HEALTH MANAGEMENT IN THE AGE OF THE INTERNET

by

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Abstract

This study examines the way people use online resources within their personal healthcare practices to better understand how individuals manage their health issues in the age of the Internet. It specifically addresses the extent to which the Internet is used as an information database and associated patterns of use, whether the Internet represents a source of support or enables a supportive encounter and the implications of using the Internet as part of the health management across relationships with medical professionals and oneself.

Using a sequential mixed methods design, the data was gathered within a larger multidisciplinary research project conducted in East York, Ontario. An initial quantitative analysis of 350 surveys describes Internet usage. The qualitative analysis of the 86 follow-up interviews of people recounting their personal health management processes demonstrated the importance of social networks, subjective health status and Internet user-style.

The facile ability to engage with health information is transforming definitions and experiences of health and relationships with medical professionals. Examining medical encounters mindful of the aspects of trust, power, knowledge and privilege

reveals an evolution to the doctor-patient relationship brought about by both information and personal empowerment.

Using the Internet reinforces primary relationships and points to the development of new relationships that are sought at moments of meaningful life events or circumstances. New types of connections are being built across the Internet based on shared experiences, health concerns and health identities. Applying Actor Network Theory furthers an understanding of how search engines and online resources can emerge as actors in health information seeking and health management processes.

Internet use is now a part of everyday life and is no longer limited to affluent early adopters as the gaps between those with access diminish in urban Canada. While its use is becoming intrinsically linked to health management it is not a panacea for improving health outcomes. As the populations' collective health knowledge increases, so does the presumption that health management is a personal imperative. This notion that the achievement of good health is an individual responsibility or the theory of Healthism, frames the interpretation of the large percentage of the sample indicating they are striving to become healthier.

Social workers need to acknowledge the place of the Internet within its practice and to balance the emphasis on individualized health management with the perspective that health outcomes reflect community mores. It is important for social workers to treat the Internet as a medium of relationships and for social workers to become knowledgeable about what these connections can provide in terms of support and information and what the limitations and risks of these relationships can be.

Dedication

For Violet,

As pioneer, writer and thinker your lessons guide me. Always, your spirit will inspire me.

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Chapter 1

Introduction

1.0 Health management in the age of the Internet

Waking up under the weather with a fever or pain used to require looking in the medical book[1] and calling my Grandmother. Now I open my laptop and research my symptoms. I take for granted that my search engine's results page will contain links to information I deem valuable and reassuring. If Google's search algorithm does not reassure, I will phone and ask my Grandmother about her medical history, or her thoughts on my condition. Should her prairie wisdom be insufficiently comforting, I will book an appointment with my physician.

The Internet[2] (and / or the World Wide Web) and its search engines direct me to far more information than any one reference book. Today I can spend endless hours reading and learning beyond a simple index, but still from the privacy of home.

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[1] The *Medical Book,* a large reference book kept in the kitchen and lifted down at the first sign of a pain, or malady. Remedies and explanations were listed in the index and sorted according to body part. As a child this fascinating resource would entertain and educate in times of illness and health.

[2] The Internet is a global network of computers providing information and communication similar to a system of highways. The World Wide Web is a series of interconnected documents attached by hyperlinks and accessible through the Internet, or the cargo that is being transported on this system highways. Search engines are a mechanism or strategy for navigating through the documents of the World Wide Web that are accessible on the Internet. For the purposes of this dissertation, the word Internet will be used to encapsulate both the Internet and the World Wide Web. Further elaboration of the Internet and theoretical conceptualizations follow in forthcoming chapters.

Sometimes the Internet leads me astray; having me believe that every symptom I imagine is somehow linked to lupus, the critical family ailment carried in my genes. Other times the Internet indulges my curiosities about rashes and bumps, and it offers helpful information of cause and treatment, not unlike my Grandmother.

Recently awaking with intense pain and no help from Google, a professional consultation gave me the diagnosis of Morton's Neuroma[3], a prescription for Internet research and a follow up appointment with a specialist. Seven excruciating days later, hours of researching foot surgery and nerve damage, the podiatrist asked simply, does it hurt when you walk and ease up when you stop? Yes. Good, then you have a "sore foot" and will be fine. What I learned about Morton's Neuroma was accurate; it was the incorrect diagnosis that directed me to misguided research. It was the doctor, not the information that was wrong.

My week of worry and thoughts of looming amputation, made me question the Internet. Should I have avoided it all together? Or was it beneficial that I could prepare for the worst? Was I empowered by the experience, or overwhelmed by the information? In the case of my foot, the information fueled a sort of hopeless panic. When an inflamed eye aroused my anxieties, the Internet became a calming friend, reassuring me that blindness was not imminent. Using the Internet for health research can just as easily fill me with confidence in advance of a visit to the doctor as it can taunt me with hypochondria.

It is the possibility for both positive and negative reactions to the Internet that

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[3] Morton's Neuroma is a serious condition that often results in foot nerve surgery and unpleasant long-term effects.

provokes my curiosity about the effects of using the Internet. My professional interest as a social worker with how people care for themselves, where they seek information and the outcomes of having the Internet at home also informs my inquiry. Consequently, this dissertation examines the way people use online resources within their personal healthcare practices to better understand how people manage their health care issues in the age of the Internet.

As Internet based technologies permeate health care provision, are people trying to self-diagnose? Are they gleaning emotional support from strangers, readying themselves for future medical encounters with online information? Or are they challenging their doctors and reforming the status quo (Brody, 1999; CBC_News, 2003, 2004, 2005, 2011; Yoffe, 2000)? These questions reflect the interests of social work, that is concerned with the health outcomes and well-being of individuals and communities.

While social work and health care began as separate and unique fields, with different objectives their intrinsic link is well documented for more than one hundred years (Auslander, 2001). Within its history, social work is responsible for changing models of health and medical care, by establishing the connection between mind and body and by producing research explicitly articulating the experiences of health and illness. Investigating health practices and health issue management continues to be relevant for social work practice. In the age of the Internet it is timely to look at how people, specifically service users, manage Internet technologies. My dissertation offers an opportunity to explore the implications of Internet use within a health management context as it applies to my social work practice and the community of social work

researchers.

The Internet and Internet use reflects the network of computer's capacity as a valuable information database, a communication device and an empowering encounter. I assert that people engage with the Internet in many different ways, each one influenced by socioeconomic status and demographics, health issues and social network characteristics. I will examine the circumstances surrounding how much time people spend using the Internet at home and work and school as they relate specifically to managing health issues.

Seventy eight percent of Canadians are Internet users and ninety-four percent of them access the Internet from home (Zamaria & Fletcher, 2008). Two thirds of those Internet users are looking for health information. At its best, online health information and communication can empower, encourage and support people to thrive. At its worst, health information can contribute to misdiagnosis, lead to treatment non-compliance and negatively disrupt long-standing relationships with medical professionals. Ultimately, people engage with the Internet and the available support and information in a variety of ways, some of which may be harmful, others of which may be beneficial. For social workers and human service workers this potential for usefulness and harm is important to be aware of because clients and their families are more likely to be involved with health information technologies in the age of the Internet.

Whether everyone is going online for information and emotional support, or people are still attending to their offline medical relationships and primary networks, the ideal setting to view how people engage with the Internet is within the homes of a general

population of people who do not necessarily have targeted health issues, but are managing a continuum of needs.

