or delaying the progression of life-threatening disease (Rapoport et al., 2004; Heath et al., 2011). This places a significant burden on the person living with a chronic illness, their family and social network, and the healthcare system as whole (Rapoport et al., 2004; Morgan et al., 2007).

In addition to the profound impact of chronic disease in Canada, the Alzheimer Society of Canada (2010) claims that we are facing a "dementia epidemic". Dementia is the most significant cause of disability among people over 65 years of age, although early onset Alzheimer's disease and dementia can strike at a much earlier age (Harvey et al., 2003). The Alzheimer Society projects that within the next 25 years the number of people living with Alzheimer's disease or associated dementia will more than double from 500 000 to 1.1 million people, increasing the cost of dementia-related care from $15 billion to $153 billion (Alzheimer Society of Canada, 2010).

A 2007 report by Morgan et al highlighted an "inconvenient truth", stating that Canada is not prepared to manage the extent of chronic disease that our healthcare system will face. This burden will largely fall on the family caregivers. The Alzheimer Society anticipates that by 2038, Canadians will be required to provide well over triple the number of hours of informal care that they provide today for people with dementia (Alzheimer Society of Canada, 2010).

Access to care

Chronic illness, dementia, and other factors related to demographic change are expected to have a profound effect on the healthcare system, including limiting access to home care, long-term residential care, primary care, and other health services (Morgan et al., 2007; CIHI, 2011). Demands for home care and long-term residential care will escalate and will compete with other health services for limited financial resources (CIHI, 2011). Both the absolute number and percentage of Canadians who are aged 80 and over will increase dramatically, with some estimates suggesting this group will increase from less than 1% of the population in 2005, to 10% in 2056 (CIHI, 2011). This segment of the population is most relevant to the overburdened and inadequate home care and long-term care facilities, where the majority of clients are seniors and the average age is 86 (CIHI, 2011). A 2011 report from the Canadian Institute for Health Information stated that it is not the official paid care services, but rather the informal, unpaid caregivers who will be “key” to enabling people to remain functional and safe in their homes.

Family caregiving in Canada

In 2002, over two million people in Canada provided informal and unpaid care for a family or friend with an illness or disability (Health Canada, 2002); however, more recent estimates suggest there may be as many as 4 to 5 million family caregivers in Canada (Canadian Caregiver Coalition, 2008). Family caregivers provide assistance with instrumental activities of daily living (IADL) and activities of daily living (ADL). IADL’s include managing and delivering medications, grocery shopping and transportation, housework, and preparing meals. ADL’s include activities such as eating, drinking, personal care and hygiene, toileting, and moving the care recipient around the home (Health Canada, 2002). In addition to physical assistance, family caregivers also offer important companionship and emotional support (Health Canada, 2002). The range and list of responsibilities, however, varies tremendously within individual family contexts and depending on the availability of local services (Fast & Keating, 2001; Health Canada, 2002; Health Canada, 2004)

Likewise, caregivers represent a highly diverse and active group of people. In a 2001 Health Canada study, it was reported that the majority of caregivers were employed in addition to their caring responsibilities (Fast & Keating, 2001). Close to half of Canadian caregivers are under the age of 45, with 34% between the ages of 45 and 59 and 17% 60 years and older, and close to two thirds of family caregivers are women (Fast & Keating, 2001). The majority of younger caregivers are looking after an elderly parent, while older people are primarily caring for a disabled child or spouse (Fast & Keating, 2001). Many caregivers do not receive any formal or paid assistance as part of their care recipient’s regular care, and close to half of caregivers reported that looking after their care recipient affected social activities (Health Canada, 2004). Additionally, over 70% of both male and female caregivers felt that they had no other reasonable option than to become a family caregiver when they were faced with the decision (Health Canada, 2004).

It has been estimated that the economic value of care that family caregivers provide in Canada is over $25 billion dollars a year (Hollander et al., 2009). This value is understood as the amount it would cost the Canadian healthcare system to replace the services provided by family caregivers (Hollander et al., 2009). This macro level understanding of the value of caregivers highlights the importance of family caregiving services, and the necessity to provide effective means to support caregivers. At the individual level, if caregivers cannot manage the stress and responsibilities associated with caregiving, it is likely they will have difficulties maintaining their caregiving role (CIHI, 2010). Many studies have recognized the importance of services for caregivers and have highlighted the necessity for the government and healthcare system to explore avenues of support for family caregivers, whether it be through interventions, support services, or monetary compensation (Arno et al., 1999; Gibson & Houser, 2007; Hollander et al., 2009).

In addition to the economic impact of family caregiving, caregiver status is also known to affect a person's physical, emotional, and social wellbeing. Caregivers are a vulnerable population who are at higher risk for psychological distress, unhealthy behaviors, mental illness, physical illness, and even death (Wilkinson et al., 2005; Schulz et al., 2008). The intensity of the caregiver distress varies with the characteristics of the patient they care for, such as type of disease, cognitive or communicative disability, the patient's prognosis, and possibilities for the caregiver to have the capacity to influence the course of the illness (Wilkinson et al., 2005). An additional factor closely associated with caregiver distress is level of service utilization and informal support, including home health and meal services, as well as assistance with activities of daily living and informal mental and emotional support (Health Canada, 2004). For caregivers of patients with chronic illness, the burden of care, or negative feelings that may be experienced when giving care, is one of the primary negative consequences of adopting the caregiver role (Goldberg et al., 2011). This type of distress has a negative impact on the caregiver's quality of life, including feelings of isolation and loneliness, and their ability to properly care for their family member or friend (Goldberg et al., 2011). These negative experiences of caregivers and the negative impact this has on their provided care are well known, however, it is difficult to provide adequate resources to meet the needs for caregiver support and information (Arno et al., 1999; Gibson & Houser, 2007; Hollander et al., 2009).

In summary, caregivers are an essential component of the Canadian healthcare system. It is a highly demanding role, often with negative health and social consequences for the caregiver, and there is a critical need to identify adequate and accessible mechanisms for their support.

Current resources and sources of support for caregivers

A variety of resources currently exist for family caregiver support. Support services can take many forms including non-judgmental listening or assistance from family and friends, religious communities or other places of worship; organized caregiver support groups that meet both face-to-face or online; telephone help-lines; social workers or counselors; self-help books; or provincial and national caregiving or disease specific organizations (Dollinger & Chwalisz, 2011; Van Mierlo et al., 2012). Effective support services such as these can prevent caregivers from becoming overburdened by their caring role (Dröes et al., 2004; Van Mierlo et al., 2012). A recent review of the literature that evaluated different support programs for caregivers of people with dementia found that personalized caregiver interventions were successful at improving quality of life, mental health status, physical functioning, competence and self-efficacy, burden, and overall attitudes of the caregiver (Van Mierlo et al., 2012). While a variety of services exist for caregiver support, these services are often not easily accessible, nor are they sufficiently available to meet all caregiver needs (Dröes et al., 2004; Van Mierlo et al., 2012). Online health tools are one potential option to fill this gap in a feasible, cost-effective, and sustainable manner.

Internet as a source of health information and support

Currently over 80% of Canadians use the Internet (Statistics Canada, 2009).

Ninety-eight percent of young adults aged 16-24 use the Internet, while 66% of people aged 45 and older use the Internet. Despite older people reporting that they use the Internet less than their younger counterparts, the 45+ age group is the fastest growing group of Internet users in Canada (Statistics Canada, 2009). Seeking health information is one of the primary reasons people use the Internet (Statistics Canada, 2005; Statistics Canada, 2007; Statistics Canada, 2010), with one study reporting that people would rather access the Internet as a first source for information over their physicians (Hesse et al., 2010). This increasing trend in health information-seeking behavior is expected to continue (Statistics Canada, 2005; Statistics Canada, 2007), but with this movement comes concern regarding the quality of the information and dismissal of legitimate health information (Briggs et al., 2002; Sillence et al., 2006; Sillence et al., 2007a). The proliferation of health information on the Internet has weakened the traditional role of health professionals and clinicians as the custodians and primary providers of health information (Sillence et al., 2007a). This ongoing rise of the Internet as a health resource has the potential to strengthen healthcare by allowing people to become more knowledgeable and involved with their health; however, this may be accomplished only if the information available is credible and used appropriately (Wantland et al., 2004; Chaudhry et al., 2006; Shekelle et al., 2009). Information on the Internet is particularly hard to control (Peterson et al., 2003), and not all people search for and utilize web resources in a similar way (Rogers & Mead, 2004) More evidence is needed to assess how people search for and retrieve health information on the Internet, how they use this information, as well as what attracts people to certain health websites over others.

The effect of public Internet use for health information has elicited varied opinions among health care professionals. Murray et al (2003) found that inaccurate and irrelevant information from unreliable sources had the potential to harm healthcare by having a negative impact on health outcomes and damaging the patient-physician relationship. Physicians also expressed concerns about patients developing unnecessary fears about their health if relying on poor information sources (Kim & Kim, 2009). Doctors were worried about Internet use inappropriately increasing healthcare costs through nonessential referrals or requests for treatments (Kim & Kim, 2009). When people, however, had found accurate, relevant, evidence-based health information on the Internet, physicians noted that this could enhance the visit, promote healthy behaviors and health outcomes, and improve the doctor-patient relationship (Murray et al., 2003; Kim & Kim, 2009). Doctors also stated that Internet use allowed them to explain complicated health issues more easily to their patients, and believed Internet use had the potential to further improve patient outcomes (van Uden-Kraan et al., 2010). Despite any concerns that doctors may have about patient Internet use, most physicians were able to address information that was retrieved by their patients, and they felt competent clarifying misguided or inaccurate information (van Uden-Kraan et al., 2010). In addition to the possible health benefits of valid online health information, the Internet is also recognized as a highly cost-effective method to deliver health information and health interventions to the public (Griffiths et al., 2006; Aalbers et al., 2011).

In a meta-analysis of studies that evaluated health websites, issues were identified regarding the quality and validity of over two thirds of web-based healthcare resources (Eysenbach et al., 2002). This is a major concern given that a recent Pew Internet & American Life Project found that close to 60% of people reported seeking health information online in the previous year (Fox & Duggan, 2013). An important area that remains to be fully understood is how different populations of Internet users search for health information on the Internet, and what motivates them to choose one health website over another.

How people search and retrieve health information on the Internet

The type of health information that people find on the Internet is a product of the decision-making process they go through to arrive at a health website (Briggs et al., 2002; Sillence et al., 2007). Given the plethora of health websites on the Internet, it is of little surprise that the public is influenced by relatively superficial aspects of websites upon their initial search for information (Stanford, et al., 2002; Sillence et al., 2007). When people first begin a search for health information, they will judge sites as good versus bad based on criteria such as attractiveness of the structure and design, number and type of advertisements, and whether the site has more of a 'corporate' or 'medical' feel to it (Stanford, et al., 2002; Sillence et al., 2007). Given the extensive amount of health information on the Internet, this type of search strategy is a pragmatic approach to quickly and efficiently narrow information choices. People spend 10 seconds or less on a web page in order to determine whether a website is relevant or useful to them (Sillence et al., 2007). This type of information highlights the necessity for website providers to consider carefully the seemingly superficial aspects of their website. Ignoring such factors may result in people hastily skipping over valid and beneficial health information.

An observational study that asked Internet users to answer various health related questions using information gathered from the web, found that none of the people consulted the "about us" section, the disclaimers, or disclosure sections of the website (Eysenbach et al., 2002). Health websites were largely rejected or accepted based upon salient and easily processed criteria. Despite this preliminary superficial search strategy, however, many people will subsequently begin a more thorough and content driven appraisal of health websites (Sillence et al., 2007). Sillence et al (2007) conducted a study with women who were searching for information related to hormone replacement therapy, and found that while the vast majority of reasons the women chose to rapidly reject a website were due to issues with the design, 83% of reasons they chose to trust a website and explore information further were based upon their evaluation of its content. They found that the credibility of the web source; information accessibility and consistency; design and layout; and social identification and personalization of the health information, were important determinants for eventual trust in the content (Sillence et al., 2007). People in this study also stated that complicated statistics, explanations of clinical trials and complex data, as well as other technical and unfamiliar information, resulted in confusion and information overload (Sillence et al., 2007).

These results highlight the need for website providers to present comprehensive, valid, and trustworthy information in a patient-friendly format that does not overwhelm people with complex facts and numbers. Researchers that have consulted end-users in the development and design of their website have found that while challenging, this type of consultation proved a valuable means to ensure their websites were appealing, engaging and well-utilized by the target audience (Franck & Noble, 2007; Thompson et al., 2012; McCarthy et al., 2012). While it is important to understand how people search for health information on the web and perform an assessment of a website, researchers have also focused on understanding how the information gathered through this source is used.

How people use health information they find on the Internet

Health information that has been retrieved through the Internet is used for a wide range of purposes, including self-diagnosis and treatment, learning about a family member or friend's illness, seeking support or reassurance from others, or as a tool for healthcare decision-making (Quintana et al., 2001; Fox et al., 2005; Perkins & LaMartin, 2012). A study that explored how to make a high-quality preventive health information website found that people wanted to participate more in their own health, and they felt that information on the Internet was a powerful means to accomplish this (Quintana et al., 2001). People said they would use health information to help determine "the right" questions to ask their doctor, or as a second opinion after they had spoken with a doctor. The study also found that most people did not view health information websites as a replacement for their doctor, but as a supplemental resource for learning or assisting with healthcare decision-making (Quintana et al., 2001). People also use the Internet to assist with more specific health actions such as weight loss attempts, understanding and choosing pharmaceuticals, and preventative healthcare (Quintana et al., 2001; Fox et al., 2005; Ballantine & Stephenson, 2011).

Health information that is found on the Internet is used for a variety of reasons, and is also presented through a variety of formats. This leads to an exploration of which types of information delivery (e.g., information based on facts, figures, experiences, etc.) are most preferred, retrievable, and used, as well as which forms may result in the most positive impact on the health and wellbeing of caregivers.

Current forms of online resources for health information and support

Traditionally, online healthcare resources have presented information in the form of facts and figures related to the signs, symptoms, treatments and outcomes of an illness (Sillence et al., 2007). This form of information presents a list of data to the user, with little focus on the patient's personal experience with the illness (Sillence et al., 2007). Although facts and figures can no doubt contribute to a person's basic knowledge of their condition, health websites should also include people's personal experiences with their illness, as these are most likely to engage site users (Sillence et al., 2007). Websites that provide a sense of personalization or social identification to the consumer are trusted and preferred over other types of information, as people feel this type of personal information is more directed towards "people like them" (Sillence et al., 2007). People appreciate that personal experience information includes familiar sounding language and highly relevant content (Sillence et al., 2007). Evidence shows that people wish to understand their illness at a deeper level than just scientific facts (Sillence et al., 2007). Through online communities, people can share their experiences with health and illness, as well as give advice and offer special insights and reflections related to the lived experience of their specific condition. Online health experience information may allow the user to become better informed about their illness, while enabling them to feel less lonely and isolated as a result of their health condition (van Uden-Kraan, 2008). This is especially beneficial for those patients who are immobile or homebound as a result of a debilitating illness (Gabriel, 2004; van Uden-Kraan, 2008). Many people who are either newly diagnosed with an illness, or are living with a long-term condition, prefer to seek support and information from people who have had similar experiences to their own (Leydon et al., 2000; Glenton, 2002; Gabriel, 2004; Rice, 2006), and this is often accomplished by utilizing online resources (Ziebland et al., 2004). Using this type of experiential information online has the ability to influence people's healthcare decisions, potentially adjusting their healthcare seeking strategies and altering the trajectory of their health condition (van Uden-Kraan, 2008). Information is a known catalyst in helping people cope with their condition, improve their overall wellbeing, and enhance their quality of life (Department of Health, 2004). Information based on patient experiences can provide added meaning to scientific facts and figures, thereby allowing people to become better informed about their condition in the context of their own life (Gabriel, 2004). Furthermore, if the experiences are collected as interviews and presented in text, audio, or video format, they can make information highly accessible to people with different levels of health literacy. Unfortunately, health information on the Internet is often presented in a way that is of limited value to people with low levels of health literacy (Hu et al., 2012). While most research has focused on the impact of *patient* health, it is possible that *caregivers* may also experience benefits as a result of using online personal experience information.

Caregivers are often subject to feelings of burden, isolation, and loneliness, and online experience-based information may help address these negative situations (van Uden-Kraan, 2008). Additionally, many caregivers are known to have low levels of health literacy (Fagnano et al., 2012) and this inability to fully comprehend health related information or directions for care, correlates with a lower quality of provided care (Ross et al., 2001; Pizur-Barnekow et al., 2011). Information that is presented through individual experiences, rather than a recitation of facts, can be more accessible to people with diverse levels of health literacy. A study by Mackert et al (2009) reported that e-health interventions have considerable potential to educate and assist low health literacy populations that may often be high-risk and hard to reach. This has been reported by others, including Whitten et al (2008), who found that people with low health literacy were receptive to health information delivered through websites, and also that these people had learned from this form of health intervention.

Internet as a resource and source of support for caregivers

Despite increasing use of the Internet as a resource for health information and support, formal evaluations of the uptake and impact of technology-based interventions remain limited (Taylor et al., 2012). While this is also true for the case of caregivers, evidence suggests this may be a promising avenue for support in this population (Lorig et al., 2010; Thinnes & Padilla, 2011; Tanis et al., 2011).

The Stanford Patient Education Center (Lorig et al., 2010) evaluated an online education and support program for family caregivers and found favorable results. Caregivers who took part in the online program showed significant reductions in caregiver burden, depression, pain and stress, as well as improvements related to caregiver self-efficacy and increased exercise. Furthermore, the authors found that the care recipient's health improved significantly, and noted that the intervention was able to reach rural and isolated populations (Lorig et al., 2010). A systematic review conducted in 2011 by Thinnes & Padilla also found favorable results for technology-based services for caregivers. This was an evaluation of the effectiveness of different types of educational and supportive strategies meant to enable caregivers to maintain their caring role, which concluded that interventions mediated by technology, including Internet-based services, had a highly positive impact on caregivers. These interventions were particularly beneficial for rural or isolated populations that did not have immediate or nearby access to other services (Thinnes & Padilla, 2011).

Active participation in online health forums was also found to improve caregiver wellbeing (Tanis et al., 2011). Caregivers who used the Internet as a means of social support experienced less strain and improved mental and physical wellbeing (Tanis et al., 2011). Tanis et al (2011) also highlighted potential drawbacks of offline support groups, including the logistical and psychological barriers of attending such groups, and they stated that the Internet can provide caregivers with an optimal opportunity to interact with others and seek social support and information that they might not otherwise receive (Tanis et al., 2011). The Internet can also influence positive lifestyle changes in older people (Aalbers et al., 2011). These findings are promising for an online caregiving initiative, as close to a fifth of caregivers are over the age of 60 (Health Canada, 2004).

Many studies have also cited the importance of considering ethnic and cultural sensitivity when developing and implementing interventions for caregiver support so that culture, values, beliefs, and customs are considered to ensure success of a support program or intervention (Perrin et al., 2010; Napoles et al., 2010; Marshall et al., 2011). While studies that have used technology-based interventions with ethnic and cultural minority caregivers in Canada have been limited, there is some evidence that this type of support strategy may be beneficial and reduce burden in these populations as well. A study by Chiu et al (2009) evaluated an Internet-based Caregiver Support Service (ICSS) with Chinese Canadians and found that frequent users experienced a reduction in caregiver burden. This population of caregivers responded well to the web-based ICSS intervention and reported generally favorable results in terms of the mode of information delivery and ease of use. Culturally relevant, Internet-based interventions will be important for providing support in ethnic and cultural minority populations, which are becoming increasingly prevalent in Canada (Statistics Canada, 2010a). Furthermore, Internet access and use among economic, ethnic, cultural, and other minorities is increasing, and people from all backgrounds appear to rely heavily on the Internet as a source of health information (Hoffman et al., 2000; Bleakley et al., 2004).

There is good evidence that health interventions delivered through the Internet can have a positive impact on caregivers' health and wellbeing (Lorig et al., 2010; Thinnes & Padilla, 2011; Tanis et al., 2011); however it appears that interventions which are developed using input from caregivers themselves may be most used and well-received by the targeted population (Zulman et al., 2011; Williams & Bakitas, 2012).

Developing web-based resources using feedback from targeted end-users

Developing a caregiver support service in collaboration or consultation with caregivers is increasingly thought to be necessary for program success (Zulman et al., 2011; Williams & Bakitas, 2012; Van Mierlo et al., 2012). Williams & Bakitas (2012) conducted in-depth interviews with caregivers to explore the lived experiences of caregiving for an adult with lung or colon cancer. They used the information gathered from the interviews to develop relevant themes that were ultimately used to develop an intervention that adequately addressed caregivers' needs and offered relevant support (Williams & Bakitas, 2012). An additional study that adapted an in-person communication intervention to an online format reported that utilizing a multidisciplinary design team, which included direct and iterative feedback from caregivers, was crucial to the development of a successful, effective and user-friendly service (Zulman et al., 2011).

Web-based interventions also require end-user feedback related to structural and design features of the web page. Studies that have involved end-users in the development of online health information tools have reported that this was an integral step in the creation of these web-based services (Franck & Noble, 2007; Thompson et al., 2012; McCarthy et al., 2012). Additionally, a study that assessed website task performance by adults aged 58-90 years, concluded that they were not disadvantaged in terms of basic Internet use, and age did not represent a significant handicap in regards to abilities to surf the web and perform basic functions on the computer. This was especially true if websites were adequately designed and easy to navigate (Priest et al., 2007).

Considering that usage of the Internet for caregiver information or support presents a relatively novel approach to offering assistance and reaching out to this population, it is important to understand their perspectives, needs, and expectations for different forms of online health information, as well as how they search for and use web-based health information. Caregivers are highly diverse and represent a complex population (Fast & Keating, 2001; Health Canada, 2004). A caregiver can be a 20 year old girl helping look after her mother with multiple sclerosis, an 83 year old man caring for his wife with COPD, or a 56 and 53 year old husband and wife caring for their 21 year old child with cerebral palsy. Furthermore, caregivers may be interested in seeking health information for themselves, their caring situation, or their care recipient. While an appreciable amount of research has explored various populations' information seeking strategies and opinions towards online health information, only a limited number of studies have explored this directly with caregivers. This population may have alternative methods of seeking health information or choosing health websites, and may use health information in a unique manner compared to other populations. Understanding how people retrieve and use health information is crucial to the development of websites that will attract and retain targeted end-users (Kreps, 2002; Atkinson et al., 2009). A thorough analysis of the targeted audience should be the first step to develop any web-based health initiative. Identifying and responding to the users' perspectives and needs is key to the eventual acceptance and utilization of that web-service (Kreps, 2002). Furthermore, people rely heavily on an attractive and user-friendly structure and design when choosing a health information website (Sillence et al., 2007). Thus, if a web-based initiative is to be well utilized by its target audience it is important to receive feedback related to structural and design elements as well.

Summary of literature review

Many studies have recognized the importance of caregiver's services and have highlighted the necessity to provide support for family caregivers in Canada (Lorig et al., 2010; Thinnes & Padilla, 2011; Tanis et al., 2011; Van Mierlo et al., 2012). Using accurate and relevant information on the Internet can be associated with improved health knowledge, better health behaviors and health outcomes, and improved physician-caregiver communication (Murray et al., 2003; Wantland et al., 2004; Cutler & Lleras-Muney, 2006; Kim & Kim, 2009).

If caregivers can find and use trustworthy information on the Internet then it is possible, in addition to simply increasing knowledge, that negative feelings such as loneliness, isolation, as well as a general lack of support, may be reduced. This may have an impact on the caregiver's overall quality of life and subsequently improve their quality of care, ultimately allowing them to maintain their caregiving role. This will become increasingly important as Canada's population ages and home care and long-term care facilities become overburdened (Morgan et al., 2007; CIHI, 2010; CIHI, 2011). People living with chronic and debilitating conditions will continue to rely heavily on family, friends, or other volunteers to provide informal care. Given that the use of online initiatives for caregivers is a relatively novel approach to information and support for this population, it will be valuable to explore caregiver's information seeking strategies and behaviors, including how they search for and choose health information websites, how they use health information found on the web, and other views towards health information websites. This information could be valuable for web-based initiatives that aim to provide support to caregivers.

Furthermore, online patient experience health information in particular may offer additional benefits to users. Evidence shows that health information that is presented through personal experiences, rather than basic facts and figures, may help people make better healthcare choices, alert them to potential health issues, and allow them to feel less lonely and isolated in their situation (Gabriel, 2004; Sillence et al., 2007; van Uden-Kraan, 2008;). It is expected that this form of information delivery may be a promising avenue of web-based support for this population. Despite the potential for success with this form of information delivery, there are important gaps in our understanding of caregivers' perspectives towards different elements of the structure, design, and content of a patient experience website.

Research Questions

The research questions addressed in this thesis are:

(1) How do caregivers retrieve and use online health information?

(2) What are caregivers' perspectives, needs, and expectations towards the structure, design, and content of a website featuring personal health and illness experiences of caregivers?

Therefore, the first objective is to explore topics related to caregivers' information behavior, including why and how they search for health information online, how they use health information accessed on the web, why they choose to trust certain website over others, and other views towards health information websites. The second objective is to collect feedback from caregivers about expectations and views towards the structure, design (e.g., layout, font, colours, images, logos, general presentation, etc.), and content (e.g., forms of information delivery, external resources, introduction videos and text, general information needs and expectations, etc.) of a personal health and illness experiences web page. Thus, the first objective will address aspects of caregivers' retrieval and use of web-based health information in a general context, while the second objective will address caregivers' perspectives, needs, and expectations towards information delivered through online personal health and illness experiences, in particular.

Methods:

This project utilized a qualitative descriptive design with semi-structured focus groups as a form of data collection (details below). A qualitative approach was used, as an in-depth description of caregivers' perspectives towards online health information was needed to answer the research questions. This study received ethics approval by the St. Mary's Research Ethics Committee as an amendment to the original "St. Mary's-McGill Health Experiences" study.

Setting

The work for this thesis was conducted within an ongoing project on health experiences based at St. Mary's Research Centre, which is part of a larger international collaboration involving research teams in fourteen countries all using similar methodology. The basis for this work was initially developed in 2000 by a research team at the University of Oxford in the UK who developed an evidence-based website featuring personal experiences of health and illness. This website (www.healthtalkonline.org) features video, audio, and text clips from interviews with people across the UK about their experiences of health and illness. The site also provides links to reliable information and resources relevant to each topic or online module (DIPEx, 2012). Healthtalkonline now features over 70 topics with over 25,000 people's stories (DIPEx, 2012). They receive over 1 million hits per month, and were recently cited as one of the top five best websites for your health in an article entitled *"The 50 Top Websites You Can't Live Without"* in the Times newspaper (The Times, 2013).