To fully understand the significance of my use of the Internet to find health information, it is vital to review the links between health information and health outcomes and the discourse surrounding medical knowledge; to identify how theory influences our concepts of the Internet and how social network analysis helps to make sense of why the Internet appears to fit seamlessly into our everyday lives.

My overarching research curiosity is about how people manage their health issues in the age of the Internet. Health management requires a relationship with a health professional, and a certain perspective on caring for the self, and popular notions of health and health care. This thesis takes the single inquiry "how do people manage their health issues in the age of the Internet?" and approaches it by asking three distinct research questions: 1) To what extent do people use the Internet as an information database and what are their patterns of use? 2) Does the Internet represent a source of support or enable supportive interactions? 3) What are the implications of using the Internet as part of health management, and changing relationships with medical professionals?

My dissertation begins with a description of the influence of health information and ends with a discussion of the implications of the ever increasing ability to quickly and easily access this health information in the age of the Internet. Health information, which includes medical knowledge, knowledge of the self and the body and public discourse about health and wellness is connected to health outcomes. This connection is

well documented within the social support literature. Such knowledge and information however, has not always been readily available or easy to access. As such, there is a difference between those with access to knowledge / information and those without. This accessibility is often mediated by one's relationship with health information providers which in turn influences our definitions of health and our experiences of health management (Lupton, 1995a).

Information typically flows through relationships, either with network members, opinion leaders, or primary group members (Burt, 1999; Katz & Lazarsfeld, 1955). Information diffusion and flow is changing with the proliferation of the Internet. This chapter considers that while the Internet is available to many and influences access to information, the Internet has not replaced all previous methods of information diffusion.

In fact, the Internet represents many ways of engaging with health information through databases (file sharing) and communication strategies (email and messaging). Such means of engagement are both theoretically and actually different. Some theorists believe the Internet affects behavior, others see the Internet reflecting human potential, for others the point of interest is the interaction with the technology, still others view Internet use to be a convenient option, used for its capacity, rather than its dominance.

When the Internet is described as a location, as in a place to go, or as a tool or device of empowerment, that can change behavior, it is being given space and form and is metaphorically made into either an object or an experience, or both. This association of metaphors and abstractions allows researchers to articulate this complex technology into concrete terms to foster an ease of understanding. The theoretical framework of the

researcher investigating the technology informs how the Internet is conceptualized.

Theoretical frameworks give language and context for research while developing a comprehensive strategy of analysis. To understand health management in the age of the Internet, my next chapter chronicles the evolution of the Internet and IT technologies. Technological determinism and Actor Network Theory are discussed in relation to current thinking about the Internet, Internet adoption and the potential consequences of its use. Actor Network Theory invites a definition of the Internet beyond simply a static metaphor to one that reflects how the way in which the Internet is being used and engaged with influences the definition and experience of it.

Chapter Three builds on the notion that the Internet facilitates access to information, to communication and to social support. By reviewing the literature associated with each style of Internet engagement in the context of personal health management, this chapter suggests what is missing from research about how Canadians manage their health issues. It is a comprehensive examination of how people are engaging with health information and social support for health issues on and offline.

Chapter Three also restates my overarching research objective, which is to investigate how people engage with the Internet when managing health issues and presents my three research questions and their associated specific inquiries. My research questions are: To what extent do people use the Internet as an information database? Does the Internet enable a supportive encounter? What are the implications of using the Internet? Therefore, I will be specifically considering: What sorts of activities are pursued online? How does Internet use fit into other health practices? To what extent do

people in different social positions vary their Internet use? How does use/non use for information and communication affect well-being? How does health issues or illness affect use of Internet? To what extent do people feel more or less empowered by the experience of using the Internet? Is there evidence of empowerment in interaction with practitioners and institutions?

Given social work's commitment to analyzing power structures and optimizing health outcomes, chapter Three ends by considering the implications of my research questions for social work practice. Relationships are the centre of social work practice and the Internet is becoming an integral part of relationships as it facilitates communication. Moreover, the Internet is far more than an information source. It not only mediates communication, it disseminates information that can both empower individuals to challenge assumptions of existing relationships and normalize health conditions by creating connection and community.

Chapter Four introduces the Connected Lives Project of which this study was a constituent part. The chapter describes the sample the research setting and the methods used in the Connected Lives Project. Data about health issues, perceived health status, Internet use and social networks were collected through survey, interview and social network data and observations. The population of East York, Ontario includes people with lifestyle, acute, terminal and mental health issues as well as non-Internet users. Following the methods and measures chapter, there are three substantive findings chapters detailing how people use the Internet as a database when they have something to look up, as a communication device when they require support and as an empowering

encounter, changing how they work differently within their medical relationships as result of having access to health information.

The Connected Lives Project gathered data between 2004 and 2005. The analysis reflects the state of affairs in the years the project was conducted. Online health information repositories were new and online support groups and communities were vastly limited in comparison to what is available today. Social networking websites, micro-blogging and highly specialized targeted health issue online communities did not exist on the Internet when I gathered my data. As such, this dissertation offers a useful record of a time *before* Internet proliferation firmly took hold of the daily life of Canadians and became integral to health management practices.

Chapter Five the first findings chapter, focuses on using the Internet for *information* and the prevalence of this type of online engagement. This chapter's focus is on highlighting how people manage their health issues using Internet based information and the consequences of that use. The role of the Internet as a database is explored in relation to other sources of information. On and offline information seekers are compared in tested hypotheses related to network size, demographics and health status.

The Sixth chapter looks in more detail at the health *communication* patterns of people in East York. Particular attention is given to those who use the Internet to communicate about their health issues and the details and patterns of that communication. Differences across demographics, health status and Internet user style are reported.

Chapter Seven looks at how Internet use is changing how people manage their health conditions. Issues of self-diagnosis, communication with medical professionals

and other types of empowerment like activities are presented and compared within the population. Particular attention is paid to the way the relationship with the Internet affords a level of familiarity that is most generally associated with network members. The consequences of these results are discussed.

The Eighth and final chapter summarizes the findings from the analysis of how people manage their health issues in the age of the Internet. My analysis points to both positive and negative implications of technologically mediated health management in turns of health care practices, doctor patient relationships and the evolution of personal definitions of health. Human service users are online and engaging with IT to address their health needs. Changes to health care practices affect the policy and practice of social workers and social work researchers working in the health care field. Evolving notions of self, health and individual responsibility for well-being have far reaching implications for practitioners no only as services going online, but as people become more comfortable and empowered to champion their own health management strategies.

Chapter Eight also offers limitations of the thesis and suggestions for future work. Despite the insights achieved in this research, I remain curious about the effects of the intimate integration of Internet use into health management strategies not only on our definition of health and wellness but also on our individual expectations regarding the possibility of assuming individual responsibility for our own positive health outcomes.

Chapter 2

Theoretical Frameworks: Access to and influence of Health Information

2.0 Introduction

I know my spouse and certain friends will help me when I am sick. They will bring home remedies and review my symptoms online. Their care and actions comprise the concept of social support. Social support also captures the sense of comfort I feel in response to receiving the tangible information and emotional connection they provide. Just knowing that the people around me have valuable things to offer is beneficial for my health and well-being.

Being able to access health information is another part of social support provision. While learning about symptoms and side effects used to be the domain of a medical appointment or specialized reading material, now I can perform research online without professional consultation. Health information is losing its mystique, as laypersons are becoming researchers and taking responsibility for their own health management.

As technology permeates health management, how will social support provision and information diffusion adapt? To both understand and investigate these questions this chapter examines the context, history and theory of social support, information diffusion,

information searching and the Internet. This chapter presents definitions of social support and the effects of information on health outcomes. Additionally, the evolution of the Internet and the ensuing digital divide is described. The concepts of information diffusion and searching will be articulated in relation to the Internet's capacity to be an information repository. Finally, a discussion of the theories that assist researchers in thinking about, articulating, describing interactions with the Internet is offered.

2.1 Health information and social support

In the 1980's researchers began to look at measurable factors that predicted how soon people would get better after falling sick and what protected them from initial onset of illness (Cohen, Underwood, & Gottlieb, 2000; Cohen & Wills, 1985; House & Kahn, 1985; Wills, 1982). Interestingly much of this research was designed to gauge the effects of social integration and isolation during a time when it was feared that the notion of community was dissolving (Barry Wellman & Frank, 2001; Barry Wellman & Hampton, 1999; Barry Wellman & Hiscott, 1985).

A review of preliminary social support research suggests the factors most closely associated with positive health outcomes that comprise social support are often referred to as: i) emotional support: the provision of care, empathy, love and trust, ii) instrumental support: tangible aid, concrete assistance, performing assigned work, or giving money, iii) informational support: the information provided to another during a time of stress that assists one with problem solving, iv) appraisal support: which involves the communication of information that is relevant to self-evaluation rather than problem

solving (Barrera & Ainlay, 1983; Cohen & Wills, 1985; Tardy, 1985). This includes expressions that affirm the appropriateness of acts or statements made by another (Dow & McDonald, 2003; Hinson Langford, Bowsher, Maloney, & Lillis, 1997).

The concept of social support emphasizes the importance of information and emotional connection for positive health outcomes in addition to the value of personal relationships with general well-being. As I investigate health information seeking in the age of the Internet I consider the possibility of the Internet use as a medium that can provide the information and emotional connections that make up social support. In the same way that interpersonal relationships are thought to locate social support provision, I think it is worth considering the interactions with the Internet as a context for social support provision. As people retrieve information from the Internet, go online for emotional connections, their health outcomes, their experiences of health and health issues will be influenced.

2.1.1 Consequences of social support

Gathering information and making emotional connections in times of need helps people feel better when they are sick (Barrera, Glasgow, McKay, Boles, & Feil, 2002; Kalichman, et al., 2000; Uchino, 2004; Weingarten, 2000). In addition to keeping them from getting sick in the first place (Cohen & Wills, 1985; Hinson Langford, et al., 1997; House & Kahn, 1985; Uchino, 2004; Barry Wellman & Frank, 2001).

When social support is material like advice, money or financial aid, it shields against immanent stress. For example, the stress of a debt is relieved when a friend offers money. When the support is offered in the form of emotional connections and supportive

relationships, it can prevent the onset of stress (Barrera & Ainlay, 1983; Cohen, et al., 2000; Cohen & Wills, 1985; House & Kahn, 1985; Uchino, 2004; Barry Wellman & Wortley, 1990). Having a friend to discuss important matters with on a regular basis can mitigate the cumulative effects of daily stressors. The combination of received and perceived support, in the form of relationships and information not only prevents and provides protection against the negative effects of health concerns; it positively affects health and well-being (Hinson Langford, et al., 1997; House & Kahn, 1985; Uchino, 2004; Barry Wellman & Frank, 2001).

Social support exerts an indirect effect on adjustment and health by directly reducing perceived and/or actual stress, which, in turn, leads to wellbeing (Mitchell, Billings, & Moos, 1982). Empirical studies of how social support operates to reduce stress and/or bolster psychological and physical well-being focus primarily on two models, the "direct" and "buffering" hypotheses.

The direct hypothesis states that social support influences psychological and physical health independently of life strains and pressures. Having friends and family around me, whether I am asking them to help or not, offers protection from life's anxieties. Whereas the buffering model maintains that social support shields and protects individuals against the deleterious consequences of stress. Those subjected to the most stress benefit the most from the stress-alleviating properties of social support. Being able to call on people when I require helps, reduces the negative consequences of the associated needs. The term buffering is used because it is believed that social support lessens the pathogenic effects of a stressor (Cohen & Wills, 1985). Thus, the buffering

effect is only seen in times of increased stress. Essentially, social support is believed to alter the appraisal of an event as stressful, by directly changing the affective response, or by providing tangible resources for problem solving (Cohen, et al., 2000).

House (1981) reviewed research investigating social support in the workplace and concluded that both the direct and buffering effects of social support were "remarkably consistent" with positive health outcomes. However, other reviewers of these studies (Cohen & McKay, 1984; Schaefer, Coyne, & Lazarus, 1981) have highlighted the conflicting evidence and methodological problems that cast doubt on House's (1981) optimistic conclusion. House (1981) found that regardless of the detailed explanations as to how social support works, the key findings are that social support is beneficial and without it, health outcomes are not as positive. When health outcomes are compromised, people remain sicker longer and have more severe symptoms. If the stresses of life have lead to illness and disease then supportive networks can offer comfort. These same networks can also insulate one against the onset of stress related sickness and discomfort.

2.1.2 Sources of social support

The social network is the structure through which social support is provided (Kahn, 1979); it is also the context for the interactive process that produces social support.

Social support is built on social network characteristics such as social ties, the links between individuals and density, the number of links in a person’s network (Barry Wellman & Frank, 2001; Barry Wellman & Wortley, 1990). However, the presence of a large social network does not necessarily indicate large amounts of support (Kahn &

Antonucci, 1980).

Individuals generally benefit from family support during times of illness, despite the potential negative consequences of the provision of that support can have on the family members themselves (Ell, 1996). People tend to seek emotional support from their family and friends and consult medical professionals for information (House & Kahn, 1985). When alternative interventions are required, people often progress through many members of their social networks with both strong and weak ties, before they attain the support strategy they require (Beverly Wellman, 1995). In as much as support can be gleaned from within and outside of the social network, support can be derived from different kinds of information. There are different implications from receiving advice or general information or topic specific material such as health information.

2.2 Health information and patient empowerment

Both knowledge of medical issues and the experience of the body or the self are facets of what is meant by health information. Health information can be used to determine differences between normal and deviant health outcomes and differentiate between wellness and disease. Sometimes, health information is the unspecified knowledge and information that is comprised within the concept of social support, received and sought in times of need. When health information is medical knowledge it was once confined to medical books and medical professionals who restricted its distribution to patients and lay persons. Today, the availability of health information online reflects a juxtaposition of the Internet's capacity to be an information repository

and an evolution in the doctor patient relationship.

This section offers a brief history of changes to the doctor patient relationship with the aim of showing that the availability of health information both reflects a change to the relationship and indirectly affects the relationship. Such availability of information affects people through their experiences with medical professionals, in the roles taken in health management and in the acquisition of social support.

Before the 1960's, medical knowledge was kept within the domain of the medical professional. Lupton's (1995) accounts of these early medical encounters depict experiences emphasizing doctors gaining compliance from the patient. The doctor was apprised of the appropriate procedure or course of action and it was up to this professional to have patient comply with the orders. That patient was often merely a passive recipient (Seçkin, 2009).