The health experience team at St. Mary's has initiated development of a Canadian version of this approach with funding from the Hospital Foundation for the first two modules (English: www.healthexperiences.ca and French: www.experiencessante.ca) (DIPEx, 2012). The first module focuses on caregivers, in which qualitative interviews were conducted with people caring for adult family members (spouses, elderly parents, children, close family friends, etc.) with a chronic physical illness. However, while this first module on experiences of caregiving targeted those caregivers who look after people with a chronic physical illness, many of the care recipients also had mental and cognitive disabilities, such as dementia or Alzheimer's disease. In the analysis for the caregiving module of healthexperiences.ca, issues were identified that are important to caregivers in the context of their family, work, and social lives. Specific topics included: what it means to become a caregiver, the effects of caregiving on personal and work life, experiences with Canadian health services, relationships and intimacy, finding information and support for their family members and themselves, useful information sources and practical tips, experiences as an ethnic or cultural minority caregiver in Canada, and other issues relevant to the topic of caregiving.

The Canadian Health Experiences research team adopted the UK Healthtalkonline guidelines as per the *"Health Experiences Research Group Research Methods Handbook"* in the development of the health and illness modules. Particular aspects of the Health Experiences study are amenable to a participatory research approach, namely the development of the new healthexperiences.ca website. Participatory research can be defined as, "research that includes the active involvement of those who are the subject of the research". Participatory research is usually action-oriented, where those involved in the research process collaborate to define the research project, collect and analyze the data, produce a final product and act on the results" (Government of Canada, 2011). Specifically, as the creation of the healthexperiences.ca web page begins, it is valuable to incorporate end-users' feedback in the developmental process. The research conducted for this thesis was not carried out using a participatory approach, but rather a component of this thesis represents a participatory aspect of the larger Health Experiences study.

The present creation and ongoing development of the healthexperiences.ca website offered an opportunity to explore caregivers' expectations and views towards the structure, design, and content of a personal health and illness experiences website. As such, the healthexperiences.ca initiative provided the basis to address the second research question for this thesis, which aims to explore caregivers' perspectives towards online personal health and illness information.

To address both research questions, three focus groups were assembled with caregivers. The focus groups were held in Winter 2012, prior to the official launch of www.healthexperience.ca. All focus groups were conducted with face-to-face sessions at St. Mary's Hospital in Montreal, Quebec, and people were recruited from Montreal and surrounding areas.

Research Design

This research followed a qualitative descriptive design, using a naturalistic form of inquiry, as outlined by Sandelowski (2000). This inquiry was exploratory in order to conduct an in-depth investigation of caregivers' experiences with information seeking and use, and perspectives towards online personal health and illness experience information. Given that current understanding of these issues is rather limited, a qualitative descriptive study provides an ideal means to explore these topics. Constructivist principles were used throughout this project, as qualitative research values multiple viewpoints and requires an in-depth understanding of what people have to say about a topic (Sandelowski, 2000). A basic or fundamental qualitative descriptive design was used for this project. As stated by Sandelowski (2000), this form of qualitative descriptive design maintains descriptive and interpretive validity, and can provide a highly accurate and congruent description of people's opinions, without purposefully imposing the researcher's own interpretive 'spin' on the information presented.

Participants

A purposeful sampling technique with maximum variation (Coyne, 1997) was used to recruit 16 caregivers for this study. While the sampling technique was purposeful, there was also an element of convenience or pragmatism, which allowed recruitment of people who would be able to contribute to the aims of the research, as well as available and willing to participate. This type of strategy is adequate for smaller, exploratory studies (Anderson, 2010). The use of convenience samples as an appropriate method of recruitment for this form of research has also been supported by others (Green & Thorogood, 2009). The aim of the participant selection for the focus groups was not to achieve a representative sample throughout different regions, but rather to secure a maximum variation sample for this topic (Coyne, 1997). Recruitment targeted male and female caregivers with a range of ages and backgrounds, different marital statuses, a variety of occupations, different disease and illness types of the care recipient, different ethnic and cultural backgrounds, and varying levels of computer and Internet use. Caregivers that were targeted for recruitment also had a variety of caregiving experiences including short and long term caring, caring for family members, friends, and other people, as well as caregivers who were currently caring for someone and those that had cared for someone in the past.

Broad inclusion criteria for the participants were adopted in order to obtain diverse feedback about how caregivers retrieve and use online health information. Likewise, it is expected that a personal health and illness information resource that is available in an online format may attract a heterogeneous population across Canada. Including a broad range of participants ensured that diverse feedback was obtained about the structure, design, and content of a personal experience website. Exclusion criteria for the selection of participants included caregivers who did not speak English, although English did not have to be their primary spoken language. People were required to be 18 years of age or older at the time of recruitment, however, it was possible for participants to have had caring experience or had begun caring for a person at the age of 17 years or younger.

Caregiver recruitment was accomplished through contacting caregiver associations and groups, members of the health experiences expert advisory panel and their personal and professional networks, the St. Mary's Family Medicine Center, snowballing through personal contacts via members of the research team, as well as contacting those people who lived in Montreal and had taken part in an in-depth interview for the healthexperiences.ca module. A total of 23 people were approached to participate in this study, of which 16 agreed to take part. Caregivers who chose to volunteer for the focus groups were compensated $40 for expenses. This amount was expected to cover costs associated with travel and parking, as well as the costs required for some of the current unpaid caregivers to find paid services to look after their care recipient while they were participating.

Data Collection

The primary method for data collection was through three focus groups. Focus groups elicit a broad range of ideas, views, and opinions about a topic, and are commonly used to explore users opinions towards a health service or product, such as a health information website (Krueger & Casey, 2000). As stated by Carey & Asbury (2012), focus groups enable the researcher to collect rich, detailed data about a topic. The size of a focus group can range anywhere from four or fewer people, to more than twelve. The focus groups for this study had five people in two groups, and six people in one group. While focus groups can take a variety of forms, the structure that was utilized for this study included a semi-structured session in an informal setting that was moderated by a lead facilitator (MSc candidate) and co-facilitator (health experiences research team member). In preparation for the meetings, the author prepared a PowerPoint presentation with visuals and an interview guide with questions and prompts (see Appendix 4 for interview guide). As is stated in Carey & Asbury (2012), this form of focus group session is typical and has been described by others.

Thompson et al (2012) provides a discrete set of recommendations for assessing web-based support resources and developing online health information initiatives. This author has been involved in numerous e-health projects (Thompson et al., 2008; Thompson et al., 2009; Thompson et al., 2012), of which the most recent established that the design of online health related initiatives should be a collaborative effort between researchers and targeted end-users of the program. These recommendations were used as a guide for this thesis. Notably, a sufficient and realistic timeline was utilized that allowed for proper execution of the project including project planning, recruitment, data collection, analysis, interpretation, and application of the results. Measures were taken to ensure that the recruited participants would represent the target population of the website. Additionally, semi-structured scripts that contained open-ended, neutral, and non-leading questions were used for the focus groups. Probes and prompts were used when necessary. Furthermore, while official ‘member checks’ (i.e., returning to the original participants to ensure the correct interpretation of the data) were not conducted, a method of frequently confirming ideas, opinions, or suggestions with people was adopted throughout the focus groups (Thompson et al., 2012).

In the days prior to the focus group session, short information documents and consent forms were distributed to people via either regular mail or email. The consent forms were written in lay language and provided an explanation of the study, the rights of the study participants, what they could expect as participants in this study, as well as contact information for the study investigators and the St. Mary's ombudsperson. The participants were asked to carefully read over the consent form and bring a signed copy to the focus group session (see Appendix 2 for sample of consent form). On the day of the focus group, before beginning, the participants were also asked to complete a short pre-focus group document which included questions pertaining to basic demographics, Internet usage, caregiving experience, and other information (see Appendix 3 for sample of document).

Focus Groups

After the participants handed in their consent and information document, which included permission to record the session, the lead facilitator, in conjunction with a senior member of the health experiences research team, provided a brief introduction about the Health Experiences initiative, the purpose of the focus group for which they were gathered there for, as well as an introduction to the research team members. The author then led the group through the questions for the session. The first part of the session pertained to how they retrieve and use health information online. To guide this part of the focus group, the lead facilitator used an interview guide with 8 questions, although additional subjects were raised by the participants and researchers as part of the discussion. Pre-identified topics included: why caregivers search for health information online, what kind of health websites they currently visit, why they will choose certain health websites over others, what type of strategy they use to search for health information online, when and why will they stop looking up health information, the best and worst aspects of health information websites, how they deal with confusing or conflicting health information on the Internet, how they use health information found on the Internet, and other topics. This first part of the session took approximately 40 minutes.

The second phase of the focus group was related to the structure, design, and content of a personal health and illness experience website. As previously mentioned, this phase of the study used the www.healthexperience.ca web page as a platform to explore perspectives on the structure, design, and content of a health and illness experience website. During this phase, the participants each had their own computer and were asked to spend 10-15 minutes observing four different preliminary website designs (see Appendix 6 for sample of each design) that had been created by the website hosting and design company, KnowledgeOne. Four designs were recommended by KnowledgeOne as an optimal number to evaluate the research questions, and elicit effective participation. Too many designs can cause confusion and an inability for people to effectively expresses their thoughts and opinions, whereas too few designs can risk not stimulating conversation.

Following this observation period, people were asked to discuss their expectations and views towards different aspects of the structure and design of a personal experience website featuring caregivers' experiences. The lead facilitator then went through specific aspects of the website designs and asked people to make more direct comments (e.g., text font/colour/size, colour scheme, screen layout, etc.) about the web pages if they had not already done so. Participants were then asked to discuss what type of information (content) they would want to see on a personal health and illness experience website on caregiving. It is important to note that people were not asked to comment on the content of the in-depth caregiving interviews that will be presented on healthexperiences.ca.

Each focus group took approximately 1.5 - 2 hours to complete. Following the session, the lead facilitator took notes about main themes that emerged from the discussion. The focus groups were audio recorded and sent for transcription, which took approximately 2 weeks to complete and return to the lead facilitator.

Data Analysis

The transcriptions of the focus group meetings were reviewed by the author. Qualitative data analysis began within the focus group discussions as the lead facilitator processed the comments, clarified and followed up with statements made by people, and summarized main ideas and themes throughout the session (Carey & Asbury, 2012). As has been outlined by Krueger & Casey (2000), a standard format and general topic guide was used to assist with facilitating discussion and to provide consistency between groups.

Transcripts of the focus groups were analyzed using an inductive thematic analysis (Patton, 1990; Braun & Clarke, 2006). This approach refers to the process of reasoning which employs the use of codes to identify broad concepts or themes from specific units of written material (Braun & Clarke, 2006). Larger units of text were coded, rather than a "line-by-line" approach, as this is more appropriate for descriptive studies (Carey & Asbury, 2012). An inductive thematic analysis employs a process of coding the data that does not require the researcher to fit the data into a pre-existing framework or structure (Braun & Clark, 2006), but rather adopts a method of "staying close" to the data and identifying broad themes (Carey & Asbury, 2012). The analysis phase of this research followed Braun & Clarke's (2006) recommended checklist to ensure rigor when utilizing a thematic analysis in qualitative research.

Data collection and analysis were not carried out until saturation was achieved, as the objectives of this thesis study held a briefer descriptive and exploratory purpose. A similar style of data collection and analysis has been described by Casey & Asbury (2012), who stated that one can still maintain a methodologically sound purpose, process, and product of descriptive research without using a prolonged and intensive data-collection and analysis phase.

The data from the written transcripts was first reviewed (and preliminary codes identified) using a pen and paper, followed by a more thorough analysis using Microsoft Word. These two methods of coding helped organize and analyze emergent, or unexpected, themes as well as those that were anticipated, using the method of constant comparison (Pope et al., 2000). Preliminary data analysis was conducted solely by the MSc candidate; however, the research team was consulted at several time points for intermediary analyses and to discuss expected, unexpected, and emergent themes arising from the data.

Results:

The results of this thesis are divided into two major *parts* that address research questions one and two independently. A qualitative analysis of the transcripts and focus group notes identified three major themes in *Part 1*, and two major themes in *Part 2*. The first part revealed how participants retrieve and use online health information, including which factors influence how they find and select health information websites, how they use information they found on the web, as well as general concerns participants had with health information on the Internet that influences their choice and use of online health information. The second part revealed the participants' perspectives about the structure, design, and content of a personal health and illness website on caregiving. Specifically, people identified factors that were important for their first impressions of a personal health and illness experience website, as well as their perceived needs for information and expectations from such a website. For a full list of themes and sub-themes refer to Appendix 5. Note: words that have been underlined in this section have a definition or explanation of abbreviation in Appendix 9.

Participant Characteristics

Three focus groups were conducted over the months of November and December 2012 at St. Mary's Hospital in Montreal, Quebec. A total of 23 people were approached, of whom 16 participated in a focus group session. The main reasons for declining participation included lack of time or interest in the project.

Two focus groups had five people, and one group contained six. All members consented to participate and gave permission to record the discussion. Focus group discussions lasted between 90 to 120 minutes. Table 1 presents characteristics of the participants. The majority of people were female (69%). One quarter of participants were under the age of 30, and one quarter were 60 years of age and over. Half were married, and just over half (56%) were born in Quebec, while the remaining participants were either from another Canadian province (31%), or a country other than Canada (13%), although all were currently living in Montreal. The majority of participants spoke English as their mother language (69%), followed by French, and then other languages.

Participants represented a diverse array of caregiving experience, with people often having cared for more than one person, including parents, spouses, siblings, friends, or other people, as well as caring for people with varying health conditions (data not shown in table). Just under half (44%) had occupations in the health care field, 25% were students, 19% were in another field of work, and the remainder listed themselves as caregivers. The majority of participants (94%) reported using the Internet at least one hour per day. One participant did not own a computer or have Internet access at home and thus reported zero hours of Internet use per day. This participant had, however, used the Internet for health information in the past and continues to use the Internet through other avenues.

Table 1: Focus group participant characteristics.

Participant Characteristic	%	n
Sex		
Female	31	5
Age		
20-29	25	4
30-39	6	1
40-49	25	4
50-59	19	3
60+	25	4
Marital Status		
Single	31	5
Married	50	8
Divorced	6	1
Unknown	13	2
Place of Birth		
Quebec	56	9
Other Canadian Province	31	5
Outside of Canada	13	2
Mother Language		
English	69	11
French	19	3
Other	13	2
Occupation		
Student	25	4
Caregiver	13	2
Profession: Healthcare	44	7
Profession: Other	19	3
Hours of Internet Use Per Day		
0	6	1
1-2	19	3
2-5	50	8
6+	25	4

PART 1: RETRIEVAL AND USAGE OF ONLINE HEALTH INFORMATION

With respect to how caregivers retrieve and use health information from the Internet three broad themes were identified via a qualitative analysis of the transcripts and researcher's notes taken during the focus groups: (A) searching for and choosing health information websites; (B) empowerment through use of online health information; and (C) concerns about health information on the Internet.

Theme 1A: Searching for and choosing health information websites

This theme centers around how the participants search for and choose health information websites including factors incorporated into their immediate decision to click on a link, or explore a website in greater depth. Participants typically employ a consistent approach to find a website that they will trust and explore further. They begin their search for health information websites using a general information portal (i.e., the web search engine Google), where they will type in a question and then choose amongst different websites based on factors such as the placement of the website link on the search results page and the website URL and domain name itself, as well as the presence or absence of advertisements on the web page and other superficial aspects of the website. Following this, they compare or *triangulate* content between various sources, with most participants returning back to a known website that they recognize and have visited before. Participants also incorporate external influences, including personal backgrounds and preferences, as well as suggestions from family and friends, into their choice of which websites they will choose to trust and explore. The details related to the process of their search and retrieval of information are presented below.

1A-I: ***Web-search and link assessment using general information portal***

Participants start their search for health related information by "asking a question", or entering a "key word", into a search engine. Following this initial search, participant will begin their selection of health information websites by assessing the website link's URL that is visible on the search results page. Focus group members tended to use the term "Google" as synonymous with a *search engine*. This approach of "asking Google" was practiced by both common and infrequent computer and Internet users. Most participants reported that the initial Google search strategy works well and leads them in the right direction:

> "When I have been to websites, because I do not have a computer [my search] is very general, say if I'm looking up Alzheimer's and things…so I would look up, I just put down [in Google] 'multiple symptom ataxia', which is what we were told [my mother] has, and I got information I wanted."

After they perform a "key word" or "question" search, most participants scan the top links on the first page of the search results. Links to websites that are at the top of the first page on Google are preferentially chosen:

> "Sometimes like the first five usually I'll look."
> "I usually start at the top of the page…whatever Google says is best."

Participants also scan the domain name of the website URL on the Google search results page to decide if they will click it or not. If a website domain name seems unreliable or irrelevant to their search, they will not click on the link:

> "Yeah I look at the 'www.whatever' you know whatever that, whatever that site is."
> "…if it's Yahoo or something you think, well I don't want that I want something a little deeper that comes from a real source."
> "Yeah, or then if [the domain name] is a strange name and it seems a bit too personal or somebody's trying to be amusing, well if it's not an amusing subject then you're not gonna probably go there."

Participants also assess the top level domain in a link's URL as another factor governing whether they will choose a specific website or not:

> "Yeah and what's after the dot also. I trust more a .com or a .gov or a .something like that than a .anything else like CN for China."

Furthermore, while the majority of participants do not normally explore past the first few links on the Google search results page, they also never click on the 'sponsored' links at the top of the Google search results, as these advertised links were described as "sketchy".

1A-II: ***Assessing credibility and trustworthiness of a web page***

After they perform a search, scan top links on the Google search results page, and choose to click on a link, participants then look at various elements (e.g., symbols or other representations of authority, advertisements, etc.) of the actual web page to decide if it is credible and trustworthy. Participants assess "symbols" and "association" names, as well as features of the layout and design of a web page to determine quality and credibility of a website:

> "For me if something looks…like someone just made it on their own thing versus like a public website that I mean has like a symbol there; like the Ontario Medical Association and you know it's very like professional. It's well laid out so I would look at that one whereas you get a website and it's like a 5th grade science project, I'm probably not going to look at it."

Participants feel that health information presented through government-affiliated websites must be credible and trustworthy:

> "Most of the time I'm going to try to look for a government or government related website because obviously they provide healthcare here so they have those resources. Yeah they know what they're talking about."

Participants also discussed how advertisements factor into their judgments about the legitimacy or trustworthiness of a website. When discussing the use of advertisements on a health information website, participants said this "is a big no." People shared frustrations with advertisements on health websites. The presence of advertisements results in them being less trustworthy of the content:

> "I would say it's less trustworthy if you're like reading the information around the advertisement like the type goes here and the advertisement like goes through."

While for others, the presence of advertisements is reason enough for them to automatically leave or decide not to visit a health information website:

> "[Advertisements] turn me off… better get a sponsor or a grant [to pay for development of the website]."

While some people read information from pharmaceutical websites, most are not likely to choose health websites from this source. Reasons for avoiding these websites are largely related to the widespread presence of advertisements on these websites, which automatically makes them suspicious of the content:

> "For me the worst part of this I find is the problem with American sites that are advertisements of some pharma companies. So when I see you know an advertisement for that type of illness or disorder you know I'm a little suspicious you know."

1A-III: ***Developing a long-term relationship with a trusted site***

While people often explore a new site if it is presented as a top result on Google and seems trustworthy and relevant to their search, they also establish a method of continuously referring back to a recognized website that they have previously visited and trusted:

> "I'm kind of going to go to sites that seem reliable and Mayo Clinic that kind of rings a bell. I've definitely been on it a few times and I'll probably look at the first 1-2 websites that come up, but I always go back to Mayo Clinic. I trust it."

Participants explore new and unfamiliar websites to gather a general understanding of a topic, but rely on trusted and recognized sites when arriving at a final answer:

> “Well I generally take a couple minutes at work and try to get an answer that I’m looking for so that’s why I’ll go to the first few websites and then I always go back to Medscape yes. When I read what they have to say I pretty much then go okay sounds reasonable and I’ll stop.”

Participants compare content between known and trusted sources to determine if they have received trustworthy and credible answers from their search. They often consult several websites, with different types of information that is targeted at different audiences, in order to arrive at a final answer to their question:

> **“**Medscape. I use Medscape also both the one for lay people and the one for professionals.”

1A-IV: *External influences*

In addition to evaluating websites based upon the criteria described above, participants also incorporate other external factors that influence their choice of websites that they trust and explore further. Two of the most salient external influences that impact on the participants’ choices of website are: their personal backgrounds and experiences; and receiving suggestions from others.

When discussing the type of information they are initially most attracted to, people relate their preferences for certain styles and modes of health information delivery to their own personal situations or professions:

> “I mean I’m a scientist so I like facts.”
> “Well I’m a poet so I go for the personal.”

Participants also receive suggestions for trustworthy and helpful websites from family and friends:

> **“**Well I’ll discuss things with my daughter. She’s a doctor of optometry so if it has anything to do with eyes she’ll consult like we can go to her and she’ll tell us a website pertaining to optometry.”

However, while people receive suggestions for health websites from family and friends, the majority of participants have never consulted a doctor or other health professional for a health website suggestion, nor has a doctor recommended a website that they should use. Discussions on this topic were short, with most participants simply stating "No" to any questions regarding discussing Internet use with a health professional. As one person stated, the closest she has come to receiving a website suggestion from a doctor was through a website brochure she grabbed in the waiting room of her doctor's office:

> "Well I guess for me sometimes there are brochures in the waiting rooms so if you take you know a particular kind of notion according to the disorder you might have some Internet links."

People in the focus groups agreed that receiving websites suggestions from their doctors would be helpful to guide them towards trustworthy and relevant information, and they would appreciate these suggestions:

> **"**But you didn't find it, somebody suggested it to you and the power of suggestion is so important you know. I mean you buy a baby carriage or you buy something or a car, chances are somebody told you about how vastly, how great this thing was and that's, that's why you go for it."

One person highlighted that her oral surgeon had once referred her to his dental website for patient use, which she appreciated and found informative:

> "My oral surgeon has his own very detailed website… it's suggested [if a patient] needs a particular service or a procedure that they go to his website and all the information is there…there's a very detailed but patient written piece with graphics and with radiographs and all that and so and then he says come back with your questions. So it saves him time and the patients have a reference. He also has all the pre and post op instructions and so that if you get a sheet and you lose it you can always find it on the website and he finds it really works for him."

Theme 1B: Empowerment through use of online health information

In terms of how participants use health information from the Internet, empowerment emerged as a major construct. The concept of empowerment is recognized as a key process that can help people assert control over factors that influence their health and wellbeing (Gutschoven & van den Bulck, 2006). For the purposes of this thesis, empowerment is defined as a "social process of recognizing, promoting, and enhancing people's abilities to meet their own needs, solve their own problems, and mobilize necessary resources to take control of their own lives" (Anderson, 1996). Participants in the present study experience empowerment by enhancing interactions with doctors or other healthcare professionals, through managing their own health, their care recipient's health and their role as a caregiver, as well as by developing social connections and receiving support online.

1B-I: ***Interactions with healthcare providers***

Participants use information from the Internet to enhance their interactions or visits with health professionals in the context of their experiences as both a *patient* and as a *caregiver*. This information may be accessed before, after, or between doctor's visits, and may be used for a variety of purposes. Information from the Internet appears to be powerful in enabling people to feel they are asking better questions and improving communication with health professionals, thus offering people a sense of control over their healthcare. Health professionals reportedly have both positive and negative reactions to the participants' Internet use for health information.

Participants look up information prior to a doctor's visit so they can be better informed about a topic, target the discussion appropriately, or find the right question to ask:

> "…so that when I got [to the doctor's office] I could be more precise about what I wanted to ask. You know rather than sort of go in and expect her to give me all the answers I researched it before I went."

Many also look up information after a doctor's visit if they have forgotten to ask a question:

> "[If] I've forgotten to ask something I've gone to get a little more information about that."

While others look up information after a doctor's visit due to time constraints or a lack of opportunity to clarify or expand on information:

> "I go for a number of reasons. I look at things for diagnostic tests and actually and into the analysis of those results and getting an idea of what the range of you know what the range of prognosis of different outcomes is. To get a realistic picture because sometimes in the doctor's office there isn't a lot of time given and they're short on explaining. And I like to understand more than just the surface."

Participants also search for information between visits so they can return with a more complete understanding of the topic. They feel this information enables them to ask more relevant questions, and in some cases people noted that their doctor perceives them more positively when they are better informed:

> "I was told that I had a plantar fascitis…and then I Googled it, got more information so then when I went back for follow up I was able to speak to him at the same level and I was able then to cue in on pertinent questions. So when he gave me the time he says hey you know what it is so he looked at me differently because I knew what—I was at the same level as him."

Health information on the Internet is also used if people feel a health professional is not familiar enough with a topic, or is not able to adequately explain something:

> "…well when my father was sick I cared for him before my mother well he had Alzheimer's disease and we didn't know in the beginning and the social worker that took us on, the family social worker, when we first met her said 'well I don't know much about Alzheimer's disease this is the first time I've dealt with a family with this disease'. It's not very reassuring on your first meeting so having a professional speak you know they should know what they're talking about."

One person reported using the Internet to understand more about a therapy, as she was frustrated with her treatment. After presenting research from the Internet to her gynecologist, the doctor agreed to alter her treatment regime:

> "I had a situation when I was dealing with menopausal issues and was having a hard time adjusting my hormone replacement…I went and searched the literature and I found a website written by an opinion leader in Canada in this area… and within that I found some of her publications in which she did case studies and she had a different approach and I brought those papers to my gynecologist and she agreed to change my treatment because of the supportive evidence in those papers."

Participants reported variable experiences with doctor's reactions when they brought in information they had found on the Internet. Some doctors were perceived by some to receive the information positively, while others stated that their doctor has acted "threatened", "defensive" or "dismissive" towards the information brought into the appointment:

> "You got a very positive response and that's really good but depending on the physician or other health professionals that you are dealing with they may find that you bringing even pertinent and good information they may feel threatened by that and they may tell you 'I'm the boss' and which is not the current model of care but it does happen all the time."

1B-II: ***Support for the caregiver in providing care***

Information on the Internet is often used to help with a care recipient's illness and to find heath services, or other needs that arise from the caregiver situation. One person, for example, used the Internet as a source of assistance and supplemental advice when there was a difference in opinion among people involved in the care of a child:

> "We had a very interesting situation within my family where my step son was having some ADD/Autism issues and there was some difference of opinion among the parents and so I as a researcher went online and I really wanted to understand better a specific answer to a way you deal with treatment…I went online and papers and things that were coming up just didn't answer my question well enough and I found a website called 'Ask'…it was all medical okay and it was a website where you went on you could ask a question and for $35 they would put you in touch with an actual medical professional and they gave you their credentials and you could chat with them… I know it sounds a little far out but I was able to have a brief chat for about 10-15 minutes and I got the answers I was looking for."

Others turn to the Internet for practical advice related to their care recipient's health condition, care management, or care-related services:

> "I don't know what to do just like well this weekend I suspect my mother has a bladder infection. She's been with me 4 months. How do I get her tested, how do I get an antibiotic? I'm just trying to figure it out… And then how do I get to bath her you know these kind of ridiculous situations."

1B-III: ***Self-care management***

Throughout the focus groups, use of health information from the Internet was discussed in the context of helping a care recipient, as well as for the caregivers' own health. In terms of their own health, the participants use the Internet to contribute to self-care and personal health management. People, for example, use the Internet to "check on symptoms", or if they are "exposed to a toxic product". One person used the Internet to understand more about her arthritis:

> "I've been just browsing the web for arthritis because I'm starting to get arthritis in my fingers and I think my father had it, my mother didn't have it so I think it's something I inherited so I've been just going…you know it's more for me specifically personally because I'm starting to see the effect of this but it's nothing, it's more personal you know it's not for someone, it's not for a caregiver at you know as being a caregiver at this point."

Participants also use information from the Internet to help make personal decisions regarding healthcare, housing, or financial problems, or to help decide on the best "next step" with regards to a specific issue. Some people use the Internet as a means of entering the healthcare system or finding a family doctor:

> "I'm thinking eventually I should get a family doctor or something like that. So because I don't I have no idea how to do that…I would do 'how to get a family doctor in Quebec' or something like that."

The Internet is also used as a means to find affordable mental health services. One person talked about how their symptoms of depression become more common when their care recipient's health deteriorates. They recognize the need to find psychological help during these times, and use the Internet as an avenue to find affordable care and take the next step to enter the healthcare system:

> "…and also the same for the psychologist, how do I find a psychologist that doesn't cost too much… Because that's a lot of money and when you're caregiving and I'm a caregiver, I earn $12 an hour and I'm paid 5-6 hours/day."

1B-IV: ***Social connections and support***

The Internet is often used as an avenue to interact or connect with others, and learn from their personal situations or experiences. This is accomplished through visiting social media outlets such as blogs, chat rooms, forums, or other sources of user-generated content. Many participants appreciate this form of information and support as a supplement to other narrative, factual, or didactic styles of information. However, opinions regarding use of the Internet as a means to receive support, provide support to others, or develop social connections are varied. In terms of posting identifiable information to provide or receive support from others, some participants feel that health matters are private and they cannot imagine sharing information through public avenues:

> "If I was going through an experience I don't think I would probably post it on my Facebook."

Some feel that even reading experiences or stories from other caregivers (without posting their own experiences) might produce negative consequences and become problematic. They feel that posts by upset people could mislead or distress others who read them:

> “Right I would not go there. I agree it could open up new problems and you know what and when in caregiving from what I have seen you know inside our own association and so on there are a lot of angry people out there because they’re frustrated and that’s—it could be very problematic, yeah.”

However, many participants feel that chat rooms, blogs, and other media through which people can interact with others, are a useful way to receive or offer support:

> “A blog’s a great way where you can type in a question to someone already experiencing that and getting that heartfelt practical peer kind of thing…”

Facebook and Twitter are also thought of as a helpful means to communicate with others:

> “No it is good that it could bring you to another page or whatever for an association of some sort. You could find the people you want to communicate with there [on Facebook].”

User-generated content is often used to “know what to expect”, or to add “context” to other sources of online health information that may not be able to provide this:

> “I find it’s nice to read [blogs], it’s always nice to see some context but I don’t necessarily like rely on them.”

Some participants even consider turning online interactions into face-to-face relationships. They see the Internet as a powerful means to reach out, seek support, and “escape” from demands of caregiving through developing offline relationships:

> “So two people both taking care of whoever might just want to meet and go to a movie or just go and have a coffee somewhere and they might not even talk about what they’re going through. It’s just that if you know the person you’re with is having a hard time then you might just not even mention it you might giggle the whole time just to get it, you know get out and do something and yeah without even not being so you know constantly dealing with it. Because you need an escape so maybe to escape that way would be something people would do.”

Theme 1C: Concerns about health information on the Internet

In addition to the assessment of trustworthiness and credibility that participants mentioned in the immediate context of searching for and choosing health information on the Internet (see Theme 1A), participants also have many general, or *peripheral,* types of concerns with health websites, which ultimately indirectly influences their interactions (i.e., retrieval and use) with web-based health information. These concerns were not discussed in the context of directly selecting health websites (as per Theme 1A), but rather were general concerns the participants had with the Internet as a form of health information delivery. Notably, the concerns that participants have with health websites go beyond simply being uncertain of the quality of the information presented online, but they are also concerned with the notion of "information overload", as well as privacy and confidentiality issues inherent on the Internet. Participants also indicated awareness of the limits to health websites in terms of abilities to improve health and the healthcare system.

1C-I: ***Uncertainty about quality of information***

Participants take active measures to prevent themselves from being misled or misinformed about their health questions. They recognize that there is extensive information available on the Internet, and that not all of it can be trusted:

> "So I'm very careful…I know that when you go on the web the worst thing you can do is to just read everything that you see..."

Various interactive social media outlets (Facebook, Twitter, blogs, forums, chat rooms, etc.) were commonly mentioned as a source of questionable, untrustworthy, and "risky" content. While this material is often used and appreciated, participants are cautious about trusting this type of information:

> "Sometimes I might be inclined to, I might be induced by the idea of talking to somebody else and then yes I might actually get influenced and with misinformation."

Many participants enjoy reading material about people's personal experiences with health and illness that is presented through social media avenues, but they are often uncomfortable and wary of this source. Participants suggested that if there was a system in place where an official health personnel or trusted organization could "monitor" information presented through such avenues, or provide a "filter" for individuals who are allowed to post or write information on them, then people may be more inclined to trust information from this source:

> "I bet there are people out there who would love to be able to just read somebody's else's personal experience' and then you'd say 'wow I didn't know that that person was going through that, we're going

> through exactly the same thing', but because it's filtered through the hospital it's trustworthy."

Others suggested these issues could be overcome by filtering specific questions. The general "tips" and "advice" related questions could go to a "public forum", while other more "medical" related question could go to professionals:

> "If it's a medical question it goes to one of the medical experts who then vets it and then answers to everybody."

However, despite many participants expressing interest in a "monitored" or "filtered" blog or chat room, issues with placing control over and refining these sources of information were raised:

> "Just because someone had an experience with something that a doctor disagrees with, does not make the experience any less real for them, and it's all about sharing experiences."

1C-II: ***Information overload***

Many participants place limits on the amount of time they will spend looking up information. They talked about how easy it can be to get lost and overwhelmed in the extensive amount of health information sites available on the Internet:

> "Well I don't go too much because too much is too much…Only a minimum basis for me."

Some stop looking up information when confident they have found an answer:

> "Yeah I usually go like a specific question so if you like find the answer you stop."

Participants feel the Internet is best to be used as a "second opinion" or to understand a little more about a topic:

> "I don't think I've spent much time basically because for the same reason. You're living through the experience you just I don't know you just want to get a second opinion that you already know yourself, so it makes you feel like it's clear in your head and kind of feel less alone knowing that you know it's that's what it is and this is what you can expect and there are other people who know, who know so, but I don't think I really spend I have spent that long."

1C-III: ***Privacy and confidentiality***

Concerns with privacy and confidentiality were identified by some older participants as major issues with user-generated content, namely with the social media features Facebook and Twitter, where other people might be able to identify them. When they see either Facebook or Twitter symbols on a health website, their first thought is in regards to the privacy of the website:

> "Yeah to me that speaks 'is this private to me?'"

When some people see the Facebook and Twitter symbols on a health website, they are worried that other people might know what kind of information they are looking at:

> "I know when I see that on a website, I know it's everywhere but it makes me a little cautious because I don't want to click somewhere and then wonder 'do people know that I'm going to be on this website?'"

Some can see the value in sharing experiences through Twitter and Facebook, but do not do this themselves:

> "I know people who do and it's just not me I don't think I would do that. I mean a lot of people do and that's a great way of reaching out to get help and I mean that's what people I guess should be doing but I don't know if I would do that."

A few of the younger participants said they can imagine posting a health or illness related experience on their Facebook if they were "inspired"; however, most younger participants were simply indifferent to the presence of Facebook and Twitter functions:

> "If you want it it's there, if you don't want it it's okay."

1C-IV: ***Limitations to online health information***

Participants highlighted the limits to what the Internet can provide in terms of attempts to improve health or offer support. They communicated that the Internet cannot be a replacement for efforts to improve barriers or problems within the healthcare system, but rather it should be a means of supplementing assistance for such issues. One participant spoke about how the Internet may be useful for many things, but there will inevitably be "gaps" in our healthcare system that cannot be addressed through web-based resources:

> "There's something though a reality I think we have to face in that it was, it is great to put everything on a website that could help, all the resources we do have…but the big point is the system is insufficient and there are gonna be gaps and there are gaps. Gaps are getting bigger and under the current administration they're just cutting and cutting and cutting."

The Internet is also not thought of as a means to solve current healthcare and health system challenges. Participants stated that “we are working in less than optimal circumstances”, and it is “a reality that you have to face”. They believe that the Internet can be helpful to the healthcare system, but it will not solve problems on its own.

PART 2: PERSONAL HEALTH AND ILLNESS EXPERIENCE INFORMATION

With respect to participants’ perspectives about the structure, design, and content of an online personal health and illness experience (PHEx) website for caregivers, two broad themes were identified: (A) factors important for first impressions; and (B) perceived needs and expectations. This second part of this thesis utilized four mock web designs created for www.healthexperiences.ca (described in the methods) as a platform to explore caregivers’ perspectives towards the structure and design of a PHEx website.

Theme 2A: Factors important for first impressions

Participants highlighted a variety of factors that would influence their first impressions of a PHEx website. Participants often agreed on different elements of a PHEx website that would invariably attract or deter a person, however, there were many instances where participants did not reach a consensus regarding their favorite or *best* website feature. Different features of the layout and design, images, introduction material, and representations of the authority and credibility of the website are important for influencing their first impressions of a website. Participants expressed various needs and expectations for a PHEx website on caregiving that were supported by most, if not all, people in the focus groups. Furthermore, while all information was discussed in the context of a PHEx website on caregiving, people noted that many of these first impressions and expectations could also be relevant to other types of health information websites.

2A-I: *Appealing and user-friendly layout and design*

In regards to different elements of the general appearance of a PHEx website relevant to first impressions, there were some areas where participants’ views were similar, and other areas where views were in contrast to each other. All participants prefer a horizontal or landscape design for the home page. They feel it is "nice to not have to scroll down on a homepage", and appreciate the opportunity to see everything on the homepage at once:

> "I think it's better to be able to see the whole page so I think the longitudinal, the landscape I think the landscape is better."

Some people had difficulty describing exactly what they did or did not like about a design, but would use words such as, "professional", "warm", "helpful", or "personal" to describe positive feelings towards a website layout and appearance. Preferences for website colour were often varied. During a conversation about colour preferences, participants noted that it would be difficult to find a colour scheme that was everyone's favourite, and that it might be best to use colours that would be unlikely to *deter* a person, even if they were not particularly their *favourite*. One person, for example, felt that the first mock PHEx website (Appendix 6 - DESIGN #1) was a personal favourite, but they also expressed that the second mock web design (Appendix 6 - DESIGN #2) might be more pleasing to most visitors of the website:

> "Yeah a good balance and very welcoming… I liked the impact of the first one (Appendix 6 - DESIGN #1) more for myself as a first impression, but I think this (Appendix 6 - DESIGN #2) is more welcoming for all people you know. I had a feeling that this would be probably a good one."

The use of dark colours for a health website is disliked (Appendix 6 - DESIGN #4). Participants do not feel dark colours are appropriate for websites related to health and illness, and perceive it gives a negative feel to the website:

> "That's a tough one (Appendix 6 - DESIGN #4). Well I find that it's very dark and it's very it's very negative and dramatic."

When considering the idea of a playful web design, participants feel this style does not belong on a health information website. They stated that a PHEx website must "exude compassion" while being "serious" and "professional looking":

> "It's got to be, to be credible it has to be somewhat serious and it has to have, people are ill here, whether they're caregivers, whether they're people with various diseases it has to be helpful and exude compassion."

A dynamic and interactive feel to a PHEx web page is preferred by most participants. They propose this can be accomplished through the use of links that "lit up when you chose it", or a scrolling banner on the home page, which allows the reader to become quickly acquainted with what to expect on the website:

> "I think those are really nice especially if you like if you're just new to the website… I was thinking it could have like it would say caregiving module and then like after 1-2 seconds it would change and say like [other topic] and then it would go through…So then you would know kind of what you could look for on the website and it's just like sort of flash past you."

When discussing first impressions of the mock web designs, many participants would compare different aspects of the layout and appearance to other websites that they had visited before. If the site reminded them of a particular website they had seen before, they would automatically compare it to that site. Sometimes this was a positive association, but on other occasions it was a negative association. One person spoke about how one design (Appendix 6 - DESIGN #3) reminded her of a mortgage company website:

> "Yeah just something that looks contrived I find it (DESIGN #3) looks almost like a Canadian Mortgage and Housing ad or something you know 'let's buy a house'… No like nothing it's so old fashioned it's just awful to me."

2A-II: *Appropriate use of relevant images*

Images had power to attract or deter people upon first glance at the website; however, with regards to participants' preferences of the best, most appropriate, or relevant image, opinions differ in many areas. The use of the *right* or the *wrong* picture is powerful in terms of either automatically deterring people away from the site, or inviting them to explore further:

> "And I went when I looked at it (Appendix 6 - DESIGN #4) I saw that very unhappy girl and that and it just turned me off immediately."
>
> "Well I'm presented by the welcoming picture (Appendix 6 - DESIGN #2). To me that was it really drew my attention to this website. I found it warm and welcoming."

Pictures on a website must reflect the topic. Participants were frustrated with pictures that they felt do not reflect a caregiver's experiences. Participants spoke negatively about the use of an electrocardiogram symbol (Appendix 6 - DESIGN #1) on a PHEx website for caregivers, as they feel that while it is a *health related* symbol, it is irrelevant to the topic of *experiences* of caregiving:

> "And it's not really about that. Caregiving is not about EKG's… nor is experience [about EKG's]."

While some participants felt the collage of real caregivers (Appendix 6 - DESIGN #3) was "welcoming" and "humanized" the website with "real people" at different "stages of caregiving", other participants were critical towards the collage of pictures of real caregivers as they felt it does not accurately represent the caregiving situation:

> "…it bothers me that in those pictures (Appendix 6 - DESIGN #3) most people are smiling. Years ago when I was in the middle of caregiving I was not smiling."

However, this same participant was conflicted as they also felt it might not be best to have pictures of unhappy caregivers on the front page:

> "Well there's 1 or 2 who look like very upset and well that's not very inspiring either, so that's a dilemma, but you work on it but that just bugs me to see those happy, glowing cheeks and nice white teeth."

It was suggested that if the smiling caregivers were presented as interacting with their care recipient, like in the second mock website (Appendix 6 - DESIGN #2) rather than sitting alone and smiling, then the happy people may seem more natural and realistic:

> "Because the people are interacting. They're interacting, they belong together you know, where the other people are all just [smiling by themselves]…"

While participants were not able to make a consensus regarding the *perfect picture* to use, stating that, "There's no one picture that's gonna please everyone", they did stress the importance of using an appropriate, relevant picture that does not overwhelm people, and also signals to the visitor the point of the website:

> "Well I think, I think having one picture if it's a really good picture makes a lot more sense than having too many. This kind of looks like they couldn't figure out which one to use so they put them all in (Appendix 6 - DESIGN #3)."

Consistent with the participants desire to have an interactive and dynamic web design, they considered using photos that could change on the homepage:

> "The photo could always also change which would be nice….Because once you see it imagine the next time you go on and there's somebody else there that would be very nice I think you know."

Participants also like the use of a Canadian maple leaf on a PHEx website. They feel this can help highlight that a certain website is a Canadian initiative and people will find experiences of Canadian people. Knowing that a resource is Canadian is important for people as it can add context and inform people about the source of the information:

> "The other thing that I liked is the Canadian Maple Leaf in the background (Appendix 6 - DESIGN #1). So that I noticed right away so right away okay it's Canadian and it matches the health experience.ca"

Similar to how participants made associations or connections between the mock web design and previous websites that they had visited, people also made associations with pictures. One participant found that the picture of a younger woman on website DESIGN #4 gave an impression of mental illness:

> "Okay and having just that picture (Appendix 6 - DESIGN #4) it kind of emphasizes, okay, mental illness 20 years old."

Images, being easily processable, are important to people and affect initial assessments of a website, but participants highlighted that they cannot make up for poor content. Since, as was stated by one participant who spoke about visiting health websites, "you really want the information."

2A-III: *Clear and informative introduction material*

The importance of ensuring that the introduction material (text and/or video) on a website is clear and informative is important for a positive first impression of a website. While participants did not agree upon the *best* way to deliver introduction material, they did indicate several ways one could present a clear and informative introduction to a PHEx website. It must be clear as to how a person enters the website from the homepage. Participants dislike clicking on ambiguous or vague links that take them to unexpected pages of a website. They suggested it must be made clear what to expect and where to go for certain information:

> "You know people come into a website and they have certain expectations, certain information they need to know I can zero right in on it and I don't have to read everything."

They want to know within seconds whether this website is useful or relevant:

> "But I can make that decision like you say within a matter of seconds I know if I want to investigate further."

Participants often cited examples of other websites that they felt presented a clear introduction into the entry of website:

> "…I understand your comment about how like giving people like clear direction for where to go….like you know like the websites like CBC and if you're watching like the news clips online or TV shows or whatever like 'click here to watch' you know. You could have like the caregiving module and the picture and then the 'click here to go to caregiving'…it would be like 'click here to learn about this thing'…"

A clear direction on how to enter the website can also be accomplished through a informative menu bar:

> **"**I also liked this little menu (Appendix 6 - DESIGN #2) because it adds direction. It's a good little index for people to go right to what they need to know."

With respect to how the introduction material to the website should be presented (e.g., through video or text format), participants vary on their opinions. Some said they would be attracted to watching a video to initially understand the purpose or aims of the website. They feel that listening to someone else explain the website could be an easy way to discover its purpose:

> "I like the idea of the movie part because you could have like I just like the idea of something like that you know to click on and hear someone talk to you right away."

While others said they would be less inclined to watch an introductory video, as they feel it might be irrelevant to their reason for retrieving the website:

> "But I just think like if the first thing I see is like [the principal investigator's introductory video] message and while that's nice that's like not why I've come on the website…"

Participants concluded that it would be helpful to have an introductory video, but that it should not be mandatory to watch in order to understand the purpose of the website. Those that would be interested in a video introduction said it should be short, concise and delivered by "somebody on top who's actually in charge of it", or through another trustworthy and knowledgeable source:

> **"**And if it was someone important enough that you wanted to hear what they had to say maybe a spokesman for the hospital… just to say as a spokesman for the hospital this is what we're doing and then you go into the softer stuff after. That just attracts me because I'd like you know as long as it's not 52 minutes long or something…"

Participants feel that, ideally, an introduction video to a PHEx website on caregiving should be delivered by a healthcare authority figure who can also relate to the visitors of the website and has had experience caregiving:

> "Or even more, you have the clarity of a doctor speaking of the caregiving module, but this doctor has also experience of caregiving in her own family so you have the double, you know the authority of the knowledge and also the authority of the experience of firsthand."

Overall, participants feel that the opening page to a PHEx website should adequately describe the purpose of the site without overloading people with too much information. They referred to other websites that they had previously visited which gave them a negative first impression as a result of overwhelming information on the homepage:

> "And that's actually it's I think it's a criticism of a lot of websites that they try and pack in too much on every page and it's overload."

2A-IV: *Representations of authority and credibility*

Another important feature that would impact on the participants first impressions of a PHEx website is information related to the authority and credibility of the website source or creators of the website. One avenue where participants say they evaluate site credibility is by knowing who funded the website, stating that they "like to have a little bit of understanding where the money comes from". Additionally, participants want to know immediately about the institution(s) in charge of developing and maintaining the content:

> "The nice representation of the partners which is important but I think that's everywhere but it should be prominent. Yeah partners and links yes so it tells you who are the affiliates and their credible bodies."

Displaying a symbol from an institution that people recognize and trust elicits a positive first impression. The mock PHEx designs displayed *McGill University* and *St. Mary's Hospital (Montreal)* logos at varying degrees of prominence. The more prominent a logo was, the more often it was located and appreciated:

> "…I like the right part (Appendix 6 - DESIGN #4), the partners to see McGill, I like that."

Theme 2B: Perceived needs and expectations

With regards to what participants perceive they would need or expect from a PHEx website on caregiving, several sub-themes were identified. Participants want information they can relate to and that is relevant to their specific situation. They also want practical tips for providing care and taking care of themselves, successful methods of coping throughout the care trajectory, as well as stories and experiences that they can relate to on a personal level. Participants also want information presented on a PHEx website to be accessible to people with varying levels of health literacy, and they prefer to have experiential-based information combined with factual information. Most participants desire many, if not all, of the various themes elaborated upon in the text below.

2B-I: ***Relatable and relevant information***

The idea of offering a website that contains relevant stories or experiences that caregivers can relate to is especially important. As caregivers, participants stated they are often “alone”, “didn’t get the support [they] needed”, and thus want to hear that someone else has experienced what they have been through:

> “And I was going to say I wanted, at the time, I would have liked to have heard other people going through the same experience as me. Because I didn’t go to any kind of a support group, I was alone.”

Relatable stories that are presented on the Internet are appreciated as they are easily accessible, and can be “reassuring”, “personal”, and allow caregivers to feel less alone:

> “Caring for my mother and when say she’s asleep or whatever I felt alone. So I would have checked on [a PHEx] website and seen ‘oh I’m not alone there’s other people’ and it’s normal to feel that.”

Participants also stated that the caregivers’ experiences on a PHEx website should be relevant to the illness of the care recipient that they care for. They feel that caregivers of people with different illnesses can have diverse experiences within their role as a caregiver, and a PHEx website must consider and reflect this:

> “You don’t want to hear any story you want to hear something that’s like…specifically related to what you’re looking for or what you’re you know if you’re taking care of someone who has autism for example or whatever, cerebral palsy it’s not going to be the same as someone that has some other condition like Alzheimer’s.”

However, it was also pointed out that caregivers could likely learn from other people’s experiences caring for people with diverse and unfamiliar diseases. They stated that it might not be wise for caregivers to limit the type of experiences they seek, in terms of disease type of the care recipient, as these other people may be able to provide meaningfully, helpful, and relevant support to almost any caregiver. Participants also feel it is important to have experiences from

Canadians. People referred to the Healthtalkonline.org PHEx initiative developed out of the UK, and stated that it might not be as useful or relevant to Canadians:

> "And because it started in Great Britain I mean it's a different type of healthcare there. I mean and also people are much closer together right because it's such a small little place with tons of people; as opposed to Canada where everybody's spread out."

Participants also want links to helpful Canadian caregiving resources to accompany the personal experiences of caregiving on a PHEx website:

> "Vancouver resources, Winnipeg resources, Montreal resources, whatever."

2B-II: ***Practical tips and advice through experiential knowledge***

People want to hear practical tips and advice from others who have been through similar situations, as they feel this can help them solve various issues inherent in the caregiving situation. One person wished to have the opportunity to listen to other caregivers' experiences with communicating with health professionals:

> "How do you get community supports that you need in a timely fashion? How to talk to community workers to that they hear you as the care [giver] and not just as an emotional family member? Making sure that you're adequately heard as a member of the healthcare team if you believe in collaborative care."

Other people agree with wanting to hear people's practical tips, with one person suggesting they would like financially related information:

> "Housing issues are huge if you've got a you know people in your family that have major health issues and thinking about the future and that kind of thing. Tax tips for caregivers as there are huge financial issues. These are very practical things that [caregivers] need help with."

Participants also spoke about the value of watching other people speak about their experiences and offer advice if a caregiver has just begun in the caring role. Exposure to other people's experiences through videos is thought to be helpful for new caregivers who may not know what to expect or handle certain situations:

> "That's one perspective and another one is just as a caregiver maybe if you're new to this or whatever maybe somebody who has experience listening to their stories would help you. But I guess the video is just the closest thing you can get to actually speaking to a real person and feeling really what they mean by the things they say."

However, if the advice or support that is being offered on a PHEx website is delivered by someone that has had no real experience with caregiving, then this information source would not be appreciated. One person spoke about how a caregiver might be offended if they were to receive advice from a person that had never been a caregiver:

> "I think any family member would find that offensive you know because part of what they're feeling is you don't know as a provider what it feels like to be in my shoes."

Another prominent topic that arose in terms of practical advice that participants want from a PHEx website on caregiving, was in regards to "how to cope with things". Participants mentioned that when they are overburdened with responsibilities that arise from the caregiving situation, it is helpful to hear how others have coped:

> "Yeah coping strategies because it's a major, major issue and what the story what someone said around the table here [who's care recipient] got sick and didn't know how you know where to go and how to deal with it I would think a lot of people have that experience as a caregiver…. I know when it happened to me I had absolutely no idea who to call or where to go or how to organize myself, yeah."
>
> "And what better way is there to do that than to watch somebody's personal experience and have them explain to you what they've been through you know."

Participants also want to know how others cope with the "psychological effects of the caregiving burden", and feel that caregiver coping strategies would be best delivered by those who have had practical experience caregiving, as they can "touch each other", and offer a "connection" that others may not:

> "People that have actually been through it rather than just instructions on how you should handle things…"

2B-III: ***Combine factual and experiential-based information***

Participants want a PHEx website to include both factual and personal elements of the caregiving experience. While they understand the essence of a PHEx website is to showcase people's personal experiences with various health topics, they also wish to have factual information delivered through the same website. They feel that a website that can combine both styles of information would be most helpful:

> **“**I think it would be—personally I would like to see the range of information both factual, patient testimonials if they are of experiences—so the hard and soft parts…”

While participants appreciate information based on caregivers’ experiences, they first want a brief, factual overview of the issue. This provides them with some basic understanding and context about the topic, which they then like to explore deeper with PHEx information:

> “I like to see that before I can get if I’m looking at a [topic] and I want to get like it’s prevalence, it’s what you know different so I can put a context around it.”

The use of videos that contain people’s caregiving experiences, along with factual information, is thought to add emotion to the topic that is not there with just text:

> “It’s just if you’re reading something you’re reading it with your own emotion whereas if you’re watching a video you’re listening to what they have to say with their emotion.”