A critique of the status quo of medical practice arose from a Marxist perspective, and from general critical structural theories, from liberal humanism and from the social movements of the 1960s and 70s. The emphasis on the importance of individual freedom, human rights and social change that were becoming a dominant discourse challenged the notions of medical dominance. This "medicalization critique" arose in response to medicine's increasing amassed power and influence and challenges the notion that individuals would have their autonomy constrained by more powerful others (Lupton, 1997).

According to Lupton (1997), this medicalization critique was one of the most dominant perspectives in the sociology of health and illness in the 1970s and 1980s. It

remains a dominant approach for feminist writers and critics who adhere to a structural critical perspective on health and illness and advocated for the consumerist approach to medicine. No doubt this perspective calls attention to the possibility of inequality in medical encounters and the delivery of health care. However, this critique neglects the positives of a difference in power between patient and professional, and neglects many patients' willingness to participate in medical dominance (Lupton, 1997).

In the late 1970s professional dominance across many service provision fields began to wane as they experienced a crisis of legitimization (Prior, 2003). This crisis led to more patient participation in treatment and care planning in many service fields, medicine and social work for example. This democratization of the decision-making processes became evident in medical practice with an increased interest in patients' knowledge of their experiences of health and illness, and an increasing value placed on lay knowledge of disease experiences and personal experiences of the body.

During the 1980's further developments influenced the accessibility of medical information. Prior's (2003) historical review of doctor patient relations refers to a striving for balance between doctors and patients by providing access to information, and information "sharing".

At the same time, Hunt and McEwan (1980) created the subjective health indicator, a tool created to procure a sense of how people feel in terms of their experiences of a medical condition. This measure of feeling was intended to redress the balance between lay and professional objectives in health measurement, something previously missing from health knowledge.

When physicians acknowledge the individual experiences of their patients, give him/her more information they are affording them more autonomy. With autonomy, the patient can look at him/herself, and recognize his/her needs for treatment and care. No longer must the patient passively receive treatment or judgment. As such, when a person is in charge of his/her own health and is acting upon their own determinations of treatment and intervention, the relationship with the medical professional shifts and the division of power changes. It is the availability and access to knowledge that influences the flow and the potential for exchange of power within the doctor patient relationship.

By understanding this potential for development, it is possible to gauge the effect of having access to health information online through the Internet and World Wide Web. Where once health information was closely guarded and enshrouded with privilege, and would not be distributed for fear of challenging the doctor patient relationship, now that health information is readily available, and arguably more accessible, it is no longer guarded or accessed solely within a relationship with a medical professional. As such, the public can access the health information of their choosing. Such freedom will ultimately influence their experience of health and their long-term health outcomes.

As the Internet took hold in the 1990s, the term “lay expert”, a phrase describing lay persons thought to hold a wealth of experiential knowledge about a particular medical condition made its first appearance in the research literature. While Prior (2003) recognizes the value of lay knowledge and “expertise”, she does highlight that lay experience is inevitably limited and idiosyncratic and can certainly be wrong. So while the access and availability of information does benefit lay persons in some circumstances,

the confidences and arrogance that might be associated with the notion of lay expert might ultimately prove to be harmful. Segal (2009) similarly voices concerns that lay persons, regardless of experiential expertise are not capable in the art of diagnosis.

With the turn of the 21st century, the infiltration of the World Wide Web and the ease of distribution of medical information, whether there is access to health information looses its emphasis for researchers. Instead, inquiry is now focused on the effects of unrestricted access to online health information. According to Nettleton (2005) the influence of online health information can have one of three effects: celebratory and empowering, concerned and dangerous, or contingent and embedded. This division within the literature continues, as online health information research is divided between those who frame web information as potentially empowering and others who see it as potentially harmful (Mager, 2009). Further discussion of this research is discussed in Chapter Three.

Today's medical encounters reveal changes to assumptions about dominance as medical relationships are democratized. Patients are becoming included in their own treatment planning as definitions of health and illness change to include experiential knowledge. The implications of this development are often framed in terms of patient empowerment, where empowerment refers to patients being able and encouraged to advocate for their own ideas about care and treatment.

Empowerment began by giving patients voice and a place within the medical encounter. Now empowerment is coming from access to information outside of the doctor patient relationship. This access not only empowers, but affects social support and

health outcomes. It is relevant to know about the evolution of access to information within the context of the doctor patient relationship because health information reflects and produces changes to that relationship, to experiences of health management and to the acquisition and provision of social support.

2.3 Information diffusion

Having access to information improves the likelihood of gleaning social support and influences relationships with medical professionals. Information is only influential however, if it is accessible. While the Internet is an efficient information repository, it does not necessarily guarantee access to or distribution of needed or sought after information. This section reviews basic concepts of information flow and offers specific examples about health information diffusion.

Katz and Lazarsfeld's (1955) ground breaking book "Personal Influence" discovered that despite optimism about the effect of mass media communication, many people do not in fact blindly accept information messages received through the media or other authoritative sources. The traditional media effects model assumes that media messages directly influence the opinions, attitudes, beliefs and behaviors of audience members. The alternate two-step communication or intermedia theory posits an indirect influence of mass media messages through the interaction of interpersonal exchanges. Katz and Lazarsfeld (1955) describe messages passing from a media source to an individual and from them to their network of influence. Information and opinions about that information are typically acquired from other people.

The influential friends, family members and acquaintances that provide the information may be labeled “opinion leaders”. Opinion leaders are regarded as authorities on, or are simply well informed about certain topics (Allen, 1977; Dimmick, 1974; Hirokawa & Lowe, 2002; Katz, 1957; Katz & Lazarsfeld, 1955). These central people influence those around them by passing on and sharing information and voicing their own opinions. Such a progression can result in learning, decisions, choices, and opinion changes among the friends, family and acquaintances they are in contact with.

Within the “two-step flow” of communication, information and ideas move from a media source to “opinion leaders” and from them to other people in their social network (the primary group). A primary group locates a person’s social reality and is defined as a system of interpersonal relations among friends, co-workers, family members, neighbors, and the like that is characterized by regular interactions (or communication).

The opinions, beliefs, attitudes, values and behaviors that media campaigns are seeking to modify are anchored in “primary groups”. However, within these primary group, some members are more susceptible to the persuasion of media messages than others. Referred to as “gatekeepers”, these individuals pass on what they read, hear or see in the media to others within their network that are less exposed to the media. Gatekeepers are not passive relays of information in a primary group, though they often exert their own biasing effect on mediated messages by either reinforcing or counteracting the messages they relay to other in their primary group (Hirokawa & Lowe, 2002; Katz & Lazarsfeld, 1955).

In some primary groups the gatekeeper and the opinion leader are the same

person. Opinion leaders essentially intervene between mass media messages and resultant opinions, decisions and actions by recipients of those messages. Opinion leaders can also promote or negate media messages circulating within the group.

After conducting an investigation of health information diffusion within medical communities where physicians described patterns of information spread, Katz (1957) found that social networks were most influential among the doctors who were integrated into the community of their colleagues. For these doctors information flowed through professional ties of a professional nature, predominately with advisors, or formal discussion partners. Health information then spread through their friendship networks to other doctors who were closely tied to the medical community.

While the paper's original aim was to create a comprehensive model of health promotion, the authors ultimately provide a concise summary of the benefits and attributes of thinking about the two-step communication model of information distribution as a means for understanding how to best diffuse health information within health promotion campaigns.