2B-IV: ***Acknowledge varying literacy levels***

Participants expressed the need for all information presented on a PHEx website to be accessible to people with varying levels of health literacy and reading comprehension. They acknowledged that you must make information available to people with different levels of reading comprehension and medical knowledge:

> “…for me it’s not as important but for others that it be in a simple language that people can understand.”

People stated that many health information websites that they currently visit are not accessible to much of the public, and they want to ensure that a PHEx website can be used and understood by lay audiences:

> “Because I find that one of the biggest problems in sites that are meant for the lay public is that it’s in language that people who do not have a medical background would have no idea what is going on or they would have a lot of questions…when you write something for the public they say you’re supposed to write it in a 5th grade language.”

It was suggested that all information on a PHEx health website should be read by “literacy experts”, or even a younger person themselves, in order to ensure that the information is delivered at an appropriate reading level. However, while a website should be accessible to people with varying levels of health literacy, participants stressed that the information should not be presented in a demeaning or condescending manner:

> "Yeah, yeah and you don't want that. That's a very generally important point. Yeah that you're not--the public is very intelligent and very capable of getting information in different ways and you should never talk down to the public and medical sites can."

2B-V: *Other suggested users of a PHEx website on caregiving*

Participants had many ideas on who *else* may be interested in using a PHEx website on caregiving. Generally speaking, most participants do not feel that older, more established health professionals would use such a website:

> "I'm not so sure how many professionals are actually gonna go to this site. Professionals #1 think they know it all; and so they're gonna go to the site that's gonna give them the medical information that they use. They're gonna go to places like Up-to-Date (*an evidence-based clinical decision support website*) to get information to respond to the phone call that says 'how do I manage pain under these circumstances?'"

Another participant has similar feelings towards health professionals accessing the site, but suggested a method to overcome this could be to offer the website to professionals as a continuing professional development course:

> "It's unlikely that in the limited amount of time that professionals have that they're gonna be going to this site because they've examined a patient with Alzheimer's. They're gonna take their office-based experience for the most part. It may be bad experience but that's what they're gonna use in the main to take away with them, unless maybe you get [a PHEx] site approved for Continuing Professional Development credits and encourage doctors to or nurses or social workers to scan these sites…"

Most participants feel that a PHEx website on caregiving could best be used as a component of medical or nursing education:

> "No teaching at the medical school or nursing school level… But by case management absolutely I mean at that level I think it's outstanding. The testimonials terrific I mean that's the way we're supposed to be teaching anyway. So for those teaching purposes it's great."

Discussion:

The Internet has revolutionized the way people access and share information. It has become an unparalleled source of knowledge and support that serves much of the planet (WHO, 2011). The Internet presents a new world of opportunities for access to health interventions and support for many populations (WHO, 2011), especially vulnerable, at risk, isolated, or over-burdened people such as caregivers (Goldberg et al., 2011; Perkins & LaMartin, 2012). However, as an area of scientific enquiry, studying how caregivers interact with, and their perspectives towards, online health information is still largely at its inception. The findings from this thesis contribute to our understanding of caregivers and web-based health information.

Caregivers represent a highly diverse population who require support and assistance with caring for themselves, as well as for their care recipient, and other needs that arise from the caregiving situation. Thus, while the aim of this study was to explore the perspectives of *caregivers* on web-based health information, many of the participants offered their opinions and perspectives in regards to their experiences as a *patient* and as a *caregiver.* When discussing use of the Internet, for example, participants considered their own health, their care recipient's health, as well as their role and responsibilities as a caregiver. This was an unexpected, but valued, contribution from caregivers that was explored throughout this project that is important to address. A person who is a *caregiver* has many roles and responsibilities and any web resource that aims to assist this population should consider these different and complimentary needs. This could be accomplished by offering multiple avenues of support and information on one website, or by simply including additional helpful resources or links that the caregiver can use beyond a particular website.

The method by which participants search for and choose health websites is largely similar to that described by others. As has been reported in other studies (Larner, 2003; van Uden-Kraan et al., 2010), participants do not typically receive suggestions for health websites from their doctors, yet would welcome this possibility. Though participants expressed concerns about the quality and reliability of health information on the Internet, this did not deter them from using this information for a variety of purposes. The avenues through which participants described using information gathered from the Internet were interpreted as forms of empowerment. This is in accordance with previous research (Arnold, 2003; van Uden-Kraan et al., 2008; van Uden-Kraan et al., 2008a; Oh & Lee, 2012), and thus might point to a key purpose of the Internet in relation to health.

Participants were enthusiastic about online health information presented through people's personal health and illness experiences, and offered constructive advice and perspectives towards the structure, design and content of such a website. Web-design, images, and introduction material were important determinants of first impressions and decisions about whether they would likely explore a site further, or leave the site. Additionally, participants identified various needs for information and expectations for a health and illness experiences website on caregiving, including relevant information in a Canadian context, and practical tips and advice for caregiving or other health issues.

This discussion is divided into two parts that explore the major themes within research questions one and two of this thesis. There will first be a discussion concerning caregivers' retrieval and use of online health information, followed by a discussion of caregivers' needs, expectations, and perspectives about an online personal health and illness experience website for caregivers. The results of this thesis will be discussed in the context of the existing literature, highlighting where these findings contribute to current knowledge, and where these results are in agreement or disagreement with previous work in this area. This section will conclude with an explanation of the importance of the findings from this thesis, as well as a discussion of the limitations to this study

RETRIEVAL AND USE OF ONLINE HEALTH INFORMATION

Searching for and choosing health information websites

Participants employ a consistent approach to search for and retrieve information that begins with entering a "key word" or "question" into Google. It is interesting to note people's apparent trust in Google to direct them to appropriate health information, a process that most certainly cannot *guarantee* people access to trustworthy and reliable information, and thus may simply reflect ease, habit, or convenience.

Participants begin their analysis of a health website before clicking on the link that will send them to the associated web page. This initial analysis is based upon a review of different aspects of the website links that are at the top of the Google search results page. If the name, suffix, or other information in a website's link appears irrelevant or untrustworthy, then they will not click on the link to see the associated web page. Using characteristics of a website's URL to form opinions about website quality has been reported by others, including Wogalter & Mayhorn (2008) who found that people perceived domain suffixes such as .gov and .edu to be more credible and trustworthy than .net or .com suffixes. However, while this form of quick appraisal may sometimes lead web-users to credible content, it also has the potential for abuse or to deceive the public. Wogalter & Mayhorn (2008) found that people had difficulty distinguishing trustworthy from non-trustworthy content when they tested websites with fictitious web names, organizations, or credentials.

Following an assessment of a website's URL, participants in the present study then click on a link and evaluate the legitimacy and credibility of the actual website they have chosen to view. To do this, they focus on superficial website elements such as *symbols* or *pictures*, the general *feel* of the layout and appearance, and whether the site is *government-affiliated* or not. Websites that have recognizable and trustworthy symbols and that *feel professional* are considered legitimate and are explored further. Additionally, websites that declare an affiliation with a governmental organization are often thought to be trustworthy. This is contrast to previous finding by Mackert and colleagues (2009) who found that there was an "almost-universal lack of trust in the government for health information" among individuals who took part in their study, which was notably based in the USA. In Mackert et al's (2009) study, one of the reasons people gave for avoiding government-affiliated websites was because they felt these sources tried to unnecessarily coerce them to see a doctor where they would have to purchase medications. Perhaps the provision of healthcare in Canada, through a universal publicly funded system, allows for different levels of trust in the government. In the UK, however, negative media publicity of the National Health Service (NHS) has caused concerns among the public about the government, and has negatively affected people's views towards information that is provided through government affiliated sources (Donnelly et al., 2008). While there are discrepancies in people's trust in government sources to provide credible information, people are more consistent with their confidence in university researchers to provide trusted information online (Mackert et al., 2009). This sentiment was shared by participants in the present study, where university logos, as well as recognized hospital logos, were reported as markers of trustworthy and credible material. It is unclear, however, whether participants valued these logos because they signified an affiliation with the organization, or because they suggested that the institution endorsed the website and its content.

Another key factor affecting credibility and trustworthiness from the participants' perspectives is the presence of advertisements. It appears that they have a strong aversion to the presence of advertisements on health websites. Participants will either become highly suspicious of the content, or may decide to reject the website altogether. Sillence et al (2007) found similar results with a group of women searching for online information related to hormone replacement therapy. They reported that busy "pop-up" advertisements were mistrusted and led to rapid rejection of a website. Other researchers that have investigated website credibility outside of health and medical information have also reported that advertisements will lower a website's credibility, and will deter people from visiting a site (Fogg et al., 2001). This aversion to advertisements may be reasonable, as advertisements often propose incorrect and unsafe information, or can promise unrealistic 'cures' for serious illness (Weitzman et al., 2011).

A similar approach to that described above regarding searching for and choosing online health information has been reported in other populations. Hansen et al (2003), for example, explored health information search strategies among adolescents and found that the teenagers would most often use search engines to ask a question, and 83% would click among the first nine links returned by the search engine. While this is similar to the findings in the present study, participants in the focus groups also considered the source of the information when scanning a website (e.g., through symbols, link URL's, organization names, etc.). Hansen et al (2003) noted that the adolescents in their study did not perform any systematic evaluation of the source of websites.

Irrespective of the above difference, much of the information regarding search strategies in this study is in accordance with previous research conducted in this area. According to Briggs et al (2002), web-users engage in a rapid, preliminary assessment of websites based upon various salient, easily processable elements. The authors propose a "staged model of trust" in which people initially screen large numbers of sites that have been retrieved via search engines, such as Google. Following this initial *heuristic* or *affect-based* assessment, Briggs et al (2002) suggest people enter a second, *analytic*, stage of information seeking. In this phase people will explore websites in greater depth, as they perform evaluative judgments of the content. Similar results were found among participants in the present study, where they reported not only comparing content from different websites, but also from different types of information (e.g., from websites targeted at both professional and lay audiences) sources. The notion of *triangulating sources* has also been described by others (Quintana et al., 2001). While this may sometimes lead the web-user to a better overall understanding of their health issue, if the sources that are compared are all of low-quality then a *triangulation* of web resources becomes futile (Robertson-Lang et al., 2011).

The stages of website acquisition ultimately lead the participants to develop a long-term relationship with a trusted site. While participants begin their search for health information using a search engine, they often return to a known or recognized website in order to arrive at a final answer to their health related question. This *long-term trusting relationship* with a website has also been described in Brigg's (2002) staged model of trust, although it is not entirely clear how this long-term trusting relationship might function with web-based *health* information sites in particular. Sillence et al (2007) investigated the notion of developing a long-term relationship with a health website, in the context of the

Brigg’s (2002) staged model of trust, and found that the evidence for this was generally unclear. Sillence et al (2007) stated, however, that this lack of clear evidence was attributed, in part, to study procedures. Although the present exploratory study is relatively small, it did appear that developing a long-term, trusting relationship with a health website was important to the study participants’ choice of which websites they visit, and ultimately revisit.

While the results of this study appear to support the *staged model of trust* that has also been found by others (Briggs et al., 2002; Sillence et al., 2007), it was also found that additional factors influence health website selection, which were not reported in the previously cited studies. It was identified that participants are not only influenced by the Google search results, visual features of the websites, and other elements of the website, but also by the participants’ own backgrounds and personal experiences. For example, when discussing the health websites they would decide to click and explore further, participants would often relate their choices (e.g., fact-based information versus personal experiences) to their interests, occupations, or other individual characteristics. While it might seem obvious that people’s selections are influenced by their experiences and backgrounds, it is nonetheless valuable information for health services researchers and web-providers. If a health information website or support service aims to be attractive to many web-users, then it may be important to provide information through multiple styles and formats of information delivery (e.g., facts, narratives, experiences, etc.). Another factor that influences the study participants’ selection of health websites is that of suggestions from family and friends. When participants are referred to a specific website through a known and trusted person, they trust the information presented on that website, and seek it out without performing the Google-initiated search strategy described previously. Notably, however, participants stated that they do not receive suggestions for reliable, trustworthy health information websites from their doctors or other health professionals. While Internet use for health information is widely popular among the public, people still trust their physicians as the most reliable source of health information (Worsley, 1989; Hesse et al., 2005). It is therefore surprising that people do not appear to discuss Internet use or receive website recommendations from their doctors. This is apparently not from a lack of interest in receiving this information, however, as a study conducted at a cognitive function clinic in the UK by Larner (2003), found that over 80% of patients and caregivers would visit websites that were recommended by their doctor. As in Larner's (2003) study, participants in the present study also stated that they would appreciate receiving website recommendations from their doctor, and would likely use such a website if suggested. It appears possible that *website suggestions from a health professional* could be a major influence in the selection of health websites among the public; however, a means to encourage this must be developed. The factors that impact on information dialogue between physician and patients or caregivers are complex. Most physicians express little difficulty addressing web-based information that is brought in by their patients, and they feel competent clarifying misguided or inaccurate information (van Uden-Kraan et al., 2010). An issue that remains, however, is the physician's challenge in suggesting up-to-date, trustworthy, and public-friendly Internet resources (van Uden-Kraan et al., 2010). Physicians express need for training in Internet use as it relates to patient health information, so that they are aware of which websites to recommend as trustworthy to their patients (van Uden-Kraan et al., 2010).

In light of the present findings related to how the study participants search for health information on the Internet, a modified conceptual framework of the *staged model of trust* proposed by Briggs et al (2002) is proposed. As previously described, this framework comprises two distinct cognitive processes to form an assessment of trust for a website: an initial heuristic-based judgment of a website, followed by a more thorough and analytical evaluation of the information content. This modified framework incorporates additional findings, realized in this thesis work, related to external influences that impact on the search and choice of online health information, as well as online information use for empowerment (which will be discussed in the following section) See Figure 1 for a modified and expanded figure of Brigg's et al (2002) *staged model of trust*.

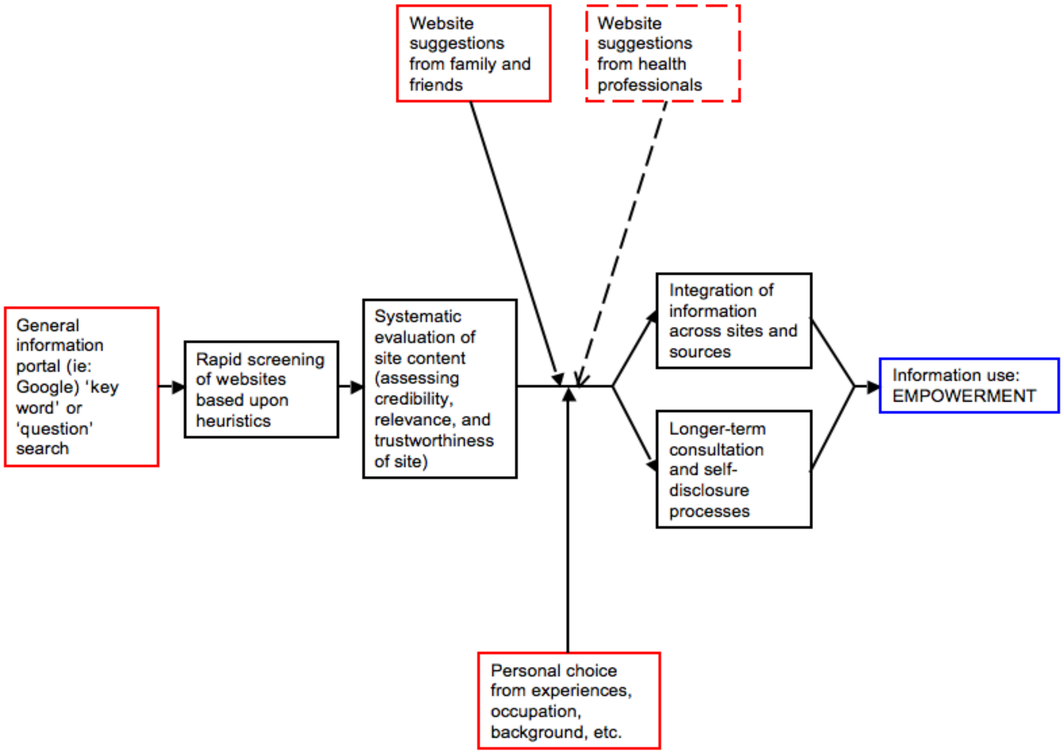

Figure 1: Modified and expanded figure of Briggs et al's (2002) *staged model of trust* (central figure taken from Sillence et al., 2004a). Boxes that are in blue and red have been added to the original figure by the author of the present study, while the black boxes are part of the original figure. People begin a search for online health information by typing key words or questions into a general information portal (i.e., "Google"). Following this, they perform a rapid screening of websites based upon various factors including the website's URL, features of the web page design, symbols and pictures, and their overall *feel* of the website. A systematic evaluation of the site content follows, which includes assessing credibility, relevance, and trustworthiness of the website from the presence or lack of advertisements, affiliation of website, source of web content, and other factors. In the present study it was also found that personal preferences, as well as website suggestions from family and friends, impact on the web-users choice of which websites they will trust and explore further. The dotted line connecting website suggestions from health professionals shows a potential avenue that could impact significantly on website selection. Integration of information across different websites and sources, as well as a long-term consultation process, which involves the web-user returning back to known and trusted websites, follows the initial screening and evaluation of websites. In the present study, it was found that this ultimately leads the participants to use the health information retrieved from the Internet for purposes related to empowerment.

Empowerment through use of online health information

Caregiver or patient empowerment is increasingly being recognized as a key process that can help people make decisions and assert control over factors that influence their health and wellbeing (Gutschoven & van den Bulck, 2006; Barak et al., 2008; Oh & Lee, 2012). While there is no definitive consensus upon the precise definition or measurement of empowerment (Barak et al., 2008; Oh & Lee, 2012), this multidimensional concept can generally be thought of as a "social process of recognizing, promoting, and enhancing people's abilities to meet their own needs, solve their own problems, and mobilize necessary resources to take control of their own lives" (Anderson, 1996). Due to its subjective or 'perceived' character, empowerment among people characterizes an experiential mental state and is often referred to in the literature as a "sense of empowerment" (Barak et al., 2008).

Seeking health information on the Internet, as well as participating in online communities, can facilitate individual empowerment (Arnold, 2003; van Uden-Kraan et al., 2008; van Uden-Kraan et al., 2008a; Oh & Lee, 2012). The Internet can serve as a supportive and learning 'environment' that allows people to discover and receive support (Barak et al., 2008; Oh & Lee, 2012), as well as offers an avenue for knowledge exchange and informational, emotional, and social support, offering people a sense of control and empowerment. In the present study, it was found that participants experienced *empowerment* from online health information use with regards to self-care and care recipient health management, to enhance communication and interactions with health professionals, and through developing social connections and support.

Study participants often search for and use information from the Internet when they are confused or unsure of the "next step" to take in regards to their own health management or that of their care recipient, and use the Internet as a tool for healthcare decision-making. An enhanced capacity to *make the right decision* is a principal feature of empowerment (Sharf, 1997). Participants also take direct control over their own health or that of their care recipient's health using information on the Internet. Participants, for example, use information from the

Internet to “diagnose” a health condition or understand symptoms that they or their care recipient has experienced. It is important to note that while Internet use for self-care and care recipient health management was discussed in the context of *empowering* the caregivers who participated in this research, this study did not assess the actual impact or outcomes arising from online health information usage. It is possible that despite the fact that the participants reported benefits such as improved understanding that led them to make the right decision for their situation, they were in fact being misled by incorrect information, thus a feeling of empowerment does not necessarily mean that the best possible decisions are being taken. Thus, it is important to be cautious about interpretation of results in this form of research as it relies on participants’ accounts of their experiences and use of health information, rather than a researcher directly observing an outcome.

Participants also use online health information to enhance interactions of the doctor-patient or doctor-caregiver relationship. The participants empower themselves by acquiring information prior to a doctor’s visit, between doctor’s visits, or after a doctor’s visit. People perceive that they improve communication with health professionals, as their web-based health information puts them “on the same level” as their doctor or other health professional. Online information use allows them to be better informed and prepared for the doctor’s visit. They also have the opportunity to answer forgotten questions, or further explore unclear topics, using the Internet. The participant, for example, who had her hormone replacement therapy regime altered through relaying web-based information to her doctor, gained direct power and control over her healthcare and treatment. Various studies have reported people becoming empowered by their information seeking initiatives, as they feel more confident and better able to communicate with their physicians (Arnold, 2003; Schillinger et al., 2004; Dutta-Bergman, 2005). Donnelly et al (2009) also investigated the public’s use of health information on the Internet and found that online health information resulted in a decline in expert (health professional) authority and increase power of the people, which had effects on the doctor-patient relationship and subsequent health management. They reported that knowledge gained through the Internet offers people new power within the formerly didactic and one-sidedness of the doctor-patient dyad (Donnelly et al., 2009). The findings in the present study corroborate this and other research by the Health Information National Trends Survey, which reported a "tectonic shift" in public health and medical information consumption, as more people turn to the Internet before physician visits (Hesse et al., 2005).

Within the context of empowerment related to the doctor-patient/caregiver relationship, study participants also spoke about varied reactions from health professionals towards them bringing in information retrieved from the Internet. Some participants reported positive responses, whereas many said their doctors had been *dismissive*, *defensive*, or *threatened* because they had brought in information or wanted to discuss information that had been found on the Internet. When it comes to confirming web-based health information with their doctors, many people are hesitant to do so (van Uden-Kraan et al., 2010). Many people report being afraid that their doctor may perceive this as a challenge to their expertise and authority (van Uden-Kraan et al., 2010). These findings highlight a potential barrier to patient empowerment through online health information use. The National Health Service (NHS) has developed an 'Expert Patients' program that advocates for patients' active involvement in their health through education initiatives meant to help them fully understand their health condition, including implications of the disease and options for treatment (Department of Health, 2004a). Despite their objective to create empowered 'expert patients', there is apparently resistance from health professionals to work with the patients to enhance patient involvement (Cooper et al., 1003). In the construct of the 'empowered patient', people are encouraged to become informed, advocate for themselves or their care recipients, and participate as equals in medical decision-making (Salmon & Hall, 2004); however, dismissive or defensive attitudes among health professionals may hinder this process. Without an open dialogue between doctors and patients or caregivers, people may meet resistance in attempts to empower themselves with online health information.

In addition to empowerment with self-care, care recipient health management, and doctor-caregiver interactions, developing social connections and support was also another avenue of empowerment that was identified in this study. Since the rise of social media websites and online discussion groups, many have investigated the potential for such features to empower people who take part in these socially active groups (Eysenbach, 2003; Hoch & Ferguson, 2005; van Uden-Kraan et al., 2008). Exchanging knowledge and experiences, receiving and offering support and reassurance, and finding recognition are all empowering processes that have been shown to take place within online support or discussion groups (van Uden-Kraan et al., 2008). Similar to research in other populations, another primary use of the Internet reported in the present study is to share in other people's personal experiences. Participants feel that factual information can provide them with a basic understanding of an issue, while personal stories or experiences presented through social media outlets, such as blogs or chat rooms, can provide added contextual meaning through understanding how others have experienced a particular health condition or other issue. Participants feel that these social media elements can add context to a health-related problem, and also can be used as a means to develop social connections and seek support online. These findings converge with past research that suggests people will use experiential information to add context around causes and consequences of illness, or to help people understand what to expect with a health related issue such as pregnancy (Lowe et al., 2009) or other health conditions (Rothman & Kiviniemi, 1999). Reading or hearing about how others experience a particular issue can alter one's orientation to their own illness (Zufferey & Schulz 2009). In the present study, participants discussed using social media outlets to contextualize and add meaning to their own health issues, in addition to issues surrounding their care recipient and their experience as a caregiver. Participants also used this form of information to develop social connections and seek peer-to-peer support from other online users. Facing a health issue or being a family caregiver can often instigate feelings of isolation and loneliness (Goldberg et al., 2011). Online peer-to-peer support groups can help people feel connected by offering support and receiving support from others (Gillett, 2003; Adair et al., 2006). While a few participants in this study said they would not use information from blogs, chat rooms, or other sources of user-generated content, most participants perceive these as helpful and supportive tools. A recent study that explored the Internet as a tool for social support for older caregivers of adults with intellectual disabilities found this to be an important source of support for caregivers (Perkins & LaMartin, 2012). They noted that social engagement often decreases with age, and the Internet represents an easily accessible and helpful way to keep people connected (Perkins & LaMartin, 2012). The authors suggested that web-based initiatives meant for caregiver support should incorporate both social support outlets and educational content in order to be most effective (Perkins & LaMartin, 2012). The suggestion to include socially interactive support features in an online health initiative has also been reported by others (Morrison et al., 2012). With the current evidence surrounding the effectiveness of online peer-to-peer support groups for caregivers, as well people's general inclination to seek out these online features, it may be prudent for social support mechanisms to be incorporated into web-based health initiatives. Issues remain, however, with regards to people's trust in information presented through blogs, chat rooms, and similar sources, as well as their uncertain feelings towards privacy and confidentiality in these settings. This, as well as additional concerns with online health information, will be discussed in the following section.

Concerns about health information on the Internet

Study participants have many concerns with health information on the Internet. Apprehensions towards not knowing what information is accurate, for example, mirrored those reported in other populations (Worsley, 1989; Hesse et al., 2005), as people are not passive recipients of health information on the Internet, but will often assess sources and triangulate content given uncertainty about which websites or information to trust (Quintana et al., 2001). Participants in the present study also said they limit the amount of health information they read on the Internet as a means to avoid *information overload*. The notion of *information overload* has been described by others, and can cause confusion, anxiety, false reassurance, and inappropriately transform decision-making processes (Sillence et al., 2007; Ziebland & Wyke, 2012). Study participants reported taking measures to protect themselves from the effects of *information overload*, by setting limits on the number of websites they retrieve, or the amount of time they spend looking up health information.

Despite being a commonly utilized and appreciated source of health information, blogs, chat rooms, and other social media sites, were often mentioned by participants in this study to contain questionable, untrustworthy, and "risky" content. This caution is reasonable given the current literature regarding the variability of information presented through such sources (Weitzman et al., 2011). While many are still interested in using sources of user-generated content for health related purposes, participation rates in online chat and discussion groups has dropped from 28% in the year 2000, to 17% in 2005 (Fallows, 2005). This reduction was largely from women, and was due to concern with "worrisome behavior" in chat rooms (Fallows, 2005). Other studies have found that web-users are unsure about the quality of information on online support groups (van Uden-Kraan, 2008). Despite people expressing concern over the possibility of receiving bad advice from these sources of information, they are still enthusiastic about visiting these sites, sharing experiences with other people, and encountering emotional support (van Uden-Kraan, 2008). A similar tension between wanting to seek out online peer-to-peer resources, and being wary of the content, was found with people in the present study. Findings from this study, and others, indicate that it is likely that a web-resource that provides people with personal experiences of health and illness, in a trust-worthy and evidence-based setting, would be highly popular among caregivers.