Since 1957, there continues to be interest about the theory of information diffusion and the ways and means that information is flowing within communities. The two-step communication model points to the value of people and relationships for information dissemination and the importance of networks and network composition when considering how ideas and facts flow from an original source. Further sections will describe empirical research on the actual workings of media influence underscoring that the electronic media is less powerful than originally conceived, and that primary relations

continue to be relevant to the flow of mass communication.

In the case of this dissertation, this theory holds relevance because information seeking and access is not just about the information source, it is about acceptance of the information itself. Relationships are important for information flow and diffusion, not just grand media outlets.

As the Internet changes how people access information and how information campaigns choose to communicate information, the relevant questions are whether or not the Internet is thought to be an authoritative source of information, or if information spread through the Internet requires opinion leaders and gatekeepers to ensure diffusion of particular messages.

A telephone survey of adults asked about knowledge of, concerns with, and interest in genetic testing, an emerging health topic, suggests that the Internet may be changing the nature of the opinion leadership, whereby it no longer needs to be an individual when online sources can provide both authoritative (such as medical journals) and interpersonal (online support groups) sources of information that are readily available outside the bounds of ones social network (Case, Johnson, Andrews, Allard, & Kelly, 2004).

This research reflects the continued relevance of the "two-step flow model that frames the thinking about not only how information is shared and communicated, but what role the Internet plays in its diffusion. If only those who are well informed are seen as trusted information sources, does the Internet's capacity as information repository position it as only a media outlet, or can it take on a role of opinion leader or gatekeeper.

Whatever the case, despite the availability of health information online, its presence does not ensure distribution, use or integration.

2.3.2 Health information campaigns

Traditionally optimistic mass communication scholars believe in the power of the media to shape and control the ideas, attitudes and behaviors of societal members (Berelson, 1959). Similarly, health campaign scholars initially assumed that the media are powerful social tools for shaping and altering the health-related attitudes, beliefs and behaviors of people. This belief was challenged however, as many mediated health campaigns produced either minimal or no overall effects on various health outcomes. In the specific case of health information seeking Lenz (1984) found that the public obtained much of their health information from acquaintances and many different, general mass media outlets within the course of their daily lives. Rarely do people glean specific health information from targeted campaigns intended to influence a knowledge base or behaviour. Instead, health information seeking follows the two-step flow of information previous described.

Medical information was once most likely to be obtained directly from health care professionals, or indirectly through friends or family members who were accessible and perceived to be opinion leaders. Information that was once obtained second-hand from friends and acquaintances, as in the traditional two-step flow model of information diffusion is now found in one step as the seeker goes online and pursues information of relevance to their particular situation, rather than receiving information distributed by an opinion leader. Today, information about diseases, treatments, and prevention is readily

available over the Internet; thus consumers may bypass some of the more traditional sources of health related information. Consequently, as the Internet expands the readily available sources of information of all types, information diffusion patterns change.

Using survey data of people looking for information about genetics, researchers found that respondents were most likely to turn to the Internet first then to medical doctors, and finally to libraries for information about cancer genetics (Case, et al., 2004). These results are interpreted with concern, as they appear to be a significant mutation to the two-step flow model. Similarly, they are mindful of the emergence of the Internet as an omnibus source may have changed the nature of opinion leadership; both authoritative and interpersonal information is available online. They question whether the Internet, with its accessibility, anonymity and potential interpersonal authoritativeness may now act as a substitute for the classic two step paradigm, supplanting the social and physical proximity dynamics of interpersonal networks.

This piece of research initiates a dialogue about the benefits of using the Internet for information seeking, and poses the question, what is the alternative to two-step flow of information? As has been pointed out by Pescosolido (1992) people do not make a single decision nor do they plan a series of choices, but rather they continue to seek help from multiple sources until they resolve their problem or exhaust their options. Because they only asked people about one type of information (genetics) which is very new and not likely to be known about by a lot of people, this might have skewed their results.

Recent concerns have been raised about the accuracy of information encountered over the Internet, just as similar concerns have been raised in the past about information

from the mass media, friends and family (Johnson, 1997). At the same time, many advocates of online health information suggest the Internet holds considerable potential for helping patients, not only because of the wealth of information, but the anonymity available when accessing it.

Despite the Internet's considerable beneficial potential, there are concerns about the quality of the information, the difficulties associated with finding the information, the lack of access for those not online, and the potential for harm that comes with over exposure to information. Benigeri and Pluye (2003), provide a concise review of literature associated with these costs and the benefits of using the Internet for health information retrieval. They neither take into account how people engage with the Internet nor the mechanism of judgment used by the information seekers. Instead, the researchers portray the Internet like a media of mass communication akin to that used in the 1950s. For them, the Internet is an opinion leader, distributing information that is immediately trusted and consumed.

Conversely Keselman et al (2008) found that when people were asked to research symptoms and to answer various questions based on what they went looking for online, they did not do very well. Some people found inaccurate information to support their own hypotheses. Others found the process to be too difficult and gave up before completing the task. So people either performed the exercise incorrectly, or gave up before they found anything helpful. When people are really emotionally invested in finding something out, they will likely have mores success. The researchers concluded there are many reasons to be concerned that mere access to electronic health information

does not necessarily empower consumers and patients. Despite the rapid growth in the number of consumer health websites, lay individuals often have difficulty locating, comprehending and applying health information. As such, it is important to not presume the Internet to be a great provider of targeted health information, despite its capacity as a repository and distribution point.

2.3.3 Information seeking

Several principles of information seeking apply to all people, no matter who they are or what context creates their information need. Results from information seeking research pre-Internet age identifies that people seek information first from their own experience, then from people like themselves (Faibisoff & Ely, 1976). People seek out information that is most accessible and with Internet infiltration this continues, since people follow habitual patterns and employ search strategies, institutions and systems used successfully in the past (Pettigrew, 1998). Additionally, people seek assistance in the form of information, from sources they perceive to be the most helpful, trustworthy and reliable, but information seekers tend to use formal and institutional sources as a last resort (Chatman, 1991; Harris & Dewdney, 1994).

Additional principles of information seeking are: an individual's situation and context help determine the information needs; the individual's social network influences the recognition of information need; the decision to seek information; and the selection of an information resource and access strategy (Sonnenwald, 1999).

Ultimately, people want emotional support and understanding from the sources they consult and these sources are considered to be helpful even if they are not accurate

(Chen & Hernon, 1982; Harris & Dewdney, 1994). Certain groups are more adept than others at expressing their needs for help and accessing potential resources and the needs of those who are not adept at expressing their information needs go largely unfulfilled (Chen & Hernon, 1982).

Dervin (2005), an expert in the field of health information searching, suggests that information seeking is itself a complex process and may rely upon external factors beyond the simple availability of information that determines where a seeker will go to find what is needed. Dervin (1999, 2001) describes a sense-making model that presents information as subjective, cognitive and situational. Information is defined as something that is partly constructed by the information seeker. The process of searching for information includes context, a mode of interpretation and a network of affinity. Readiness, trust, and other behavioral factors (in combination) influence the process, especially when people are looking for health information (Dervin & Nilan, 1986).

The assumption that information is exchanged when the recipient has a relationship with the source is not exclusive to information seeking theory. This also rings true in social network analysis. Information flows through networks of trust on the basis of closeness, or more specifically, on the basis of communication with others (Nardi, 1995). Furthermore, Nardi suggests that information is exchanged through effective communication, achieved by a field of connection afforded by affinity, attention and commitment. Information transfer and exchange is thus contextualized within social networks.