Study participants proposed various solutions to overcome the trust issues inherent in online discussion groups. One idea, for example, to include "monitoring" or "prescreening" functions was popular among many group members. They suggested that certain questions could be vetted, with tips and advice related questions sent to a public forum, whereas health professionals could answer medical questions. This idea to monitor blog entries has been suggested by other web-users (Thompson et al., 2012), where individuals who took part in a focus group for the development of a nutritional website felt that a blog would be an important component of the site, but only if it were "prescreened". Caregivers in the present study, however, highlighted the potential danger of controlling information on online discussion groups. It was stated that despite the fact that people may post unscientific or unconventional information, these are still their legitimate *experiences* of health and illness. It is possible that deleting or limiting certain posts could be construed as censoring or discrediting people's health experiences.

In terms of the social networking websites Facebook and Twitter, most participants are indifferent to the presence of these functions on health information websites; however, some have considerable concern about whether or not they are safe, secure, and anonymous while browsing a site that offers these functions. Most participants realize that utilizing Facebook and Twitter functions on a website are optional, and these functions do not impact on their interaction or experience with a website; however, some are still wary of accidentally pressing a button that might tell others they are looking up sensitive information. This issue appeared to arise from a generation gap, as the older participants were more cautious and had an aversion to the presence of these functions, while the younger participants were mostly indifferent. It is interesting to note, however, this *indifference* among younger participants towards using Facebook and Twitter for health related purposes, given that younger people are currently apt to be sharing much personal information on the web. This is possibly a result of the sensitivity of many health related topics, which young adults might not be so willing to share. For example, previous research shows that the level of sensitivity of a particular piece of information is inversely related to a person's inclination to share that material with others (Whiddet et al., 2006). Former studies have also shown that credibility issues, in addition to the privacy and confidentially issues that were recently discussed, are more of a concern to older adults than younger adults (Kaiser Family Foundation, 2001). In a study by the Kaiser Family Foundation (2001), just over one quarter of seniors reported that they trust health information on the Internet "a lot" or "some", compared to over half of younger adults. In terms of a website for caregivers, who can be anyone, young or old, it is likely that a generation gap could be significant in terms of what they deem is trustworthy on a website. It is possible that one website on caregiving, even if it relays information about multiple experiences, stages, and ages of caregivers, may not be attractive and trusted by both younger and older caregivers.

Another topic that was explored with regards to concerns with online health information was that of issues surrounding the limitations of what health websites can provide. All participants had used and appreciated health information on the Internet, but they made note of the fact that a website is not a simple fix for the many current healthcare challenges. This acknowledgement of the limits to online health information is reflected in the body of research that shows either little, no, or a detrimental effect to online health initiatives (e.g., Verheijden et al., 2004; Kosma et al., 2005).

PERSONAL HEALTH AND ILLNESS EXPERIENCE INFORMATION

While the first part of this study focused on retrieval and use of health information by caregivers in a general context, the second part of this study shifted towards their perspectives about online health information in the form of personal health and illness experiences. They highlighted several factors of the structure, design, and more superficial aspects of the content (e.g., introduction text and videos), that would be important in determining their overall first impressions of a PHEx website on caregiving. Participants also elaborated on their needs and expectations of the information and content presented on a caregiving website based upon people’s personal experiences with health and illness. While all discussions were considered in relation to a PHEx caregiving website, it was noted that much of this information could be relevant to other health information websites for caregivers.

Factors important for first impressions

Participants highlighted multiple factors that would be important for their first impression of a personal health and illness experience website for caregivers. These factors fit into various domains including layout and appearance, images, introduction material (e.g., text and videos), and representations of authority and credibility. Participants discussed how these different features would influence their initial perceptions or feelings towards a PHEx website. The notion of the "power of first impressions" has been described by others and is thought to be paramount to "human-machine" interactions (Crutzen et al., 2012). People form judgments about websites based upon a first impression that can be established in under a second (Lindgaard et al., 2006). This first impression is also known to have a lasting effect, as people are more likely to revisit a website if their initial first impression was positive (Xiang & Fesenmaier, 2006). A recent publication by Crutzen and colleagues (2012) stated that it is necessary for health services web-developers to better understand factors that influence people's first impressions of a website. Therefore, understanding caregivers' first impressions of a PHEx website on caregiving will be vital in order to develop PHEx-based Internet health initiatives that will be attractive and utilized by this population.

The factors that were identified to influence the participants' first impressions of a PHEx website constitute much of the "user's experience". According to Crutzen et al (2009), a "user's experiences" refers to the total time span a person will visit a web-delivered intervention, and it encompasses how that person will interact with the website, their opinion of it, as well as their feelings during and after visiting the website. A user's experience with a website will influence whether or not they revisit a website, as well as how long they spend on a site (Crutzen et al., 2009). Garret (2002) distinguishes a conceptual framework for web design that offers five levels or "planes" that conceptualize a user's experience with a website. These planes range from varying degrees of "concrete" to "abstract", and include the *surface*, *skeleton*, *structure*, *scope*, and *strategy* of the website (see Appendix 7 for depiction of these five planes). The factors found to be relevant to the participants' first impressions in the present study can be understood in terms of the *surface*, *skeleton*, and *structure* of the website, while the needs and expectations for the content is relevant to the *scope* and *strategy*.

On the *surface,* the user perceives the visual design and presentation of a web page (Garret, 2002). Elements of the *surface* are the most external plane and include features such as text, colours, illustrations, photos, or other images, of which these may or may not form some sort of a function or link that will take you elsewhere within the website (Garret, 2002). *Surface* features were highly important determinants of whether the study participants would trust the website, decide whether it was relevant to them, or encourage them to explore the site further. In terms of *surface* elements of a PHEx caregiving website, participants expressed that the website should use colours with a "good balance" that should not be "too dark". While they had difficulty agreeing on the "perfect" picture to use, they expressed that it should accurately reflect the topic. *Surface* material was important to the participants in terms of forming a judgment about the credibility and trustworthiness of the website. Using well-placed and visible hospital or university names or logos on the website could alert people to credibility features within seconds of being on the homepage. The use of the Canadian maple leaf prominently displayed on the website to showcase the site's origin was supported by all participants in the focus groups, regardless of which province they were from, or whether they were internationally born or not. Various studies have reported that symbols such as 'Health Check' or 'Smart Pick' on food packaging, are not only valued by the public, but can also guide people to healthy food choices (Carlson, 2010; Emrich et al., 2012). While displaying symbols such as the Canadian maple leaf or a university logo could help some health services researchers attract users to their websites, as a cautionary measure, it is possible that these symbols could also be abused by untrustworthy sources, thus securing a false sense of trust in people who visit illegitimate health websites.

In terms of introductory material (e.g., text or video) on the *surface*, participants said it was important to know within seconds if the website would be relevant to them. Introductory material was thought best to be delivered through both text and video formats; however, participants also stated that it is important to be able to understand the purpose of the website through either the text *or* the video, and that people should not be required to read and watch both. Additional factors of a web-design, or *surface* elements, that have been reported by others as important for first impressions, but were not reported in the present study, include the presence of spelling errors or "dead-links" on the website (Wathen & Burkell, 2002). These also affect people's judgments of website credibility and will deter people from visiting a site (Wathen & Burkell, 2002).

Another finding that arose in regards to the *surface* of a PHEx website was in regards to the participants associating different features of the images, layout, or design to other organizations, subjects, or even websites they had visited before. One participant disliked one of the mock website designs (see Appendix 6 – Design #3), because the images, colours and other aspects of the design reminded them of a Canadian mortgage and housing website. Other comments similar to this were made at numerous times throughout the three focus groups. In some cases, the use of the 'wrong' image even confused people about the purpose of the website. One person, for example, felt that the young female wearing black clothing signified a website about mental illness. These findings indicate that when developing a new web-initiative it is valuable to recognize how elements of the design and images may instigate familiarity with other companies, organizations, products, or subjects. As was seen in the present study, people developed feelings and opinions about a website based upon past experiences with related images, colours, and other features of the layout and design. Health service providers should be aware of the possibility for this to occur and ensure they evaluate the effect that the chosen images or design has on end-users. While it is possible that some health service providers could use this to their advantage (e.g., exploiting people's trust in governmental websites by using a web design similar to that of Health Canada's website), the public should also be wary of illegitimate health websites using familiar design to improve trust and credibility.

The *skeleton* lays 'beneath' the *surface* and refers to the optimal design and arrangement of elements such as buttons, tabs, photos, text, illustrations, or other visual material, across the web page (Garret, 2002). A well-designed *skeleton* allows for maximum effect and efficiency on a website (Garret, 2002). Participants expressed that the *skeleton* of a website should not be too busy. They could all agree that the photos, text, and other navigational elements should remain simple and not become too busy or overwhelming on the website, as a complicated and busy interface does not offer a positive first impression. This has also been reported by others who have investigated web design in the context of Internet health initiatives (Crutzen et al., 2012).

The *structure* of a website is more of an abstract concept than the *skeleton*, and defines how a website intervention will ultimately function (Garret, 2002). As per a description that Garret (2002) provides, "the skeleton might define the placement of the interface elements on our checkout page; [while] the structure would define how users got to that page and where they could go when they were finished there." The *structure* should be flexible enough to accommodate changes or additions to the website (Crutzen et al., 2009). The notion of *structure,* according to Garret (2002), is largely concerned with how users will move through a website's content efficiently and effectively. In terms of the *structure* of a PHEx caregiving website, it was evident that many of the participants wanted a clear entry into the website, and did not want to have to click on many different links, through trial and error, to arrive at a specific web page they were interested in. They stated that it should always be clear where each link would lead you (e.g., with "click here to learn more about XXX" labeled links). Through the focus groups it was clear that participants often become frustrated on websites that they cannot efficiently navigate in a logical and predictable manner. If links send them to unknown sections of the website, or they are unsure how to reach a specific section of the website, this is likely to negatively influence their first impression and deter them from visiting the site. Through the focus group discussion, it became apparent that acknowledging *structure* is highly important to participants in terms of ease of use and effortless exploration of a website.

In the present study, the *scope* and *strategy* planes were elaborated upon under the theme: "Perceived Needs and Expectations", that will be discussed in the following section.

Perceived needs and expectations

The *structure* gives a shape to the *scope*, which constitutes what the features and functions of the *structure* ultimately are. For example, an airline website may allow users to save personal information so that they can use it the following time they book a flight. The *scope* of a site would determine whether or not a website actually includes this functional feature. Furthermore, the *scope* of a website will determine the general content requirements (e.g., personally useful, tailored, relevant) of a website, however not the overall objectives of the site, which are determined by the *strategy*. In the context of the *scope* of a PHEx website for caregivers, participants mentioned various functional specifications such as communicative features or online support groups through blogs, chat rooms, or other discussion groups. End-users requests and preferences to include such features on a health website have been reported by others (van Uden-Kraan et al., 2008; Thompson et al., 2012). As was discussed earlier, one of the avenues through which the participants in the present study experienced empowerment was in regards to developing social connections and support on the Internet. While the participants expressed concerns about the privacy and validity of information presented through this source, they also feel that engaging with others in an online format is a powerful means to offer or receive support, learn form other people's experiences, and receive advice.

An additional feature concerning the content requirements of the *scope* of a PHEx website was in regards to the participants' desire to have health information presented through both factual and experiential forms. Participants felt they could develop a more complete and holistic understanding of a topic if they had multiple types of information to reference. This is aligned with previous research with other populations, which has shown that when making health decisions, people will draw on numerous sources of information, which include their own and other's experiences, as well as more "traditional" fact-based information (France et al., 2011). A study conducted with sixty-two people with various health issues showed that people avoid making important health decision based solely upon other people's personal experiences (Entwistle et al., 2011). The results of Entwistle et al's (2011) study support that which was found in the present study, which suggest that people are both attracted to people's experiences, but wary of making decisions based solely on this source.

Additional information related to the *scope* of a PHEx website on caregiving was elaborated upon by the participants including wanting all information presented on a PHEx website to be accessible to people with varying levels of health literacy. They expressed that they find that many medical websites are inaccessible to lay audiences, and this is a major limitation and obstacle of online health information. It is interesting to note that despite these concerns over health literacy, participants in this study expressed that they *themselves* are not concerned about not being able to understand health information online, but that they are worried about *other* people being vulnerable or misled as a result of lower health literacy. This has been observed by others (Entwistle et al., 2011), who have found that people rarely present themselves as inexperienced, naïve, or unskilled to evaluate health information, but will often express concerns about *other* people. It is unclear if this was found in the present study due to a possibly intelligent and informed group of individuals, or if it is arising from a belief that one is more medically literate and knowledgeable than others. Regardless, offering online information that is readable and understandable by the most possible number of people is a helpful way to avoid marginalizing certain web-users. Mackert et al (2009) suggested a website should provide several "layers of content" to meet the needs of both lower and higher literate populations. They suggested this could be accomplished with the use of audio or video elements to provide more basic content, while a more complete and in-depth description of a topic could be added through additional text (Mackert et al., 2009). Participants in the present study also stated that while a health website should provide information that is understandable by low-health-literate populations, it should also not "talk down" to people. Perhaps providing information through multiple "layers", as suggested by Mackert et al (2009), could help circumvent such issues.

Finally, the *strategy* incorporates the Internet-intervention developer's objective for the site, as well what the end-users of the web-initiative want from the site. A developer's objectives, for example, for a health web-initiative could be to 'increase vegetable and fruit consumption', while an end-users needs may involve 'losing weight'. Both would fundamentally determine the overall *strategy* of a website. A researcher's objectives for a PHEx website may differ depending on the individuals performing the research and the overall project goals, however, objectives for a PHEx on caregiving from the perspective of a caregiver end-user, were explored in this study. The participant's needs and expectations for the *strategy* of a PHEx website on caregiving was elaborated upon through the sub-themes, 'relatable and relevant information', 'practical tips and advice through experiential knowledge', and 'suggested users of a PHEx website on caregiving'.

Relatable and relevant information was a major construct that emerged from the data. Participants felt this could be accomplished on a PHEx website for caregiving by reading, watching or listening to other people speak about an issue. It was also felt that relatable and relevant information meant providing the information in a *Canadian* format, where the experiences were not only delivered by Canadians, but that the source of the website was also Canadian. It appeared that this need for *relatable* and *relevant* information came largely out of the participants' desire to feel less lonely or isolated in their situation, to have reassurance that their feelings or experiences are normal, and to understand that there are other people like them. This desire to hear other's experiences in order to moderate their sense of isolation or loneliness has been reported by many others, and is one of the primary reasons people seek out experiential type information (Ziebland & Wyke, 2012). Caregivers in particular may have a strong inclination to seek out emotional support through other people's stories, as the caregiving situation often fosters feelings of isolation and loneliness that are difficult to overcome (Goldberg et al., 2011). This can result from people feeling trapped in their caregiver role, developing conflicting feelings towards their care recipient, or being over-burdened with responsibilities that prevent them from living a normal social life (Goldberg et al., 2011). Caregiving can challenge one's personal identity, and it is suggested that simply knowing that other people are in a similar situation can reduce feelings of isolation, and give people a sense of belonging (Harvey et al., 2007; Ziebland & Wyke, 2012).

Using experiential information for practical tips and advice on how to manage problems or issues encountered through the caregiving situation would also be highly valued by participants. The opportunity to explore what has worked for other people and to see how others have solved various problems was deemed necessary to include in a PHEx website on caregiving. Research with other populations of web-users has found that practical tips and advice through experiences were also valued because they are presented in a pragmatic way that is easily understood (Ziebland & Wyke, 2012). In a qualitative study about how the Internet affects patient's experience of cancer, experiential knowledge was central to how people received practical advice with issues related to their cancer (Ziebland et al., 2004). Even nurses and other health professionals were often not able to provide the practical advice that other people on the Internet could offer (Ziebland et al., 2004). Another study with caregivers of children with a genetic condition reported that the caregivers' most trusted and valued source of information came from other parents in online social media sites, rather than their doctors (Schaffer et al., 2008). The parents attributed this greater trust in online communities to the fact that the other parents had a highly emotional and personal stake in the topic, which doctors may not have (Schaffer et al., 2008).

See Figure 2 for a modified framework of Garret's (2002) 'web-user's experience' in regards to caregivers' perspectives, needs, and expectations for a PHEx website on caregiving.

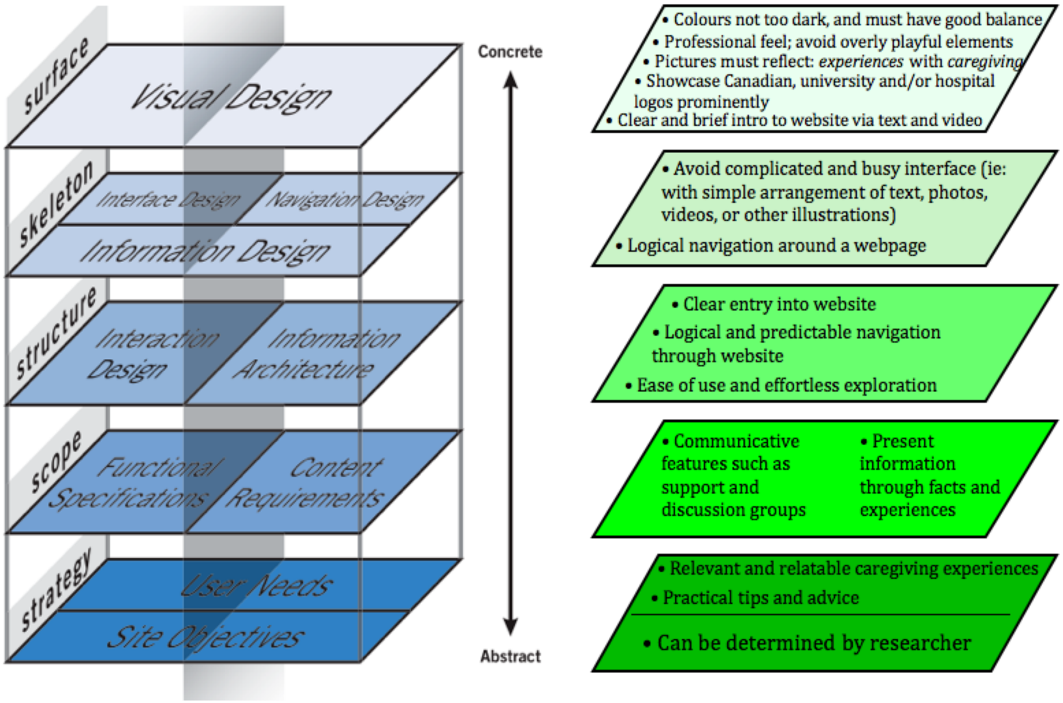

Figure 2: A modified framework of Garret's (2002) 'web-user's experience' in regards to caregivers' perspectives, needs, and expectations for a PHEx website on caregiving. The blue figure on the left depicts the original user's experience design by Garret (2002), while the green figure on the right has been added by author to highlight participants' feedback concerning perspectives, needs, and expectations of a PHEx website. This information is shown in the construct of Garret's (2002) five planes of a user's experience: strategy, scope, structure, skeleton, and surface.

While receiving caregiving information through other people's personal experiences can offer support and assistance, this type of information also presents some risks. This was not explored in much detail throughout the focus groups in this study; however, various risks, including obtaining too much unfiltered information (e.g., through support group and peer-based mechanisms) have been noted by others (Hartmann et al., 2012). A recent systematic review by Hartmann (2012) and colleagues found that while caregiver support interventions could improve issues such as coping abilities, knowledge, and depression, they could also have a negative effect on levels of anxiety and could even reduce caregiver quality of life. It is possible that increased feelings of anxiety or lower quality of life may result from new, early stage caregivers receiving irrelevant, demoralizing, or intimidating information from more experienced caregivers, who may be likely vent considerable negative feelings and experiences that may overwhelm or discourage the new caregiver. If personal experiences of caregiving are presented through the Internet, there is no filter on what early stage caregivers may access. It is possible that having access to numerous, unfiltered experiences could be cause for anxiety and harm to some caregivers.

Participants also suggested other users that could benefit from a PHEx website on caregiving. It was clear that many participants felt that more established physicians would be unlikely to use the site. It was thought that these physicians may not have the time, or might "think they already knew best" from their own experiences practicing medicine. In regards to the lack of time, this may be a reasonable judgment given that a physician's ability to seek out all information that is pertinent and valuable to their practice and patient care is becoming increasingly difficult, as a result of the vastly growing rate of the medical knowledge base (Abernethy et al., 2010; McGowan et al., 2012). Additionally, according to the current theoretical framework, *the Technology Acceptance Model*, by Yousafzai et al (2010), the acceptance of a technology is determined by its perceived usefulness and perceived ease of use. Evidence for this theory has been established in a study of physicians' acceptance of medical information delivered through online social media sites (McGowan et al., 2012). If one or both of these factors (i.e., perceived usefulness and ease of use) are not met with regards to a physician's attitude towards a PHEx caregiving website, then it is likely that it will not be used by this population. In order to ensure that physicians will utilize such a website, it must be explicitly clear to them how this website will positively impact their practice or patient care, and must also be targeted and simple to use. While participants had reservations about the use of a PHEx website among established professionals (unless used for continuing medical education credits), people saw a pragmatic and valuable use for this type of website to educate medical or nursing students about experiences of caregivers. Studies conducted on other websites that showcase personal health and illness experiences, have also shown that the public feels this form of information delivery would be beneficial for educational purposes (Newman et al., 2009).

Limitations and Future Directions

The main limitations in this research are primarily related to the study sample and methodology. First, the findings of this study are limited by the fact that the participants in the focus groups were not representative of the Canadian population of caregivers. As is apparent in the table of "Participant Characteristics", for example, there is an over-predominance of healthcare workers in our sample. This is likely a result of the close contacts within the research team that were used for participant recruitment. It is possible that a large group of healthcare workers could introduce bias into the results of the study as they may be more comfortable and familiar with computers and health information on the Internet, and may also have different needs and expectations for a web-based caregiving resource. This limitation, however, was abated by the fact that the focus group discussions were not dominated by the healthcare workers, but rather each person spoke freely and equitably.

Secondly, while the focus groups included a convenience sample of participants that had a diverse array of caregiving experience, they did not encompass all caregiving characteristics and situations, such as disease types of the care recipients, relationship of care recipient to caregiver, length of time spent in caregiving role, and age of the caregiver. It is likely that specific types of caregivers may interact with health information on the Internet differently than the participants in this study, and may have different needs, expectations, and preferences for personal health and illness information online. In particular, due to ethical constraints, this study only included people aged 18 and over, and thus only offers results from *adults* who had experience caregiving. In reality, caregivers can be younger than 18 and this population will likely have different information needs, as well as search for and use information in a different manner. Further research on younger caregivers, as well as specific groups of caregivers (e.g., individuals caring for people with dementia, schizophrenia, multiple sclerosis, Parkinson's disease, or other disease types of the care recipient) and web-based health information is warranted.

An additional limitation is that participants in this study were largely from urban environments. As was suggested in the literature review, Internet based interventions may be particularly helpful to rural and isolated populations (Lorig et al., 2010; Thinnes & Padilla, 2011). It is possible that people from these areas may have different needs and perspectives towards health information on the Internet, and web-based interventions that are developed for urban populations may not be as beneficial for rural populations. It may be helpful to conduct similar focus groups with rural and isolated Canadian populations to note any pertinent differences; however, that was not possible within the scope of this study. Furthermore, the focus groups included a limited number of male participants (5 out of 16 total participants), and thus the results may be limited by a largely female perspective. While the proportion of male caregivers is growing, females continue to make up the majority of family caregivers (Health Canada, 2002) and therefore the present study may be thought to simply reflect the actual Canadian caregiving population.

Previous findings have shown that health interventions are most beneficial when specifically targeted at a group of individuals (Franck & Noble, 2007; Chiu et al., 2009; Williams & Bakitas, 2012; Van Mierlo et al., 2012). It is likely that additional research in the area could delineate differences between specific populations of caregivers; however, the aims of this study were exploratory and offer a glimpse into Internet use by the caregiving population as a whole. Furthermore, many of the findings in this study support previous research with various diverse populations (e.g., adolescents, healthy adults, patients with cancer, etc.), and thus point to some universal principles of online information retrieval and use, as well as general perspectives towards web-based PHEx information.

Additional limitations to this study include the ability to generalize the findings to other caregivers across Canada. A larger quantitative or mixed-method study that examines how people interact with health information on the Internet, including perspectives towards personal health and illness information, may be an appropriate method to validate and generalize the results of this exploratory qualitative study. Additionally, most research, including this thesis, which has explored caregivers and web-based health information has been short term or cross-sectional; however, it has been well established that caring for someone is not a static process, but involves changes in activities, feelings, and other processes, over time (Pearlin, 1992; Lagner, 1995; Robles-Silva, 2008). These changes can impact on a caregiver's wellbeing, burden, and support network, and would no doubt have an effect on the information and support needs of the caregiver. A longitudinal study that addresses how caregivers needs change over time, and how this might impact on online health information seeking, utilization, and perspectives, would be valuable future research. These findings could assist researchers and other healthcare providers to develop web-resources that assist caregivers throughout their care trajectory, and not simply at a single stage.

A final potential limitation is that data collection, coding, and analysis were conducted by a single individual (MSc candidate). Though this can offer the author a greater familiarization and comprehension of the data, the resultant codes, analysis and overall descriptions depend largely on the perspectives, biases, and sensitivities of a sole individual (Sandelowski, 2000). To reduce the significance of this limitation, the results and analysis were continuously reviewed and checked with two senior members of the research team.