How will this translate to searching for health information online? Is the Internet

a tie whom one trusts and from whom information flows? Or is the Internet, as an information source, a media outlet requiring an intermediary to pass along appropriate content? It is important to be apprised of information seeking theory because those patterns may or may not play out when considering how, where and when people search for information within their health management strategies.

Hargittai's (2003, 2004, 2005) work suggests, it is not simply relationships that provide information, but the interplay of factors that determine the information within reach of users, especially in the context of information afforded by the use of the Internet. Based on the investigations of people looking for cultural information, the author concludes that the wealth of data and content diversity available online does not guarantee ease of accessibility. Successful Internet searching is contingent upon age, education and skill rather than income and socioeconomic status characteristics.

2.4 Information flow and the Internet

Information seeking researchers are captivated by the power and presence of the Internet, since Internet based information searching is a complex process. Information seeking is more than retrieving tangible artifacts from the Internet. Simply recording patterns of search and retrieval is ultimately insufficient. Information seeking is a perceived experience with passing through multiple channels, influenced by personal and situational variables. Therefore it is important to investigate an Internet based information seeking process through a wide lens to ensure all the significant influential factors are captured and considered.

When looking at information diffusion in the context of Internet means thinking about issues of access and availability of the Internet itself and not just the information it leads to. Initially, the Internet was not available to everyone, and researchers investigated the digital divide. Then, as issues of access to online resources waned in North America, differences across Internet users were classified according to skills. All the while, a debate over the influence and benefit of the Internet persisted.

The following section intends to review the history of the Internet, the significance of the digital divide and the utopia/dystopia debate of the online experience as they pertain to understanding how people access health information in the age of the Internet.

2.4.1 History of the Internet

Joseph Licklider, an electrical engineer at the Massachusetts Institute of Technology (MIT) envisioned a globally interconnected set of computers through which everyone could access data and programs from any site and called it the "Intergalactic Network" concept (Licklider & Taylor, 1968). Licklider was also appointed to the US Department of Defense, Advanced Research Projects Agency, and by 1969, the Advanced Research Projects Agency Network (ARPANET) became the first group of networked computers that could communicate with each other. Four universities were connected and became a research system where computer scientists could communicate and solve problems while building online connectivity. By 1973, this early version of the Internet was used primarily for email discussion.

In the late 1970's Vint Cerf and Robert Kahn came up with the Internet Protocol

(IP), which streamlined the networking standard. Since there were only 188 host computers in the network, assigning numeric addresses remained efficient. By 1984, the domain name service was created which allowed for the organization and classification of all online sites.

In 1991, Tim Berners-Lee, an English computer scientist, built the first web browser, including an integrated editor that could create hypertext documents on a NeXt computer, as a way for people to share information. The hypertext format allowed people to see documents on screen without having to download them first. The first browser was soon developed and it enabled a fluid use of online images and graphics. By 1996, 45 million people were using the Internet worldwide. By 1999, the number of international users reached 150 million.

With any new technology there are early adopters, those who start using the technology first; either because of financial possibility, access or interest. Once the early adopters catch on, others (late adopters) will follow. Being mindful of the challenges to keeping up with technological trends without sufficient financial backing or opportunities for access, the US and Canadian governments each strove to construct both urban and rural Internet access. All the while, researchers investigated the differences between those with access and those without. Understanding the history and current relevance of this research is vital to diffuse uneasiness about those with access and those without.

2.4.2 The Digital Divide

The digital divide is a term coined to capture the gap between those with access to the Internet and those without. Such characteristics as gender, education, ethnicity,

income and language could account for this divide across the digital landscape. As rates of Internet adoption are increasing steadily, the distinctions between users and non-users is no longer as visible using the same lens.

Initial thinking stated that the Internet was only beneficial to those with access, and that gave an unfair advantage to many (Kolko, Nakamura, & Rodman, 2000; Liff & Shepherd, 2004). A second wave of digital divide research pointed to a skills divide, as it now seemed as though gender and income were not the primary reasons for a difference across usage rates (Hargittai, 2003, 2004, 2005). The current third wave of digital divide research attempts to include access to bandwidth and language (Rains, 2008; Zamaria & Fletcher, 2008).

2.4.3 Utopia/dystopia: debates about the Internet

The invention of the Internet and evolution of the World Wide Web into households was celebrated and upheld as a panacea for all manner of domestic and workplace issues of communication, connection across distance and efficiency. The Internet promised wealth, connection and a global economy for all (Raymond, 2001; Rheingold, 1993; Barry Wellman & Hampton, 1999).

When the stock market crashed in the late 1990's, the Internet became a dangerous playground and stern warnings accompanied the pursuit of online activities. Use of the Internet now predicted isolation, loneliness, addiction and worse (Kraut, et al., 1998)! Post crash research emphasized the technological privilege of the elite as race, gender, education and income tended to predict early Internet use at alarming rates (Kraut, et al., 1998).

Fortunately, the dystopian worldview was short lived and Internet researchers again recognized its value in assisting people to search for information and communicate with others, while making it easier to form and maintain relationships (Boase & Wellman, 2006; Miyata, Wellman, & Boase, 2005; Wang & Wellman, 2010).

Despite the worries about the potential impact of the Internet, the differences between the people with access and those without, the perspective persists that it is essential that everyone be able to get to the Internet and have the skills and training necessary to use the world wide web to its full potential (van Kemenade & Health Canada, 2002).

As the Internet continues to evolve, the networks and software and hardware linking the computers in the intergalactic capacity continue to thrive. It is the thinking, or the theories that inform the conceptualizations, reifications and metaphors of the Internet that also evolve.

2.5 Conceptualizations of the Internet

For my software engineer husband, the Internet is a series of networked computers communicating over IP, linked by routers and electricity. For myself as social worker, the Internet is a realm of possibility, empowering information on a screen; relationships and support a keystroke away. This duality of tangible object and abstract concept makes the Internet ripe for interpretation and reification.

While the Internet is about computers, its content can entertain, empower, teach and break down barriers. Its software can expand social networks, foster communication

and facilitate the acquisition of social support. The act of going online to interact with its expansive potential can challenge and extend how individuals view themselves and others. It is theory that helps to put these potentials into context.

The way someone describes the Internet, the language they use to account for it identifies the theory to which they ascribe. When a researcher places significance on one aspect or function of the Internet, they are identifying the theoretical framework that grounds their thinking. Of course reification, treating an abstraction as a material thing, is difficult to avoid when trying to describe and discuss complex artifacts.

The following section reviews theories associated with thinking about the Internet, and frameworks for conceptualizing how people integrate the Internet into their everyday lives, and the associated consequences. With an understanding of the multiple frameworks, it will be possible in the next chapter to understand how the Internet functions in different way for different people, where context and need predict use and interpretation and ultimately how engaging with the Internet has far reaching implications for the user.

Marshall McLuhan (1964), wrote, “The medium is the message”, forever linking technology with communication; cause with effect. Certainly, that can be true, or does it not miss the subtle nuances of the context of the arrangement?

Early descriptions of new technologies often centre on how these technologies make people do things, or how the technologies are going to change the world. The pencil, the printing press, the light bulb, each one set up as the panacea to the worlds problems and something that would ever make the world different. Thorstein Veblen

(1921), an American sociologist, is credited with coining the term technological determinism (TD) and he was thought to explain social and historical phenomena in terms of one determining factor. For example, the printing press is the reason why education is possible. The first theorists who described technology in this way, assumed that new developments would condition social change (Chandler, 1995).