Conclusion

The research conducted for this thesis contributes knowledge of how caregivers search for and use health information from the Internet, as well as offers a greater understanding of caregivers' perspectives on the structure, design, and content of a PHEx website for caregivers. In regards to the first part of this study, it was found that the caregiving participants had similar methods of searching for and choosing online health information to other populations previously studied. This involved two distinct processes, which included an initial heuristic-based judgment of a website that was followed by a thorough analytical evaluation that eventually led the participants to develop a long-term relationship with a trusted site. Additionally, external influences such as personal preferences, occupations, or backgrounds, as well as suggestions from family and friends, (yet not from health professionals) were found to impact on website choices in this study. Information from health websites was largely used for empowerment, as has been reported previously, which may point to a primary purpose of web-based health information use. In regards to empowerment related to the use of online health information to enhance the doctor's visit, it was reported that some health professionals do not react positively to the participants bringing in health information. Furthermore, it was identified that the majority of participants had not received suggestions for credible, useful, and trustworthy websites from their doctor. These issues with the public's use of online health information and physicians' attitudes and behaviors could present an obstacle for caregivers' access to reliable sources of online health information, and the opportunity to improve health or become empowered in this way. Physicians now have less control over health information that is accessed and used by their patients. Not surprisingly, this shift in the availability of information has elicited both positive and negative views from physicians regarding use of the Internet as a tool to improve health (Kim & Kim, 2009; van Uden-Kraan et al., 2010). However, regardless of a physician's perspective on this matter, it is evident that the public will continue to use the Internet for health information and health advice, and opinions show that doctors must be prepared to handle this appropriately (Tonsaker et al., 2013). Effective use of online health information can enhance the patient-physician health partnership (Murray et al., 2003), and doctors could play a significant role in directing people to appropriate web-resources and helping manage people's use of online health information. The present results indicate that caregivers are open to receiving website suggestions from their doctors, which may be an important catalyst to direct this population towards trustworthy and reliable online health information. In order to foster effective use of online health information, the doctor and caregiver or patient must develop an open dialogue about health information websites. In addition, health professionals should perhaps be trained with regards to which websites to suggest, as this absence of dialogue could simply reflect a lack of awareness amongst professionals regarding trustworthy and appropriate websites for public use.

Caregivers' perspectives, needs, and expectations of a PHEx website on caregiving were aligned with other populations' needs for similar forms of online health information. A recent realist review conducted by Ziebland and Wyke (2012) reported that the role of online information based on personal health and illness experiences is a new field that lacks a thorough understanding and theoretical and methodological basis. They urged that a general understanding of this field needs strengthening, especially given the virtual explosion of websites that offer this form of information (Ziebland & Wyke, 2012). The results of this thesis contribute to the PHEx literature, and offer a greater understanding for caregivers' perspectives towards the structure and design of a PHEx website, as well as perceived needs and expectations for the content of PHEx websites. Professional layout and appearance, balanced light colors, relevant yet subtle use of images, as well as clear, concise, and directive introduction material were all highly important for first impressions of a PHEx website. In terms of what information participants wanted from a PHEx website, they mentioned relatable information in a Canadian context, as well as practical tips for solving real-life problems. Furthermore, they wanted fact-based information, in lay language, combined with the personal experience-based information on the same website. As was previously stated, a person who is a *caregiver* has many roles and responsibilities, and any web resource that aims to assist this population should consider these different needs. This could be accomplished through offering multiple avenues of support and information on one website (e.g., facts, personal experiences, discussion groups, etc.), or by simply including links to additional resources or other sites that could provide this material.

Enhancing the evidence-base for effective web design and web content is crucial to increase acceptability and use of health intervention websites; however, while this study explored caregivers' *perceived needs* and *expectations* from a PHEx website on caregiving, it did not assess the *impact* of using such information. A current UK National Health Service funded study at the University of Oxford will evaluate the impact of people's use of online PHEx information on their health and healthcare (see www.ipexonline.org). Reading and hearing other people’s accounts of health and illness experiences will be an increasingly prominent feature of e-health (Ziebland & Wyke, 2012). Findings from the present study verify this, as participants expressed considerable interest in seeking health information through blogs, chat rooms, and other personal experiential-based information; however, they were also wary and cautious about trusting information through these user-generated sources. While the findings of this study may result in improvements in the targeted development of PHEx websites, evaluating the impact of PHEx websites could represent a logical next step in order to understand the value of this type of information source.

Despite it being true that the Internet can misinform and mislead people (Walji et al., 2004; Betsch et al., 2010), and controversies still exist in regards to its value as a health information source, evidence suggests that relevant, valid, evidence-based information can be helpful for the public (Murray et al., 2003; Kim & Kim, 2009). Health websites will continue to grow as a primary source of health information for the public, irrespective of results from web-evaluation research or health professionals’ views on the matter. The Internet can revolutionize the way health information is provided to caregivers, but that potential cannot be realized without understanding their needs, expectations, and preferences for this form of information delivery. Improving insight into how caregivers search for and use online health information will help lay the necessary foundation for developing and optimizing web-based resources for caregivers, as well as to help understand how online health information use may impact this population. Understanding caregivers’ perspectives towards online PHEx information will assist health services providers to develop useful, relevant and attractive evidence-based PHEx caregiving web-resources.

Please refer to Appendix 10 for a description of the knowledge translation activities that took place following the completion of this project, as well as how this research contributes to the science of family medicine.

References:

Aalbers, T., Baars, M., Rikkert, M. (2011). Characteristics of effective Internet-mediated interventions to change lifestyle in people aged 50 and older: a systematic review. *Ageing Research Reviews.* 10(4):487-97.

Abernethy, A., Etheredge, L., Ganz, P., Wallace, P., German, R., Neti, C., Bach, P., Murphy, S. (2010). Rapid-learning system for cancer care. *Journal of Clinical Oncology.* 28(27):4268-74.

Adair, C., Marcoux, G., Williams, A., Reimer, M. (2006). The Internet as a source of data to support the development of a quality-of-life measure for eating disorders. *Qualitative Health Research.* 16(4):538-46.

Alzheimer Society of Canada. (2010). *Rising Tide: The Impact of Dementia on Canada.* Retrieved online from: http://www.alzheimer.ca/~/media/Files/national/Advocacy/ASC_Rising%20 Tide-Executive%20Summary_Eng.ashx

Anderson, J. (1996). Section H Empowering Patients: Issues and Strategies. *Social Science Medicine.* 43(5):697-705

Anderson, C. (2010). Presenting and evaluating qualitative research. *American Journal of Pharmaceutical Education.* 74(8):141.

Arno, P., Levine, C., Memmott, M. (1999). The economic value of informal caregiving. *Health Affairs (Project Hope).* 18(2):182-8.

Arnold, L. (2003). Delivering empowerment: Women's narratives about the role of pregnant bulletin boards. *Qualitative Research Reports in Communication.* 4:45-52.

Atkinson, N., Saperstein, S., Pleis, J. (2009). Using the internet for health-related activities: findings from a national probability sample. *Journal of Medical Internet Research.* 11(1):e4.

Ballantine, P., Stephenson, R. (2011). Help me, I'm fat! Social support in online weight loss networks. *Journal of Consumer Behaviour*. 10(6):332-337.

Barak, A., Boniel-Nissim, M., Suler, J. (2008). Fostering empowerment in online support groups. *Computer in Human Behavior*. 24:1867-1883.

Berland, G., Elliott, M., Morales, L., Algazy, J., Kravitz, R., Broder, M., Kanouse, D., Muñoz, J., Puyol, J., Lara, M., Watkins, K., Yang, H., McGlynn, E. (2001). Health information on the Internet: accessbility, quality, and readability in English and Spanish. *Journal of the American Medical Association.* 285(20):2612-21.

Betsch, C., Renkewitz, F., Betsch, T., Ulshöfer, C. (2010). The influence of vaccine-critical websites on perceiving vaccination risks. *Journal of Health Psychology.* 15(3):446-55.

Bleakley, A., Merzel, C., van Devanter, N., Messeri, P. (2004). Computer Access and Internet Use among Urban Youth. *American Journal of Public Health.* 94(5):744-6.

Braun, V., Clarke, B. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology.* 3:77-101.

Briggs, P., Burford, B., De Angeli, A., Lynch, P. (2002). Trust in Online Advice. *Social Science Computer Review*. 20: 321-32.

Canadian Caregiver Coalition. (2008). *Caregiver Facts.* Retrieved online from: http://www.ccc-ccan.ca/media.php?mid=146.

Carey, M., Asbury, J. (2012). Focus Group Research. Walnut Creek, CA. Left Coast Press, Inc.

Carlson, L. (2010). Front-of-the-pack and on-shelf labeling: tools for spotting nutritious choices at the supermarket shelf. *Nutrition Today.* 45(1):15-21.

Case, D. 2002. *Looking for Information: A Survey of Research on Information Seeking, Needs and Behaviour.* London: Academic Press.

Chaudhry, B., Wang, J., Wu, S., Maglione, M., Mojica, W., Roth, E., Morton, S., Shekelle, P. (2006). Systematic review: Impact of health information technology on quality, efficiency, and costs of medical care. *Annals of Internal Medicine*. 144(10):742-52.

Chiu, T., Marziali, E., Colantonio, A., Carswell, A., Gruneir, M., Tang, M., Eysenbach, G. (2009). Internet-based caregiver support for Chinese Canadians taking care of a family member with Alzheimer disease and related dementia. *Canadian Journal on Aging.* 28(4):323-36.

CIHI (Canadian Institute for Health Information). (2010). *Analysis in Brief, August 2010 Systems Performance: Supporting Informal Caregivers – The Heart of Home Care*. Retrieved online from: https://secure.cihi.ca/free_products/Caregiver_Distress_AIB_2010_EN.pdf

CIHI (Canadian Institute for Health Information). (2011). *Health Care in Canada, 2011: A Focus on Seniors and Aging*. Retrieved online from: https://secure.cihi.ca/free_products/HCIC_2011_seniors_report_en.pdf

Cohen, C., Colantonio, A., Vernich, L. (2002). Positive aspects of caregiving: rounding out the caregiver experiences. *International Journal of Geriatric Psychiatry.* 17(2):184-8.

Cooper, H., Booth, K., Gill, G. (2003). Patients' perspectives on diabetes health care education. *Health Education Research.* 18:191-206.

Coyne, I.T. (1997). Sampling in qualitative research. Purposeful and theoretical sampling; merging or clear boundaries? *Journal of Advanced Nursing*. 26(3): p. 623-30.

Crutzen, R., de Nooijer, J., Brouwer, W., Oenema, A., Brug, J., de Vries, N. (2009). A conceptual framework for understanding and improving adolescents' exposure to Internet-delivered intervention. 24(3):277-84.

Crutzen, R., de Kruif, L., de Vries, N. (2012). You never get a second chance to make a first impression: The effect of visual complexity on intention to use websites. *Interaction Studies*. 13(3):469-477.

Cutler, D., Lleras-Muney, A. (2006). *Education and health: evaluating theories and evidence.* Cambridge, MA, NBER (Working Paper No. 12352). Retrieved online from: http://www.nber.org/papers/w12352

Department of Health. (2004). Better information, better choices, better health. *London, Stationary Office*.

Department of Health. (2004a). White Paper. In: *The NHS Improvement Plan: Putting people at the heart of public services.* London: DoH.

DIPEx. (2012). Annual Review: The DIPEx Charity 2012.

Dollinger, S., Chwalisz, K. (2011). Reaching Rural Caregivers With a Multicomponent Telehealth Intervention: The Telehelp Line for Caregivers. *Professional Psychology-Research and Practice.* 42(6): 528-534.

Donnelly, L., Shaw, R., van den Akker, O. (2008). eHealth as a challenge to 'expert' power: a focus group study of internet use for health information and management. *Journal of the Royal Society of Medicine.* 101(10):501-6.

Dröes, R., Meiland, F., Schmitz, M., van Tilburg, W. (2004). Effect of combined support for people with dementia and carers versus regular day care on behaviour and mood of persons with dementia: results from a multi-center implementation study. *International Journal of Geriatric Psychiatry.* 19:673-684.

Dutta, Bergman, M. (2005). The relation between health-orientation, provider-patient communication, and satisfaction: An individual difference approach. *Health Communication.* 18(3):291-303.

Emrich, T., Mendoza, J., L'Abbé, M. (2012). Effectiveness of front-of-pack nutrition symbols: a pilot study with consumers. *Canadian Journal of Dietetic Practice and Research.* 73(4):200-3.

Entwistle, V., France, E., Wyke, s., Jepson, R., Hunt, K., Ziebland, S., Thompson, A. (2011). How information about Other People's Personal Experiences Can Help with Healthcare Decision Making: A Qualitative Study. *Patient Education and Counseling.* 85(3):291-8.

Eysenbach, G., Powell, J., Kuss, O., Sa, E. (2002). Empirical studies assessing the quality of health information for consumers on the World Wide Web, a systematic review. *Journal of the American Medical Association.* 287:2691-2700.

Eysenbach, G. (2003). The impact of the Internet on cancer outcomes. *CA: a cancer journal for clinicians.* 53(6):356-71.

Fagnano, M., Halterman, J., Conn, K., Shone, L. (2012). Health literacy and sources of health information for caregivers of urban children with asthma. *Clinical Pediatrics.* 51(3):267-73.

Fallows, D. (2005). How women and men use the Internet. Washington, DC: Pew Internet & American Life Project. Retrieved online from: http://www.pewinternet.org/~/media/Files/Reports/2005/PIP_Women_and_Men_online.pdf.pdf

Fast, J., Keating, N. (2001). Informal Caregivers in Canada: A Snapshot. *Research on Aging Policies and Practice.* Retrieved online from: http://www.rapp.ualberta.ca/en/Publications/~/media/8B5C7AB6D5FF4E619BB0FC242775A6B8.pdf

Fogg, B.. Marshall, J., Laraki, O., Osipovich, A., Varma, C., Fang, N., Paul, J., Rangnekar, A., Shon, J., Swani, P., Treinen, M., Hall, C. (2001). What makes web sites credible? A report on a large quantiative study. *In CHI 2001 Conference Proceedings.* New York: ACM SIGGHI.

Fox, S., Duggan, M. (2013). Pew Internet & American Life Project - Health Online 2013. Retrieved online from: http://www.pewinternet.org/~/media//Files/Reports/PIP_HealthOnline.pdf

Fox, N., Ward, K., O'Rourke, A. (2005). The 'expert patient': empowerment or medical dominance? The case of weight loss, pharmaceutical drugs and the Internet. *Social Science and Medicine.* 60(6):1299-309.

France, E., Wyke, S., Ziebland, S., Entwistle, V., Hunt, K. (2011). How personal experiences feature in women's accounts of use of information for decisions about antenatal diagnostic testing for foetal abnormality. *Social Science Medicine.* 72(5):755-62.

Franck, L., Noble, G. (2007). Here's an idea: ask the users! Young people's views on navigation, design and content of a health information website. *Journal of Child Health Care.* 11(4):287-97.

Gabriel Y. (2004). The Voice of experience and the voice of the expert- can they speak to each other? In *Narrative Research in Health and Illness* Eds Hurwitz B, Greenhalgh T, Skultans V. London: BMA Books, Blackwell.

Garrett, J. (2002). The Elements of User Experience: User-centered Design for the Web. *New Riders Press, Berkeley.*

Gibson, M., Houser, A. (2007). *AARP Data Digest. Valuing the Invaluable: A New Look at the Economic Value of Family Caregiving* (Data Update). Washington, DC: American Association of Retired Persons.

Gillet, J. (2003). Media activism and Internet use by people with HIV/AIDS. *Sociology of Health and Illness.* 25(6):608-24.

Glenton, C. (2002). Developing patient-centred information for back pain sufferers. *Health Expectations*. 5(4): 319–329

Goldberg, A., Rickler, K. (2011). The Role of Family Caregivers for People with Chronic Illness. *Medicine & Health Rhode Island.* 94 (2), 41-42.

Government of Canada. (2011). TCPS -2 Glossary. Retrieved online from: http://www.pre.ethics.gc.ca/eng/policy-politique/initiatives/tcps2-eptc2/glossary-glossaire/.

Green, J., Thorogood, N. (2009). Qualitative Methods for Health Research: Second Edition. SAGE Publications.

Griffiths, F., Lindenmeyer, A., Powell, J., Lowe, P. Thorogood, M. (2006). Why are health care interventions delivered over the internet? A systematic review of the published literature. *Journal of Medical Internet Research.* 8(2):e10.

Gutschoven, K., Van den Bulck, J. (2006) June. "Towards the Measurement of Psychological Health Empowerment in the General Public". *Paper presented at the annual meeting of the International Communication Association, Dresden International Congress Centre, Dresden, Germany. Retrieved online* from http://www.allacademic.com/meta/p91359_index.html

Hansen, D., Derry, H., Resnick, P., Richardson, C. (2003). Adolescents searching for health information on the Internet: an observational study. *Journal of Medical Internet Research.* 5(4):e25.

Harvey, K., Brown, B., Crawford, P., Macfarlane, A., McPherson, A. (2007). 'Am I normal?' Teenagers, sexual health and the Internet. *Social Science Medicine.* 65(4):771-81.

Harvey, R., Skelton-Robinson, M., Rossor, M. (2003). The prevalence and causes of dementia in people under the age of 65 years. *Journal of Neurology, Neurosurgery, and Psychiatry.* 74(9):1206-9.

Health Canada. (2002). *National Profile of Family Caregivers in Canada – Final Report*. Retrieved online from: http://www.hc-sc.gc.ca/hcs-sss/alt_formats/hpb-dgps/pdf/pubs/2002-caregiv-interven/2002-caregiv-interven-eng.pdf

Health Canada. (2004). *Informal/Family Caregivers in Canada Caring for Someone with a Mental Illness – Final Report.* Retrieved online from: http://www.hc-sc.gc.ca/hcs-sss/alt_formats/hpb-dgps/pdf/pubs/2004-mental-care-soins/2004-mental-care-soins-eng.pdf

Heath, J., Mackinlay, D., Watson, A., Hames, A., Wirz, L., Scott, S., Klewchuk, E., Milford, D., McHugh, K. (2011). Self-reported quality of life in children and young people with chronic kidney disease. *Pediatric Nephrology.* 26(5):767-73.

Herxheimer, A., McPherson, A., Miller, R., Shepperd, S., Yaphe, J., Ziebland, S. (2000). Database of patients' experiences (DIPEx): a multi-media approach to sharing experiences and information. *The Lancet*. 355(9214): 1540-3.

Hesse, B., Nelson, D., Kreps, G., Croyle, R., Arora, N., Rimer, B., Viswanath, K. (2005). Trust and sources of health information: the impact of the Internet and its implications for health care providers: findings from the first Health Information National Trends Survey. *Archives of Internal Medicine.* 165(22):2618-24.

Hesse, B., Moser, R., Rutten, L. (2010). Surveys of physicians and electronic health information. *New England Journal of Medicine.* 362(9):859-60.

Hoch, D., Ferguson, T. (2005). What I've learned from E-patients. *PLoS Medicine.* 2(8):e206.

Hoffman, D., Novak, T., Schlosser, A. (2000). The Evolution of the Digital Divide: How Gaps in Internet Access May Impact Electronic Commerce. *Journal of Compute-Mediated Communication.* 5(3).

Hollander, M., Liu, G., Chappell, N. (2009). Who cares and how much? The imputed economic contribution to the Canadian healthcare system of middle-aged and older unpaid caregivers providing care to the elderly. *Healthcare Quarterly*. 12(2), 42-49.

Houghton, A., Wolstenholme, C., Hudson, I. (2001). What questions do patients ask in a cardiology newsgroup and how reliable are the answers? *British Journal of Cardiology.* 8:165-8.

Hu, X., Bell, R. Kravitz, R., Orrange, S. (2012). The prepared patient: information seeking of online support group members before their medical appointments. *Journal of Health Communication.* 17(8):960-78.

Kaiser Family Foundation. (2001). How young people use the Internet for health information. Retrieved online from: http://www.kff.org/entmedia/loader.cfm?url=/commonspot/security/getfile.cfm&PageID=13719

Kelly, W., Connolly, B., Bilous, R., Stewart, A., Nag, S., Bowes, D. Loader, B., Muncer, S. (2002). Reader beware: diabetes advice on the web. *Practical Diabetes International.* 19(4):108-10.

Kim, J., Kim, S. (2009). Physicians' perceptions of the effects of Internet health information on the doctor-patient relationship. *Informatics of Health and Social Care.* 34(3):136-48.

Kosma, M., Cardinal, B., McCubbin, J. (2005). A pilot study of a web-based physical activity motivational program for adults with physical disabilities. *Disability and Rehabilitation.* 27(23):1435-42.

Kreps, G. (2002). Evaluating new health information technologies: expanding the frontiers of health care delivery and health promotion. *Studies in Health Technology and Informatics.* 80:205-12.

Krueger, R., Casey, M. (2000). *A Practical Guide for Applied Researd.* 3rd Edition. California: Sage Publications.

Langner, S. (1995). Finding meaning in caring for elderly relatives: Loss and personal growth. *Holistic Nursing Practice.* 9(3):75-84.

Larner, A. (2003). Use of the internet and of the NHS direct telephone for medical information by a cognitive function clinic population. *International Journal of Geriatric Psychiatry.* 18(2):118-22.

Lewis, D. (1999). Computer-based approaches to patient education: a review of the literature. *Journal of the American Medical Informatics Association*. 6(4):272-82.

Leydon, G., Moynihan, C., Boulton, M., Mossman, J., Boudioni, M., McPherson, K. (2000). Cancer patients' information needs and information seeking behaviour: in-depth interview study. *British Medical Journal.* 320: 909-13.

Lindgaard, G., Fernandes, G., Dudek, C., Browñ, J. (2006). Attention web designers: You have 50 milliseconds to make a good first impression! *Behaviour & Information Technology.* 25:115-126.

Lorig, K., Thompson-Gallagher, D., Traylor, L., Ritter, P., Laurent, D., Plant, K., Thompson, L., Hahn, T. (2012). Building Better Caregivers: A Pilot Online Support Workshop for Family Caregivers of Cognitively Impaired Adults. *Journal of Applied Gerontology.* 31(3):423-437.

Lowe, P., Powell, J., Griffiths, F., Thorogood, M., Locock, L. (2009). Making it all normal: the role of the internet in problematic pregnancy. *Qualitative Health Research.* 19(10):1476-84.

Mackert, M., Kahlor, L., Tyler, D., Gustafson, J. (2009). Designing e-health interventions for low-health-literate culturally diverse parents: addressing the obesity epidemic. *Telemedicine Journal and E Health.* 15(7):672-7.

Marshall, C., Larkey, L., Curran, M., Weihs, K., Badger, T., Armin, J., García, F. (2011). Considerations of culture and social class for families facing cancer: the need for a new model for health promotion and psychosocial intervention. *Families, Systems, and Health.* 29(2):81-94.

McCarthy, O., Carswell, K., Murray, E., Free, C., Stevenson, F., Bailey, J. (2012). What young people want from a sexual health website: design and development of sexunzipped. *Journal of Medical Internet Research.* 14(5):e127.

McGowan, B., Wasko, M., Vartabedian, B., Miller, R., Freiherr, D., Abdolrasulnia, M. (2012). Understanding the Factors That Influence the Adoption and Meaningful Use of Social Media by Physicians to Share Medical Information. *Journal of Medical Internet Research.* 14(5):e117.

Morgan, M., Zamora, N., Hindmarsh, M. (2007). An inconvenient truth: a sustainable healthcare system requires chronic disease prevention and management transformation. *HealthcarePapers.* 7(4):6-23.

Morrison, L., Yardley, L., Powell, J., Michie, S. (2012). What design features are used in effective e-health interventions? A review using techniques from Critical Interpretive Synthesis. *Telemedicine Journal and E Health.*

18(2):137-44.

Murray, E., Lo, B., Pollack, L., Donelan, K., Catania, J., Lee, K., Zapert, K., Turner, R. (2003). The impact of health information on the Internet on health care and the physician-patient relationship: national US survey among 1,050 US physicians. *Journal of Medical Internet Research.* 5(3):e17.

Napoles, A., Chadiha, L., Eversley, R., Moreno-John, G. (2010). Reviews: developing culturally sensitive dementia caregiver interventions: are we there yet? *American Journal of Alzheimer's Disease and Other Dementias.* 25(5):389-406.

Newman, M., Ziebland, S., Barker, K. (2009). Patients' views of a multimedia resource featuring experiences of rheumatoid arthritis: pilot evaluation of www.healthtalkonline.org. *Health Informatics Journal.* 15:147.

Oh, H., Lee, B. (2012). The effect of computer-mediated social support in online communities on patient empowerment and doctor-patient communication. *Health Communities.* 27(1):30-41.

Patton, M. (1990). Qualitative evaluation and research methods. NewBury Park: SAGE Publications.

Pearlin, L. (1992). The Careers of Caregivers. *Gerontologist.* 32(5):647-647.

Perkins, E., LaMartin, K. (2012). The Internet as Social Support for Older Carers of Adults With Intellectual Disabilities. *Journal of Policy and Practice in Intellectual Disabilities.* 9(1):53-62.

Perrin, P., Heesacker, M., Uthe, C., Rittman, M. (2010). Caregiver mental health and racial/ethnic disparities in stroke: implications for culturally sensitive interventions. *Rehabilitation Psychology.* 55(4):372-82.

Peterson, G., Aslani, P., Williams, K. (2003). How do Consumers Search for and Appraise Information on Medicines On the Internet? A Qualitative Study Using Focus Groups. *Journal of Medical Internet Research*. 5(4) e33.

Pizur-Barnekow, K., Darragh, A., Johnston, M. (2011). "I cried because I didn't know if I could take care of him": toward a taxonomy of interactive and critical health literacy as portrayed by caregivers of children with special health care needs. *Journal of Health Communication.* 16 Suppl 3:205-21.

Pope, C., Ziebland, S., Mays, N. (2000). Qualitative research in health care. Analysing qualitative data. *British Medical Journal.* 320(7227): p. 114-6.

Priest, L., Nayak, L., Stuart-Hamilton, I. (2007). Website task performance by older adults. *Behaviour & Information Technology.* 26(3):189-195.

Quintana, Y., Feightner, J., Wathen, C., Sangster, L., Marshall, J. (2001). Preventive health information on the Internet. Qualitative study of consumers' perspectives. *Canadian Family Physician.* 47:1759-65.

Rapoport, J., Jacobs, P., Bell, N., Klarenbach, S. (2004). Refining the measurement of the economic burden of chronic diseases in Canada. *Chronic Disease in Canada.* 25(1):13-21.

Rice, R. (2006). Influences, usage, and outcomes of Internet health information searching: Multivariate results from the Pew surveys. *International Journal of Medical Informatics*. 75, 8-28.

Roberto, K., Jarrott, S. (2008). Family caregivers of older adults: A life span perspective. *Family Relations.* 57(1):100-111.

Robertson-Lang, L., Major, S., Hemming, H. (2011). An exploration of search patterns and credibility issues among older adults seeking online health information. *Canadian Journal on Aging.* 30(4):631-45.

Robles-Silva, L. (2008). The caregiving trajectory among poor and chronically ill people. *Qualitative Health Research.* 18(3):358-368.

Rogers, A., Mead, N. (2004). More than technology and access: primary care patients' views on the use and non-use of health information in the Internet age. *Health and Social Care in the Community*. 12 (2): 102-110

Ross, L., Frier, B., Kelnar, C., Deary, I. (2001). Child and parental mental ability and glycemic control in children with Type 1 diabetes. *Diabetic Medicine.* 18(5): 364-9.

Rothman, A., Kiviniemi, M. (1999). Treating people with information: an analysis and review of approaches to communicating health risk information. *Journal of the National Cancer Institutes Monograph.* 25:44-51.

Salmon, P., Hall, G. (2004). Patient empowerment or the emperor's new clothes. *Journal of the Royal Society of Medicine.* 97(2):53-6.

Sandelowski, M. (2000). Whatever Happened to Qualitative Description? *Research in Nursing & Health.* 23: 334-340.

Scanfeld, D., Scanfeld, B., Larson, E. (2010). Dissemination of health information through social networks: twitter and antibiotics. *American Journal of Infection Control.* 38(3):182-8.

Schaffer, R., Kuczynski, K., Skinner, D. (2008). Producting genetic knowledge and citizenship through the Internet: mothers, pediatric genetics, and cybermedicine. *Sociology of Health and Illness.* 30(1):145-59.

Schillinger, D., Bindman, A., Wang, F., Stewart, A., Piette, J. (2004). Functional health literacy and the quality of physician-patient communication among diabetes patients. *Patient Education and Counseling.* 52(3):315-23.

Schulz, R., Sherwood, P. (2008). Physical and mental health effects of family caregiving. *American Journal of Nursing.* 108 (9 Suppl), 23-7; quiz 27.

Sharf, B. (1997). Communicating breast cancer online: support and empowerment on the Internet. *Women & Health.* 26(1):65-84.

Shekelle, P., Goldzweig, C. (2009). *Costs and benefits of health information technology: An updated systematic review*. Report for the Quest for Quality and Improved Performance (QQIP).

Sillence, E., Briggs, P., Herxheimer, A. (2004). Personal experiences matter: What patients think about hypertension information online. *He@lth Information on the Internet.* 42: 3-5.

Sillence, E., Briggs, P., Fishwick, L., Harris, P. (2004a). Trust and mistrust of online health sites, in CHI '04: Proceedings of the SIGCHI Conference on Human Factors in Computing Systems. *ACM Press, New York, NY, USA*. 663-670. Retrieved online from: http://www.usna.edu/Users/cs/augustin/Courses/IT460/Article%2005%20-%20Trust%20in%20Websites.pdf

Sillence, E., Briggs, P., Harris, P., Fishwick, L. (2006). A framework for understanding trust factors in web-based health advice. *International Journal of Human-Computer Studies*. 64: 697-713.

Sillence, E., Briggs, P., Harris, P., Fishwick, L. (2007). How do patients evaluate and make use of online health information? *Social Science & Medicine*. 64: 1853-62.

Sillence, E., Briggs, P., Harris, P., Fishwick, L. (2007a). Going online for health advice: Changes in usage and trust practices over the last five years. *Interacting with Computers*. 19: 397-406.

Stanford, J., Tauber, E., Fogg, B., Marable, L. (2002). Experts vs. online consumers: A comparative study of health and finance web sites. Consumer Web watch research report. Retrieved online from: http://www.consumerwebwatch.org/pdfs/stanfordPTL.pdf

Statistics Canada. (2005). *Characteristics of household Internet users, by location of access*. Household Internet Use Survey (HIUS), 1999-2003.

Statistics Canada. (2007). *Summary Table: Characteristics of individuals using the Internet, by location of access* (2005-2007), Canadian Internet Use Survey (CIUS).

Statistics Canada. (2009). *Canadian Internet Use Survey.* Retrieved online from: http://www.statcan.gc.ca/daily-quotidien/100510/dq100510a-eng.htm

Statistics Canada. (2010). *The Daily: Canadian Internet Use Survey*. Retrieved online from: http://www.statcan.gc.ca/daily-quotidien/100510/dq100510a-eng.htm

Statistics Canada. (2010a). *Projections of the diversity of the Canadian Population*. Retrieved online from: http://www.statcan.gc.ca/daily-quotidien/100309/dq100309a-eng.htm

Tanis, M., Das, E., Fortgens-Sillmann, M. (2011). Finding care for the caregiver? Active participation in online health forums attenuates the negative effect of caregiver strain on wellbeing. *Communications-European Journal of Communication.* 36(1):51-66.

Taylor, L., Bahreman, N., Hayat, M., Hoey, F., Rajasekaran, G., Segev, D. (2012). Living kidney donors and their family caregivers: developing an evidence-based educational and support website. *Progress in Transplantation.* 22(2):119-28.

The Times. (2013). The 50 Top Websites You Can't Live Without: *The 5 best sites for your health by Mark Porter.* Saturday, January 26th, 2013.

Thinnes, A., Padilla, R. (2011). Effect of educational and supportive strategies on the ability of caregivers of people with dementia to maintain participation in that role. *American Journal of Occupational Therapy.* 65(5):541-9.

Thompson, D., Baranowski, T., Cullen, K., Watson, K., Liu, Y., Canada, A., Bhatt, R., Zakeri, I. (2008). Food, fun, and fitness internet program for girls: Pilot evaluation of an e-Health youth obesity prevention program examining predictors of obesity. *Preventive Medicine.* 47(5):494-497.

Thompson, D., Baranowski, T., Baranowski, J., Cullen, K., Jago, R., Watson, K., Liu, Y. (2009). Boy Scout 5-a-Day Badge: Outcome results of a troop and Internet intervention. *Preventive Medicine.* 49(6):518-526.

Thompson, D., Cullen, K., Boushey, C., Konzelmann, K. (2012). Design of a website on nutrition and physical activity for adolescents: results from formative research. *Journal of Medical Internet Research.* 14(2):e59.

Tonsaker T., Trpkov, C., Bartlett, G. (2013). Health Information on the Internet: Goldmine or Minefield? *Canadian Family Physician.* ACCEPTED 01/21/2013: AWAITING ASSIGNMENT TO BATCH.

Van Mierlo, L., Meiland, F., Van der Roest, H., Dröes, R. (2012). Personalised caregiver support: effectiveness of psychosocial interventions in subgroups of caregivers of people with dementia. *International Journal of Geriatric Psychiatry.* 27(1):1-14.

van Uden-Kraan C. (2008). Empowering processes and outcomes of participation in online support groups for patients with breast cancer, arthritis, or fibromyalgia. *Qualitative Health Research*. 3:405-17.

Van Uden-Kraan, C., Drossaert, C., Taal, E., Seydel, E., van de Laar, M. (2008a). Self-reported differences in empowerment between lurkers and posters in online patient support groups. *10(2):e18.*

van Uden-Kraan, C., Drossaert, C., Taal, E., Smit, W., Seydel, E., van de Llar, M. (2010). Experiences and attitudes of Dutch rheumatologists and oncologists with regard to their patients' health-related Internet use. *Clinical Rheumatology.* 29(11):1229-36.

Verheijden, M., Bakx, J., Akkermans, R., van den Hoogen, H., Goodwin, N., Rosser, W., van Staveren, W., van Weel, C. (2004). Web-based targeted nutrition counseling and social support for patients at increased cardiovascular risk in general practice: randomized controlled trial. *Journal of Medical Internet Research.* 6(4):e44.

Walji, M., Sagaram, S., Sagaram, D., Meric-Bernstam, F., Johnson, C., Mirza, N., Bernstam, E. (2004). Efficacy of quality criteria to identify potentially harmful information: a cross-sectional survey of complementary and alternative medicine web sites. *Journal of Medical Internet Research.* 6(2):e21.

Wantland, D., Portillo, C., Holzemer, W., Slaughter, R., McGhee, E. (2004). The effectiveness of Web-based vs. non-Web-based interventions: a meta-analysis of behavioral change outcomes. *Journal of Medical Internet Research.* 6(4):e40.

Wathen, C., Burkell, J. (2002). Believe it or not: Factors influencing credibility on the web. *Journal of the American Society for Information Science and Technology.* 53(2):134-144.

Weitzman, E., Cole, E., Kaci, L., Mandl, K. (2011). Social but safe? Quality and safety of diabetes-related online social networks. *Journal of American Medical Informatics Association.* 18(3):292-7.

Whiddett, R., Hunter, I., Engelbrecht, J., Handy, J. (2006). Patients' attitudes towards sharing their health information. *International Journal of Medical Informatics.* 75(7):530-41.

Whitten, P., Love, B., Buis, L., Mackert, M. (2008). Health education online for individuals with low health literacy: Evaluation of the Diabetes and You website. *Journal of Technology in Human Services.* 26:77-88.

WHO (World Health Organization). (2011). Safety and security on the Internet: challenges and advances in Member States: based on the findings of the second global survey on eHealth. *Global Observatory for eHealth series – Volume 4.* Retrieved online from: http://www.who.int/goe/publications/goe_security_web.pdf

Wilkinson, A., Lynn, J. (2005). Caregiving for advanced chronic illness patients. *Techniques in Regional Anesthesia and Pain Management.* 9 (3), 122-32.

Williams, A., Bakitas, M. (2012). Cancer family caregivers: a new direction for interventions. *Journal of Palliative Medicine.* 15(7):775-83.

Wogalter, M., Mayhorn, C. (2008). Trusting the internet: Cues affecting perceived credibility. *International Journal of Technology and Human Interaction.* 4(1):75-90.

Worsley, A. (1989). Perceived reliability of sources of health information. *Health Education Research.* 4(3):367-376.

Xiang, Z., Fesenmaier, D. (2006). Assessing the initial step in the persuasion process: Meta tags on destination marketing web sites. *Information Technology & Tourism.* 8:91-104.

Yousafzai, S., Foxall, G., Pallister, J. (2010). Explaining Internet banking behavior: Theory of reasoned action, theory of planned behavior or technology acceptance model? *Journal of Applied Social Psychology.* 40:1172-120.

Ziebland, S., Chapple, A., Dumelow, C., Evans, J., Prinjha, S., Rozmovits, L. (2004). How the internet affects patients experience of cancer: A qualitative study. *British Medical Journal*. 328: 564-567.

Ziebland, S., Wyke, S. (2012). Health and illness in a connected world: how might sharing experiences on the internet affect people's health? *Milbank Quarterly.* 90(2):219-49.

Zufferey, M., Schulz, P. (2009). Self-management of chronic low pack pain: an exploration of the impact of a patient-centered website. *Patient Education and Counseling.* 77(1):27-32.

Zulman, D., Schafenacker, A., Barr, K., Moore, I., Fisher, J., McCurdy, K., Derry, H., Saunders, E., An, L., Northouse, L. (2012). Adapting an in-person patient-caregiver communication intervention to a tailored web-based format. *Psycho-oncology.* 21(3):336-41.

APPENDIX 1: EXAMPLES OF PERSONAL HEALTH AND ILLNESS EXPERIENCE INFORMATION ON THE INTERNET

Nine avenues through which patient experience information currently appears on the Internet. Table has been adapted from Ziebland & Wyke (2012).

Sources of online information based on personal health and illness experiences	Links to website examples
1. General health information sites	
Medicinet is a health information website website that includes patient experiences	www.medicinet.com
NHS Choices has created short films in which people talk about their conditions	www.nhs.uk/planners/yourhealth/pages/realstories.aspx
2. Blogs	
Blogs from people with cancer	carolinemfr.blogspot.com/
A blog written by Dave de Bronkart, who is a leading spokesperson for the e-patient movement	epatientdave.com/
3. Social networking websites	
Facebook has pages dedicated to specific conditions (e.g., diabetes).	http://www.facebook.com/pages/Diabetes-The-Patient-Experience/118564931491729
Twitter (microblogging platform) has numerous health feeds.	www.Twitter.com/health
4. Online forums	
Everyday Health hosts groups and online forums for different conditions. Many condition-specific forums are available.	www.everydayhealth.com/forums/
5. Homemade videos and illustrations	
Kindle a Light is a YouTube channel where people post home videos about their own mental health issues	www.youtube.com/profile?src_vid=2FqafTcrhKY&user=kindlealight&feature=iv&annotation_id=annotation_623992
Health related photo and image sharing	www.flickr.com
6. Online collections of video and audio clips on health experiences	
Healthtalkonline and Youthhealthtalk Have a collection of people's experiences of health-related conditions and illnesses.	www.healthtalkonline.org www.youthhealthtalk.org
Healthy Place hosts an array of video clips of patients' experiences of mental health problems along with other health information.	www.healthyplace.com/

APPENDIX 1: EXAMPLES OF PERSONAL HEALTH AND ILLNESS EXPERIENCE INFORMATION ON THE INTERNET

7. Testimonials	
Personal experiences of quitting smoking are provided by a health care provider organization	www.sacred-heart.org/smokingcessation/page.asp?ID=355 asp?ID=355
Nicorette has a video channel on which people discuss how they quit smoking	www.nicorette.com/about/quit-smoking-success-stories.aspx
8. Decision-making aids	
Prosdex is an online decision aid for PSA testing. It uses short video clips of people describing their own experiences and reasoning	www.prosdex.com/index_content.htm
Foundation for Informed Medical Decision Making provides advice for making informed medical decisions. The site uses video clips of patients' experiences of decision-making.	informedmedicaldecisions.org/patient_experience.html
9. Consumer review/reputation sites	
Reputation sites are where users can write and read reviews of health care that people have received.	www.patientslikeme.com www.ratemds.com

APPENDIX 2: CONSENT FORM

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CONSENT FORM FOR PARTICIPATION IN A FOCUS GROUP

Caregivers and Web-based Health Information: An Exploratory Qualitative Study of Information Seeking, Information Use, and Perspectives

Name of Researchers: Tabitha Tonsaker, Susan Law, Ilja Ormel - Funded by the St. Mary Hospital Foundation

PARTICIPANT INFORMATION SHEET

Hello, my name is Tabitha Tonsaker. I am a Masters of Family Medicine student conducting research at St. Mary's Research Centre. I am conducting this project under the guidance of Susan Law (the Principle Investigator) and Ilja Ormel (the research coordinator). You are being invited to participate in a focus group for a research study. A focus group is a gathering with a small number of people (between 6 and 8) that are brought together to discuss their opinions or ideas towards a topic. Questions are asked in an interactive group setting with a researcher. The purpose of this study is to better understand caregivers' perspectives towards health information on the Internet. Your participation in this study is voluntary and you may withdraw or refuse to participate in the study at any time. You may refuse to answer any questions during the study or you may stop at any time. Before you decide if you want to take part or not, I want to tell you why the research is being done, and what you can expect if you do take part. Please read this information sheet carefully.

What is the purpose of the study?

A McGill St. Mary's research team is developing a website based upon peoples' personal experiences of health and illness. The first module of the website will focus on Canadian experiences of caregiving. The results will contribute to the new website: www.healthexperiences.ca, which will present audio, video, and text material of peoples' personal stories. Healthexperiences.ca is a website that will contain people's stories of health and illness, provide details about support groups & other resources (e.g. self-help books), and be used as a teaching and learning area for healthcare professionals and trainees. The specific objectives of this study that you are being asked to participate in are to determine caregivers preferences for the structure and design of the website, and explore caregivers use of the Internet for health information.

Why have I been chosen?

We are looking for people who have had experience in a caregiving role. We will be holding three separate focus groups that will be conducted with caregivers. We have contacted you because you have had experience caregiving.

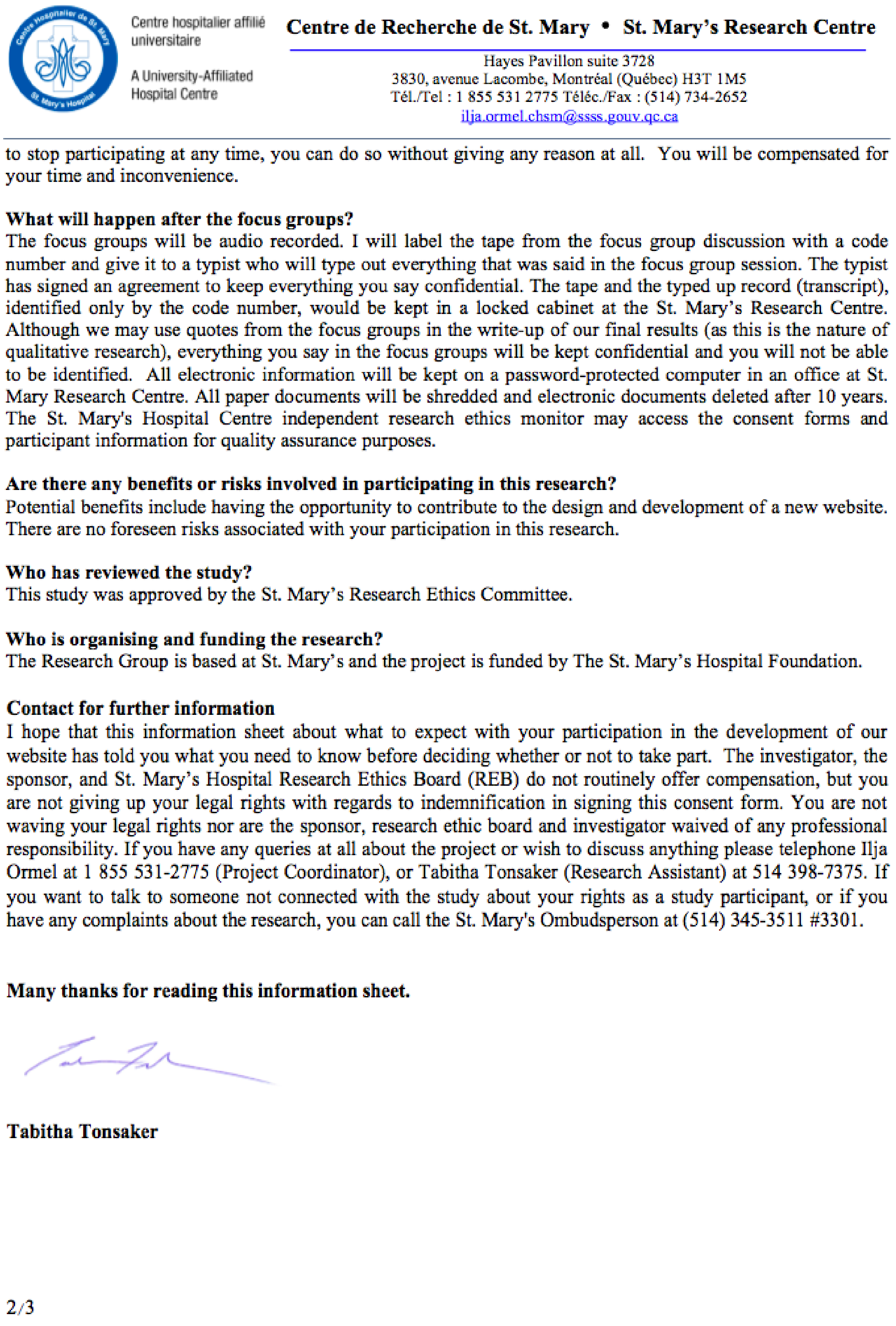
Do I have to take part?

No. It is entirely up to you to decide whether or not you want to take part. If you decide to take part, you will be given this information sheet to keep. You will also be asked to sign the 'consent form'. If you decide to participate, you are still free to stop at any time without giving a reason. No questions will be asked if you choose to stop.

What will happen if I take part?

You will be given the 'consent form'. You only sign this form if you agree to take part in the study. You will be given a copy of the consent form to keep. If you complete the consent form you will be asked to participate in a focus group session in an office space at St. Mary's Hospital. This session will be held with 5-6 other caregivers, where you will be asked to offer your input towards issues that are important to you, as a potential website user, in terms of Internet use and the structure and design of healthexperiences.ca. We will show you options for the structure and design of the website and then we will openly discuss the group's opinions. For example, we will openly discuss topics about features of the website such as site layout and design, navigation of the site, relevance of links, and general formatting. The time it takes for the focus groups varies depending on how much participants have to say, but most focus groups will last at least an hour. Remember, if you want

APPENDIX 2: CONSENT FORM



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to stop participating at any time, you can do so without giving any reason at all. You will be compensated for your time and inconvenience.

What will happen after the focus groups?
The focus groups will be audio recorded. I will label the tape from the focus group discussion with a code number and give it to a typist who will type out everything that was said in the focus group session. The typist has signed an agreement to keep everything you say confidential. The tape and the typed up record (transcript), identified only by the code number, would be kept in a locked cabinet at the St. Mary's Research Centre. Although we may use quotes from the focus groups in the write-up of our final results (as this is the nature of qualitative research), everything you say in the focus groups will be kept confidential and you will not be able to be identified. All electronic information will be kept on a password-protected computer in an office at St. Mary Research Centre. All paper documents will be shredded and electronic documents deleted after 10 years. The St. Mary's Hospital Centre independent research ethics monitor may access the consent forms and participant information for quality assurance purposes.

Are there any benefits or risks involved in participating in this research?
Potential benefits include having the opportunity to contribute to the design and development of a new website. There are no foreseen risks associated with your participation in this research.

Who has reviewed the study?
This study was approved by the St. Mary's Research Ethics Committee.

Who is organising and funding the research?
The Research Group is based at St. Mary's and the project is funded by The St. Mary's Hospital Foundation.

Contact for further information
I hope that this information sheet about what to expect with your participation in the development of our website has told you what you need to know before deciding whether or not to take part. The investigator, the sponsor, and St. Mary's Hospital Research Ethics Board (REB) do not routinely offer compensation, but you are not giving up your legal rights with regards to indemnification in signing this consent form. You are not waving your legal rights nor are the sponsor, research ethic board and investigator waived of any professional responsibility. If you have any queries at all about the project or wish to discuss anything please telephone Ilja Ormel at 1 855 531-2775 (Project Coordinator), or Tabitha Tonsaker (Research Assistant) at 514 398-7375. If you want to talk to someone not connected with the study about your rights as a study participant, or if you have any complaints about the research, you can call the St. Mary's Ombudsperson at (514) 345-3511 #3301.

Many thanks for reading this information sheet.

Tabitha Tonsaker

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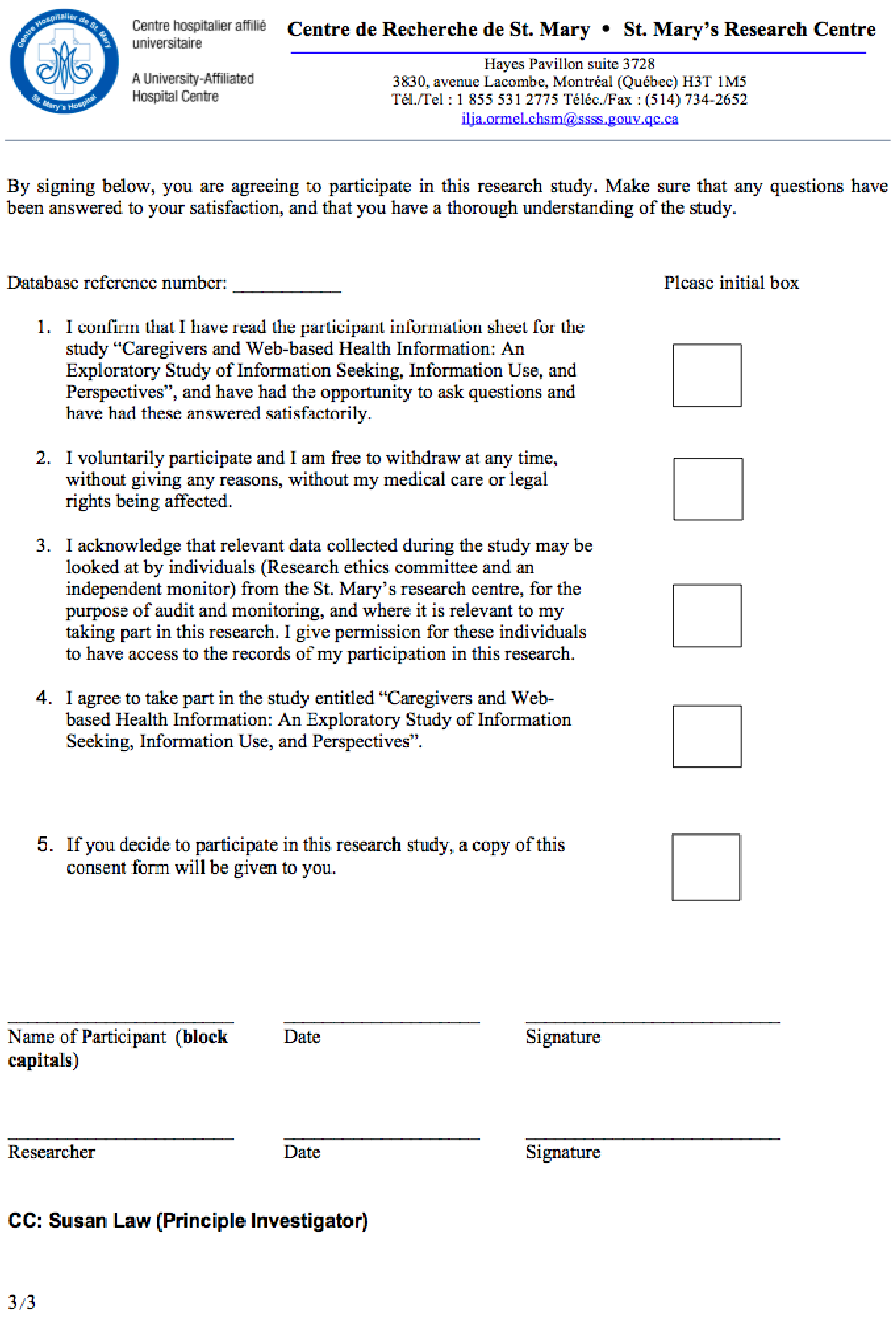
APPENDIX 2: CONSENT FORM



Centre hospitalier affilié universitaire

A University-Affiliated Hospital Centre

Centre de Recherche de St. Mary • St. Mary's Research Centre

Hayes Pavillon suite 3728
3830, avenue Lacombe, Montréal (Québec) H3T 1M5
Tél./Tel : 1 855 531 2775 Téléc./Fax : (514) 734-2652
ilja.ormel.chsm@ssss.gouv.qc.ca

By signing below, you are agreeing to participate in this research study. Make sure that any questions have been answered to your satisfaction, and that you have a thorough understanding of the study.