Technological determinism has it roots in the scientific method and positivism and reductionism, which ultimately aim to reduce complex issues to singular elements. One of the basic tenants of TD is the possibility of offering a single independent variable that can be attributed to change. When research investigates the impact of technology, they are looking for a cause and effect relationship or a simplification of the interaction. Technology changes society at every level according to the TD theory. Computers, televisions and communication tools directly impact society, and directly shape a range of social and cultural phenomena. The human factors and social arrangements are seen as secondary. In the case of the Internet, much research and academic commentary reflects a tendency towards TD.

Technological determinism simplifies talking about equipment like refrigerators and pencils. But it is insufficient for articulating the complexity of the Internet. The Internet is literally and metaphorically a tangled web, able to be many things at the same time. Regarding the Internet through a lens of determinism suggests that the Internet is shaping and directing behavior to happen. I believe it is more valuable to extend from this simple description of impact towards a comprehensive idea that looks at the relationships between technology and humans.

Applying social theory when thinking about the Internet is important because it positions alternatives that can likely coexist when trying to figure out how people are using an object, without looking at the impact of that use. I want to study the context and the layers of Internet use, and I want to investigate the complexity simultaneously. One need not be seduced by the simplicity of TD and only consider cause and effect. There can be an acknowledgment of the value of language and context as meaning is constructed within the interaction.

In order to investigate and articulate the interaction between user and machine I turn to Actor Network Theory. Bruno Latour provides language and a framework for considering the intricacies within the interactions that comprise relationships. Actor Network Theory (ANT) allows networks to be made of both people and technologies. With ANT social ties are not restricted to interactions between humans. In fact, ties and social relations need not be confined to face to face encounters. As such, ties and associations can be impermanent, existing only in the moment of interaction. By arguing for the need to reach beyond the existing confines of social ties as restricted to human actors, ANT allows for the consideration of the place of objects in our relations, as their functions change.

> Objects, by the very nature of their connections with humans, quickly shift from being mediators to being intermediaries, counting for one or nothing, no matter how internally complicated they might be (Latour, 2005, p. 79).

This shows how the roles of objects are fluid and transitory, but if the moments of interaction between humans and objects can be witnessed, it is possible to investigate the

ensuing relations, as one can with other human ties. In other words, Latour's theory permits an analysis of the relationships between human and non-human actors (Mager, 2009). Latour invites social scientists to see patterns of involvement, associations and interactions, not just between humans, but in many other forms (LaMendola, 2010). ANT is ultimately interested in what people and things become as result of their associations and the power that emerges from their dynamic configurations (Greenhalgh & Stones, 2010). As such, research questions stemming from ANT tend to ask " what is the network, and what phenomena are emerging from it?" (Greenhalgh & Stones, 2010, p 1288).

For this dissertation ANT is providing the framework for looking at the relation of human and the Internet. ANT recognizes an expanded conceptualization of the Internet. The Internet is no longer one object, it becomes a product of its interaction with the human user. The Internet can be viewed as something both shaped by the person using it, and as something shaping that experience. Together they are co-creating their relationship and are making the context for their mutual influence.

While critics of ANT disapprove of the reduction of human actors to the same plane as machines (Greenhalgh & Stones, 2010; Mager, 2009), for the purpose of my analysis, I see ANT as raising the Internet to the plane of human users. In my view, ANT provides a suitable framework for considering the intricacy of the interactions we have with the Internet. Thus allowing my analysis to consider the influence and implications of Internet use beyond a positivist cause and effect model.

Sherry Turkle[4] (2005) a professor at MIT does what Actor Network Theory suggests and considers the possibilities of an individual's interaction with the Internet. Much of her recent work concerns the psychological effects of cyberspace, the notional realm in which electronic information exists or is exchanged. She self identifies as proudly holding joint citizenship to both the world of cyber culture and psychoanalytic culture. Furthermore, she posits that the interaction with the Internet allows for an expression of the self that is different from the version of the self who lives offline.

Turkle acknowledges using that perspective to make sense of the Internet and the chance of creating the self, using new technology. Computers and the Internet offer a safe place to construct, test and transform versions of oneself. This flexibility of self can be expressed in the ever changing medium of technology, a medium that affords an opportunity to be in constant communication with all aspects of the self simultaneously. This possibility could be interpreted as being empowered by the Internet. The Internet creates a space where people can enact a different version of themselves. And what is empowerment, if not the opportunity to act with greater power? The Internet produces an environment, where you can behave differently, because of anonymity, normalization or a freedom from social isolation. Turkle's work provides the perspective that something interesting is possible from the online experience, a transformative experience. Could it be that engaging with the Internet is empowering?

Turkle (1999) is not alone in her perspective that identity needs to be regarded as a social practice, where multiplicity and flexibility of self are paramount. Kenneth

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[4] http://www.mit.edu/people/sturkle

Gergen provides companionship for Turkle as he articulates the concrete experience of living the saturated self (Gergen, 1991). He brings the postmodern experience of self, as an inundated entity with competing modes of expression demanding attention in a way that is material. He grounds postmodern theory in everyday experience; because the multiple demands made on the self are a product of technology (Gergen, 1991).

Gergen warns of the loss of self, while giving hope to the possibility of multiplicity. He, like Turkle sees the self as a multiple. But Gergen goes further, takes the argument to a level recommending new thinking of the self, self in relation (Gergen, 1996). He builds this new construction on the binary of self and other, and recommends embracing a new complexity in favor of new concepts of self without the discourse of individualism. Gergen sees new technologies emphasizing the importance of connection, rather than autonomy (Gergen, 2002). Unlike the television, which invites looking at, computers and the Internet invite us to look out, to connect (Gergen, 2002). New technologies enhance dialogue thus encouraging relational being. Technologies allow for the releasing of 'self'. Letting go of the atomic self, the self expressed as a dichotomy and instead creating space for new ways of thinking about the self; no longer as a dichotomy, but rather as a state of inclusion (Gergen, 2002).

Gergen supports this position by presenting a way to rethink the self as vision of the relational sublime. This is important because he warns that the self as we know it, the self as a static unified expression of authenticity is gone. Technology brings the theory of multiplicity to life. Using the Internet's communication tools, multiple narratives are created and expressed simultaneously. Advancements in technology allow for numerous

dialogue boxes to be open at once, allowing Internet users to experience the concept and reality of multiplicity at once.

Gergen and Turkle's discourse articulates the self as a multiple rather than as a static entity and their challenge of new language creation stems from the influence of technology. The relevance of the dialogue about self for those who practice Social Work is the notion of self in relation to identity, community and the discordance of self in relation to other. By creating a juxtaposition of the possibility of technology to influence everyday life with the possibility of re-conceptualizing the self, we permit a new challenge for Social Work practitioners. Since the 'self' is a primary component of the therapeutic process, expanding the concept of self allows for Social Workers to bring new language into the dialogue of therapeutic practice and theoretical discourse.

The work of Latour, Turkle, Gergen and the contrasting views of TD have come together to illustrate the many ways the Internet can be conceptualized and described. Integrating these theoretical frameworks allows my work to investigate how people use the Internet to manage their health issues and acquire health information in a novel manner. In so doing, I was able to lay the framework for thinking about both how people's access to information is changing, as is the accessibility of health information in the age of the Internet. Also, how the Internet is conceptualized influences the role the Internet can play in both information provision and acquisition.