Database reference number: ___________

Please initial box

1. I confirm that I have read the participant information sheet for the study "Caregivers and Web-based Health Information: An Exploratory Study of Information Seeking, Information Use, and Perspectives", and have had the opportunity to ask questions and have had these answered satisfactorily. ☐
2. I voluntarily participate and I am free to withdraw at any time, without giving any reasons, without my medical care or legal rights being affected. ☐
3. I acknowledge that relevant data collected during the study may be looked at by individuals (Research ethics committee and an independent monitor) from the St. Mary's research centre, for the purpose of audit and monitoring, and where it is relevant to my taking part in this research. I give permission for these individuals to have access to the records of my participation in this research. ☐
4. I agree to take part in the study entitled "Caregivers and Web-based Health Information: An Exploratory Study of Information Seeking, Information Use, and Perspectives". ☐
5. If you decide to participate in this research study, a copy of this consent form will be given to you. ☐

______________________	____________________	_________________________
Name of Participant (**block capitals**)	Date	Signature
______________________	____________________	_________________________
Researcher	Date	Signature

CC: Susan Law (Principle Investigator)

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APPENDIX 3: PARTICIPANT INFORMATION SHEET

Centre hospitalier affilié
universitaire

A University-Affiliated
Hospital Centre

Centre de Recherche de St. Mary • St. Mary's Research Centre

Hayes Pavillon suite 3728
3830, avenue Lacombe, Montréal (Québec) H3T 1M5
Tél./Tel : 1 855 531 2775 Téléc./Fax : (514) 734-2652
tabitha.tonsaker@mail.mcgill.ca

Focus Group: Participant Information Sheet

Sex/Gender: ___________________________

Age: _________________________________

Marital Status: _________________________

Place of Birth: _________________________

Mother Language: ______________________

Occupation: ___________________________

Hours of Internet use per day: ____________

Please provide a one-sentence description of your caregiving experience:
(ex: I had a short-term experience caring for my mother with multiple sclerosis.)

____

____

APPENDIX 4: FOCUS GROUP INTERVIEW GUIDE

Focus Group Interview Guide

Distribute consent forms and participant information sheets. Collect signed consent forms and completed participant information sheets prior to beginning focus group.

A) Introduction (10-20 min):

The lead facilitator gives a brief introduction to the research team and the purpose of the focus group using the text below as a guide:

1) Introduction to research team
2) Reminder of audio recording of focus group, privacy and confidentiality
3) Focus Group Overview
    - Goal of focus group:
        a) to explore how caregivers seek and use health information from the Internet
        b) to explore caregivers' perspectives towards the structure, design, and content of a personal health and illness website on caregiving
    - Guidelines for focus group:
        a) the role of the lead facilitator is to guide the discussion, but all participants are encouraged to talk with the facilitator, and other group participants throughout the focus group
4) Focus group participants are asked to introduce themselves and briefly state their caregiving experience (if they wish)
5) Thank participants for taking part in this research, and communicate the importance of them being there

B) Seeking and Using Online Health Information (30-40 min):

Several questions (with prompts) can be used to initiate discussions about how the participants search for and use online health information. If participants do not understanding a certain question, or have difficulty coming up with a response, then prompts to each question can be offered one-by-one (not shown). Additional topics to those presented below can also be raised by the lead facilitator, or the participants, throughout the focus group.

Questions included in the focus group discussion (list is not exhaustive):

1) Why do you search for health information on the Internet

2) What health information websites do you currently visit and why?
3) How do you search for health information on the Internet?
4) How do you decide upon which website links to click?
5) When will you stop looking up health information on the Internet?
6) What are the best and worst parts of health information websites?
7) What will make you trust certain health websites over others?
8) How do you feel about the use of social media features on health websites?
9) What do you do with health information found on the Internet?

C) Online Personal Health and Illness Experience Information (30-40 min):

To initiate discussions about the structure and design of a PHEx website on caregiving, the lead facilitator will show the four mock web designs provided by KnowledgeOne. Participants are asked to observe the four designs for ten minutes before having an open discussion regarding the designs with the facilitators and other group participants.

If participants do not touch upon all aspects of the web designs, then the following prompts (or alternative web designs – not shown) may be used to initiate discussion:

1) Font and text size
2) Colour scheme
3) Links
4) Structure and navigation
5) Overall feel and general appeal

To initiate discussion about the content of a PHEx website on caregiving, the lead facilitator will provide one question to initiate discussion. Once again, additional topics to that presented below can also be raised by the lead facilitator or participants throughout the focus group.

1) What would you want from a PHEx website on caregiving?

D) Conclusion – Debriefing

The lead facilitator provides a brief overview of what was discussed throughout the focus groups. Thank participants again for taking part in a focus group, and ask if there is anything else they would like to add before leaving.

APPENDIX 5: LIST OF THEMES AND SUB-THEMES

List of themes and sub-themes from qualitative analysis of results. Note that there is no particular chronological order to how the themes were discussed throughout the focus groups: different themes were elaborated upon at various times throughout the sessions.

PART 1: Retrieval and usage of online health information

Theme 1A: Searching for and choosing health information websites

- ***1A-I: Web-search and link assessment using general information portal***
- ***1A-II: Assessing credibility and trustworthiness of a web page***
- ***1A-III: Developing a long-term relationship with a trusted site***
- ***1A-IV: External influences***

Theme 1B: Empowerment through use of online health information

- ***1B-I: Interactions with healthcare providers***
- ***1B-II: Support for the caregiver in providing care***
- ***1B-III: Self-care management***
- ***1B-IV: Social connections and support***

Theme 1C: Concerns about health information on the Internet

- ***1C-I: Uncertainty about quality of information***
- ***1C-II: Information overload***
- ***1C-III: Privacy and Confidentiality***
- ***1C-IV: Limitations to online health information***

PART 2: Personal health and illness experience information

Theme 2A: Factors important for first impressions

- ***2A-I: Appealing and user-friendly layout and design***
- ***2A-II: Appropriate use of relevant images***
- ***2A-III: Clear and informative introduction material***
- ***2A-IV: Representations of authority and credibility***

Theme 2B: Perceived needs and expectations

- ***2B-I: Relatable and relevant information***
- ***2B-II: Practical tips and advice through experiential knowledge***
- ***2B-III: Combine factual and experiential-based information***
- ***2B-IV: Acknowledge varying literacy levels***
- ***2B-V: Other suggested users of a PHEx website on caregiving***

APPENDIX 6: MOCK WEBSITE DESIGNS #1-4

Website Design #1:

Caregiving Module

Caregiver is someone who is responsible for the care of someone who has poor mental health, physically disabled.

Topics that are covered:

- Discovery Needs
- Discovery Support Systems
- Dealing with Personal Challenges
- Dealing with HC Services
- Meaning of the Experience
- Personal Aspects in Caregiving

Welcome to healthexperiences.ca

Watch Dr. Susan Law video

We would like to hear your story! We are looking for volunteers who would like to share their experiences of family caregiving. Your involvement would be somewhat like a conversation where we will ask you to tell us your caregiver story. A researcher from our team will come to your house for the interview, but it could be somewhere else if that is easier for you. Your participation would involve one interview session which normally lasts about one hour.

The results will be published on this website that will be open to the public to provide a source of reliable information and support to other caregivers as well as to educate health professionals about what it's really like to be a caregiver. With your participation you can help others understand and learn about people's experiences in caregiving and support other caregivers that may have had similar experiences.

Tell us about your experience

Help others who are going through the same by adding your experience to the hundreds on Healthtalkonline, in writing or on video.

STILL NEED CONVINCING? GET SOME INSPIRATION HERE »

healthtalkonline.org
youthhealthtalk.org

Healthtalkonline and its sister website, Youthhealthtalk, let you share in more than 2,000 people's experiences of over 60 health-related conditions and illnesses.

CLICK HERE TO VISIT »

Social Network

- Join our Facebook page
- Follow us on twitter for latest news
- Our Profile on LinkedIn

Contact info

3830 Lacombe Avenue, Montreal,
Quebec, H3T 1M5
info@healthexperiences.ca
(514) 345-3511 (514) 345-3512

Partners and Links

International links: Germany Japan Spain

APPENDIX 6: MOCK WEBSITE DESIGNS #1-4

Website Design #2:

Caregiving Module

Caregiver is someone who is responsible for the care of someone who has poor mental health, physically disabled.

Topics that are covered:

- Discovery Needs
- Discovery Support Systems
- Dealing with Personal Challenges
- Dealing with HC Services
- Meaning of the Experience
- Personal Aspects in Caregiving

Welcome to healthexperiences.ca

We would like to hear your story! We are looking for volunteers who would like to share their experiences of family caregiving. Your involvement would be somewhat like a conversation where we will ask you to tell us your caregiver story. A researcher from our team will come to your house for the interview, but it could be somewhere else if that is easier for you. Your participation would involve one interview session which normally lasts about one hour. The interview will be in your preferred language.

The results will be published on this website that will be open to the public to provide a source of reliable information and support to other caregivers as well as to educate health professionals about what it's really like to be a caregiver. With your participation you can help others understand and learn about people's experiences in caregiving and support other caregivers that may have had similar experiences.

Contact info

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☎ (514) 345-3511 (514) 345-3512

Tell us about your experience

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STILL NEED CONVINCING? GET SOME INSPIRATION HERE »

healthtalkonline.org
youthhealthtalk.org

Healthtalkonline and its sister website, Youthhealthtalk, let you share in more than 2,000 people's experiences of over 60 health-related conditions and illnesses.

CLICK HERE TO VISIT »

Links to Partners Sites

Germany Japan Spain

Our Caregivers Speak:

Richard: " speaks about the enormous emotional & physical stresses related to caregiving for... "
CLICK HERE FOR FULL INTERVIEW »

Joanna: " Worries about the eventual possibility that her mum will need more intensive care... "
CLICK HERE FOR FULL INTERVIEW »

Rachel: " If you're not taking care of yourself then you're not taking care of the other person... "
CLICK HERE FOR FULL INTERVIEW »

Site map / Terms of use / Privacy policy / Disclaimer / Help
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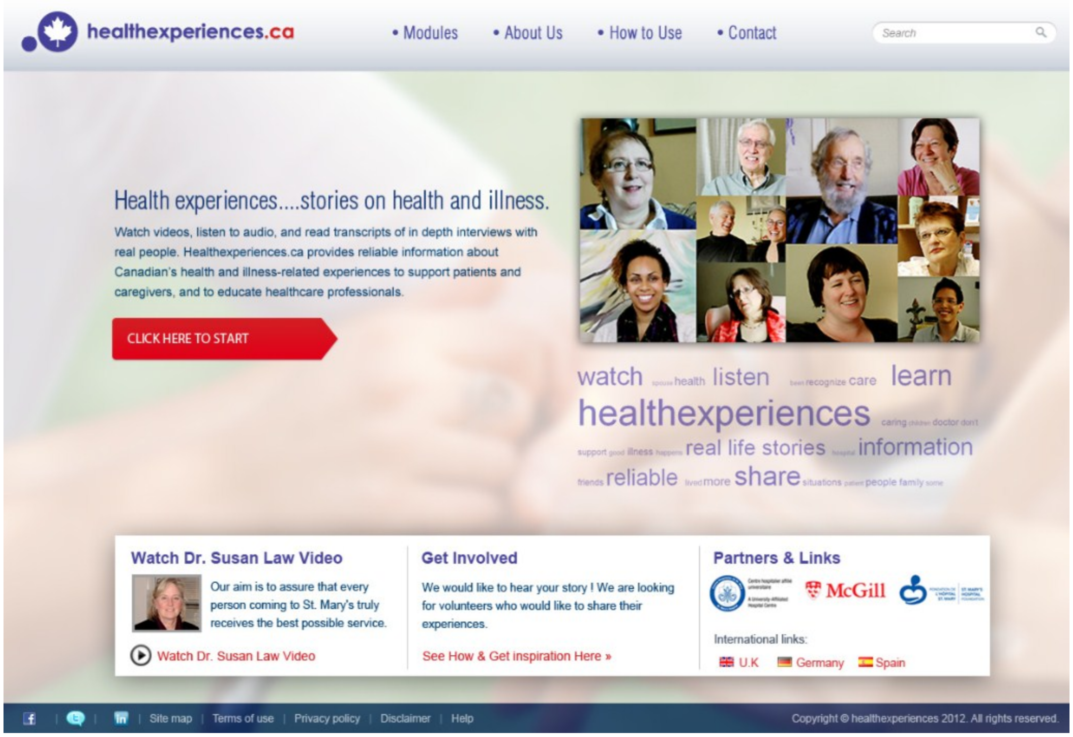
APPENDIX 6: MOCK WEBSITE DESIGNS #1-4

Website Design #3:



Health experiences....stories on health and illness.

Watch videos, listen to audio, and read transcripts of in depth interviews with real people. Healthexperiences.ca provides reliable information about Canadian's health and illness-related experiences to support patients and caregivers, and to educate healthcare professionals.

Watch Dr. Susan Law Video

Our aim is to assure that every person coming to St. Mary's truly receives the best possible service.

Watch Dr. Susan Law Video

Get Involved

We would like to hear your story ! We are looking for volunteers who would like to share their experiences.

See How & Get inspiration Here »

Partners & Links

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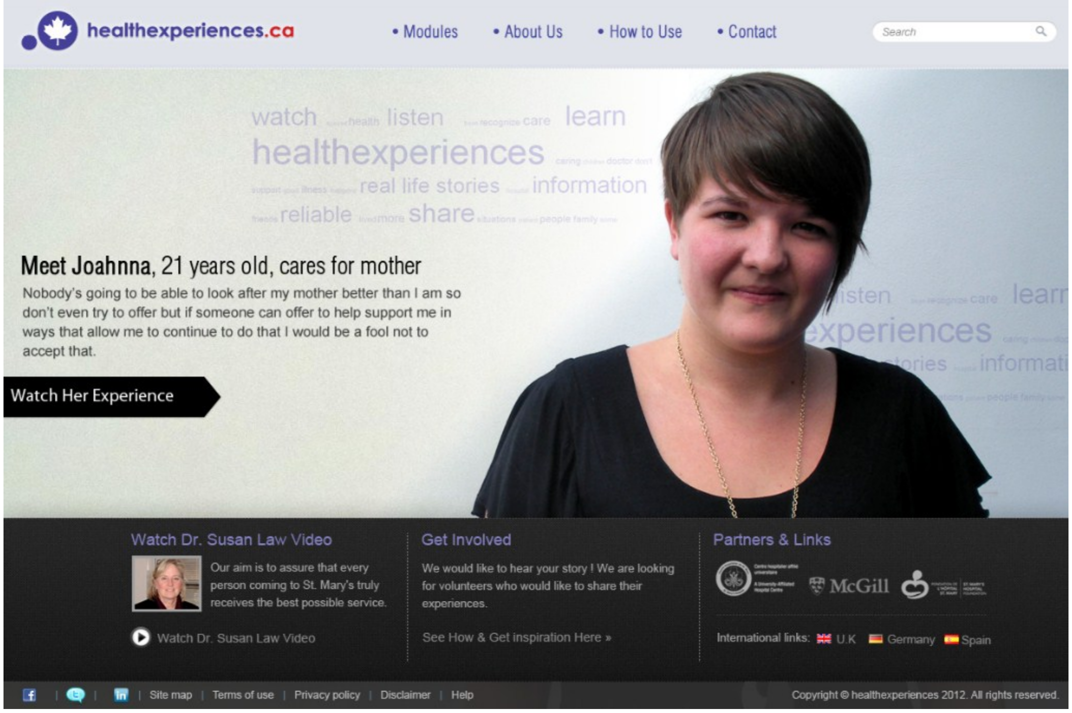
APPENDIX 6: MOCK WEBSITE DESIGNS #1-4

Website Design #4:



Meet Joahnna, 21 years old, cares for mother

Nobody's going to be able to look after my mother better than I am so don't even try to offer but if someone can offer to help support me in ways that allow me to continue to do that I would be a fool not to accept that.

Watch Dr. Susan Law Video

Our aim is to assure that every person coming to St. Mary's truly receives the best possible service.

Watch Dr. Susan Law Video

Get Involved

We would like to hear your story ! We are looking for volunteers who would like to share their experiences.

See How & Get inspiration Here »

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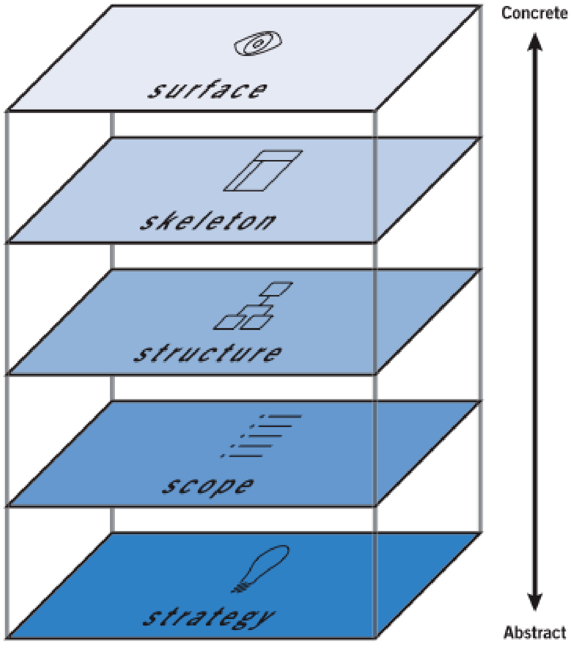
APPENDIX 7: GARRET'S (2002) FIVE PLANES OF WEB-USER'S EXPERIENCE



Description: Garret's (2002) five planes of a web-user's experience: *surface, skeleton, structure, scope,* and *strategy.* The five planes provide a conceptual framework for the "user's experience". With each subsequent plane from the *surface* to the *strategy*, the web issues that are addressed become more abstract and less concrete.

APPENDIX 8: FINAL WEBSITE DESIGN

Final Website Design Page 1:

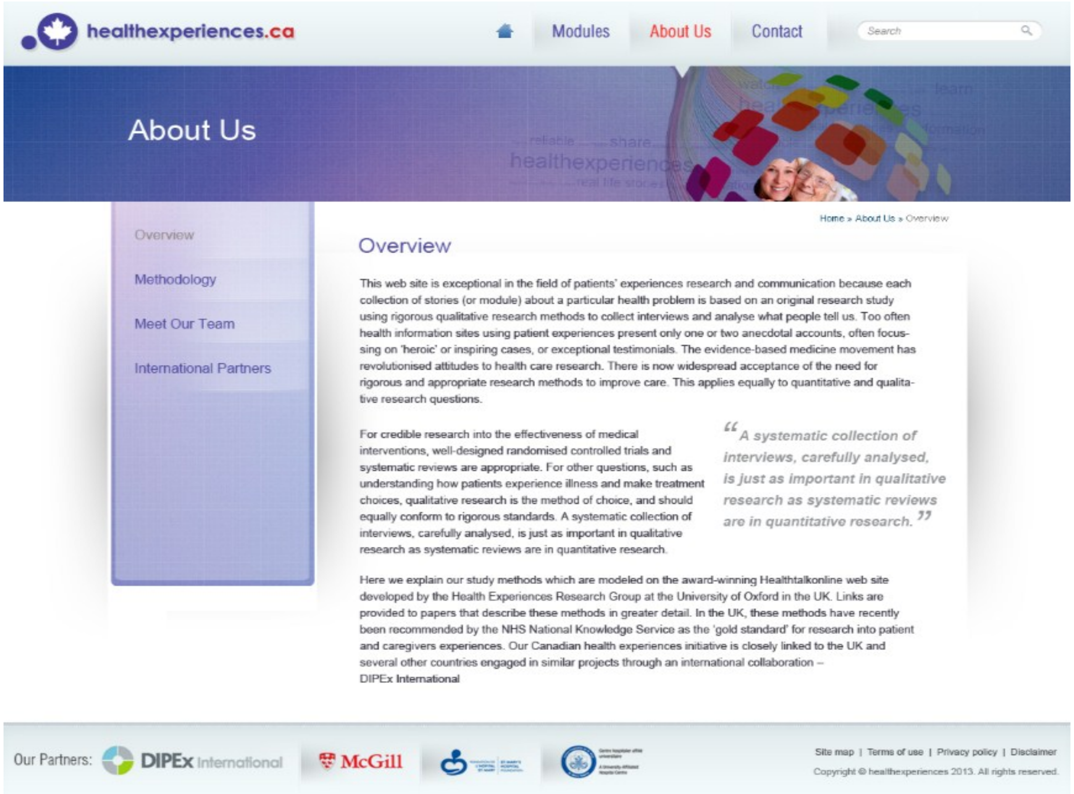
Caregiving Module

This will be our first module of the series, the launch will be in May 2013. Our newsletter will provide you with some more info in the meantime, you can provide 2-3 more lines on text if needed.

Copyright © healthexperiences 2013. All rights reserved.

APPENDIX 8: FINAL WEBSITE DESIGN

Final Website Design Page 2:



Overview

This web site is exceptional in the field of patients' experiences research and communication because each collection of stories (or module) about a particular health problem is based on an original research study using rigorous qualitative research methods to collect interviews and analyse what people tell us. Too often health information sites using patient experiences present only one or two anecdotal accounts, often focussing on 'heroic' or inspiring cases, or exceptional testimonials. The evidence-based medicine movement has revolutionised attitudes to health care research. There is now widespread acceptance of the need for rigorous and appropriate research methods to improve care. This applies equally to quantitative and qualitative research questions.

For credible research into the effectiveness of medical interventions, well-designed randomised controlled trials and systematic reviews are appropriate. For other questions, such as understanding how patients experience illness and make treatment choices, qualitative research is the method of choice, and should equally conform to rigorous standards. A systematic collection of interviews, carefully analysed, is just as important in qualitative research as systematic reviews are in quantitative research.

> *"A systematic collection of interviews, carefully analysed, is just as important in qualitative research as systematic reviews are in quantitative research."*

Here we explain our study methods which are modeled on the award-winning Healthtalkonline web site developed by the Health Experiences Research Group at the University of Oxford in the UK. Links are provided to papers that describe these methods in greater detail. In the UK, these methods have recently been recommended by the NHS National Knowledge Service as the 'gold standard' for research into patient and caregivers experiences. Our Canadian health experiences initiative is closely linked to the UK and several other countries engaged in similar projects through an international collaboration – DIPEx International

APPENDIX 9: DEFINITIONS AND ABBREVIATIONS

[1]**Blog:** Blog is a word that was created from two words: “web log.” Blogs are usually maintained by a person or a business with regular entries of commentary, descriptions of events, or other material such as graphics or video. Entries are usually displayed in reverse-chronological order. "Blog" can also be used as a verb, meaning ‘to maintain or add content to a blog’.

[1]**Chat room:** A space of communication over the Internet that refers to one-to-one communication through a text-based chat application commonly referred to as instant messaging applications.

[1]**Domain name:** Domain names are used in URLs to identify particular web pages. For example, the domain name in the URL “http://www.google.ca/” is “google.ca”.

[1]**Facebook:** A social networking website (www.facebook.com) where online communities can share interests and/or activities. Facebook connects people with friends and others who work, study, and live around them.

[1]**Forum:** A message board or online discussion website that originated as the modern equivalent of a traditional bulletin board. The messages on a forum are archived for future viewing.

[1]**PHEx:** Personal health and illness experiences.

[1]**Top level domain:** Every domain name has a suffix that indicates which TLD it belongs to. There are only a limited number of TLDs. For example: .gov, .edu, .com, and .net.

[1]**Twitter:** Twitter is a microblog, which is a form of blogging that allows users to send brief text updates or other micromedia to be viewed by the public or a restricted group.

[1]**URL:** Uniform Resource Locater. The complete address of a website: also refereed to as the ‘web address’. For example, the full URL for the Google search engine website is: http://www.google.ca/.

[1]**Definitions modified from www.wikipedia.com**

APPENDIX 10: KNOWLEDGE TRANSLATION/APPLICATION OF RESEARCH FINDINGS AND CONTRIBUTION TO FAMILY MEDICINE

Components of the results from this thesis were applied to the Health Experiences initiative led by the St. Mary's Hospital-McGill University team as an integral part of their personal health and illness website development plan. As was discussed in the methods, sections of the work completed for this thesis represented participatory research elements of the larger Health Experiences study. Additional aspects of the Health Experiences study, beyond this thesis project, also included participatory research elements. As part of this website initiative, for example, the research team meets with an expert advisory committee consisting of active and former caregivers, family physicians, social workers, researchers in chronic disease, and a Quebec caregiving association representative. The advisory panel provides advice on parameters of the project and offers assistance with quality assurance by reviewing topic summaries and prominent themes from the caregiving interviews. The advisory committee is also consulted for relevant and useful information resources for caregivers, as well as contributions to sections of the website that describe evidence-based treatments or therapies. Additionally, the Health Experiences study enables the caregivers who participated in the in-depth interviews to take part in the development of the final product by offering them an opportunity to review their transcripts, audio and video material, in order to make the final decision on what will be available for analysis and selection of clips to be showcased on the website.

All relevant feedback concerning the structure and design of a PHEx website gathered as part of the work for this thesis, was translated directly back to the company (KnowledgeOne) who has been contracted by the research team to design and host healthexperiences.ca. Communication with KnowledgeOne primarily took place via face-to-face meetings at St. Mary's Hospital and at the KnowledgeOne offices in Montreal. Following a thorough analysis of the focus group transcripts, the research team developed a presentation with feedback from the caregiving participants in order to guide KnowledgeOne in their efforts to design www.healthexperiences.ca. Collaboration and communication about the web design continued until the research team was satisfied that KnowledgeOne had developed a website that represented caregivers' opinions and addressed their online health information needs. See Appendix 8 for final website design. Additionally, while much of the content of healthexperiences.ca is determined by the in-depth interviews with caregiving participants across Canada, feedback concerning caregivers' preferences for other aspects of the content of a PHEx website (introduction text and videos, socially interactive elements, experiential and factual information, links to external resources etc.) was translated back to the research team creating healthexperiences.ca.

Additional knowledge translation activities included disseminating results of this project through presentations at various national and international conferences in Canada and the USA, as well as at various seminars and meetings at St. Mary's and McGill University.

Providing care for the elderly, people with dementia, or those with chronic illness, is a central role of family physicians in Canada. The growing burden of disease will require innovative and collaborative strategies and partnerships across the healthcare system, but much of this duty will fall within the domain of family medicine and also to family caregivers. Caregivers are a key component of the Canadian healthcare system; collaboration between family caregivers and family physicians will be increasingly crucial to address the burden of chronic illness, dementia, and other illnesses in Canada.

APPENDIX 10: KNOWLEDGE TRANSLATION/APPLICATION OF RESEARCH FINDINGS AND CONTRIBUTION TO FAMILY MEDICINE

Caregivers make considerable sacrifices and face a significant burden of care, which impacts both their ability to continue providing care, as well as affects their own health and wellbeing. Recognizing the importance of family caregivers, providing them with better support, and strengthening their collaboration with physicians is an important goal in family medicine. Caregivers who are better supported may experience improvements to their own health and wellbeing, and also offer improved care to the patient. The Internet and e-health is an exploding resource and has a tremendous potential to become an asset to patients, caregivers and physicians alike. Support services delivered through web-based material can help achieve improved health of the care recipient and support the caregiver in their role. Furthermore, empowerment of caregivers through helpful, relevant, user friendly and trustworthy web-based information could strengthen their relationship with family doctors, and foster improved communication and collaboration in a primary care setting, in addition to improving health outcomes of both the caregiver and patient.