In the following chapter, I describe research that primarily assumes a TD perspective in addition to literature that questions the intersection of the individual and the technology they use. Within my review of how people are managing their health

issues and acquiring health information in the age of the Internet I explore the questions that arise from current research and defend how my work seeks to address them.

Chapter Three describes how people use the Internet while looking beyond its original intention of being a file sharing mechanism for engineers. I intend to find out whether the primary focus is for file sharing, communication, and whether engagement with this interconnected network can create an emotional response beyond that typically associated with using a keyboard and screen. To do that, I will I look at a using the Internet as source of information and location of social support. Finally, I will consider the effects and consequences of including Internet use within ones' health management strategies on relationships with medical professionals and oneself.

Chapter 3

The Internet and Health Management: a Literature Review

3.0 Introduction

Within the Internet's capacity to be a file-sharing database and a communication tool, it offers health information and strategies for communicating about health issues with others. Both information gathering and communication fall under the auspices of social support. Social support is linked with positive health outcomes and as a social worker it is important to be knowledgeable about how people manage health issues and improve their health outcomes now that the Internet facilitates information sharing and communication.

The foundation of my research motivation is a progression from learning about personal ailments in the medical book and receiving emotional support from my Grandmother, to researching health topics with Google and gleaning support from strangers' online testimonials to ultimately working with the Connected Lives research team. This chapter links my curiosity to find if there are others like me, having made the transition from text to type, with timely research reports about how others use the Internet to manage their health issues.

Chapter Two reviewed definitions of social support, demonstrated the important of accessing health information for more positive health outcomes and described the processes and effects of information and how everything is changing with the Internet. It outlined how conceptualizations of the Internet determine its scope of perceived influence.

This chapter builds on the theories important for thinking about health management and looks more specifically at Internet use. I have already established that the Internet affects social support provision, and this chapter will explore this further. In Chapter Three, I investigate: a) rates of engagement with the Internet as an information repository and a communication tool, b) how the Internet is used for social support acquisition for specific health concerns and c) how using the Internet for information and emotional support, as aspects of personal health management strategies, has consequences visible within the doctor patient relationship and the relationship with oneself.

Stemming from gaps in existing research, Chapter Three also reiterates my research questions in more detail. Finally, the relevance of this research for social work practitioners is discussed.

3.1 Measuring Internet Use

When the Internet functions as a database for file sharing and information retrieval, users generally open a search algorithm-based-web browser and type in topics of interest that generates a list of Universal Resources Locators (URLs, or web pages).

As more North Americans adopt Internet use into their everyday lives national survey researchers at the Pew American and Life Project, Harris Poll, Canadian Internet Project, and Statistics Canada monitor online activities. The first Internet use survey research investigated *whether* people were going online to gather health information. As such the surveys queried the rates of Internet usage and the tasks being performed online. Later studies considered *the role* of the Internet in health management strategies and *how* the Internet and Internet based information facilitates communication with physicians and medical professionals. As such, Internet health based information searchers were asked to describe if and how the Internet helped them to make decisions and provide care. This shift in research agenda signifies the acceptance of Internet based information searching into the everyday activities of a majority of North Americans. While early descriptions of general Internet use dramatized issues of the digital divide, emphasizing the differences between who is accessing the Internet and who is not, subsequent research was more oriented towards the similarities and differences across those who are engaged with online health information. Factors generally associated with the digital divide (gender and employment) that once predicted general Internet use are also associated with searching for health information. However, when considered in a multivariate analysis, these factors are less powerful and in some cases no longer significant (Rice, 2006). Research now finds that broadband connectivity is a stronger predictor of Internet usage rates, rather than gender and income level.

3.1.1 General rates of Internet usage for health information seeking

Once using the Internet to search for health information took hold in North America, The Pew Internet and American Life Project (2002) performed a telephone survey tracking Americans daily Internet use. This work detailed how and when the Internet fits within people's everyday lives. With a 33.5% response rate, Rainie (2002) found that 11 million Americans used the Internet, and concluded the Internet is embedded in daily tasks and holds a place within everyday life. In 2000 25% of American adults looked online for health information. By 2009, 74% of American adults go online and 61% of adults look online for health information (Fox & Jones, 2009).

In 2005, 8.7 million Canadian adults (35%) used the Internet to search for medical or health related information (Underhill & McKeown, 2008). A number of demographic factors influence whether a person will search for health information: being a woman, being married, having children and when they first started using the Internet. These studies show that Canadian health information searchers tend to have a higher level of education, and to report a high-income level (Underhill & McKeown, 2008).

3.1.2 Predicting Internet use: Gender

Cotton and Gupta (2004) identified that women are more likely than men to seek health information online and they are more concerned about the credibility of that information. Women also seek health information from doctors and nurses more frequently than men according to General Social Survey conducted in 2000.

In a comparison of female web-users and female non-web-users that seek health

information Warner (2007) found that when information is sought in relation to a doctor's visit, women who use the Internet seek information at a higher rate than the non-web-users. The web-users are also more likely than non-web-users to communicate with medical professionals about the health information they found, and reported that their decisions about health treatments were influenced by that same health information. In most cases, female web-users are more aware of a variety of health information resources.

Web-users are also more likely to use these multiple information channels. Female web-users do not report that finding health information from any source or medium to be easier than any other. Web-users are generally able to find answer to their health questions and report more success with finding health information and report a higher level of usefulness of the information. This proclivity to get information from different avenues is likely the result of the disadvantages of Internet use, including information retrieval problems, general disorganization of the web, concerns about accuracy and the problems of proprietary interests associated with health information websites.

When general health information, not related to a specific medical appointment is sought, non-web-users are more likely than web-users to search for health information from offline sources. According to Warner (2007) it is not the technology that drives health information searching, instead it is either a general curiosity or a gender specified role that predicts the engagement.

3.1.3 Predicting Internet use: Speed and savvy

The Internet is changing how people engage with information and the drivers for this change are broadband adoption and personal motivation (Fox, 2008). Fifty-five percent of American households with a broadband connection are starting to make a habit of online information gathering. Seventy-eight percent of people with a home broadband connection look online for health information. Twelve percent of those people look for health information in a typical day. Fox (2008) contends that broadband allows people to engage more deeply with information sources and each other.

Using data collected in 2005 by the National Cancer Institute, Rains (2008), hypothesized that those with broadband would use the Internet differently for health purposes. Rains (2008) explored the implications of a broadband connection and tested for inequalities on adopter demographics in the adoption of broadband versus dial up connections. The second objective was to investigate the relationship between broadband access and health-related Internet use. The odds of adopting broadband were greater for those in urban areas, with more education and who were younger. Those with broadband were more likely to report using the Internet for health related communication and were also more likely to engage in information seeking online.

For Canadians, it is the number of other online activities one pursues that is the primary predictor of whether an Internet user will search for health information. Breadth of use indicates a level of Internet sophistication; as it increases, so do the odds of seeking health information (Underhill & McKeown, 2008).

3.1.4 Predicting use: Health Status

Canadians, who go online to search for health information, search for information on specific diseases. They are also likely to be online five or more hours per week. Of those who visited a family doctor, more than one third discussed the information they obtained from their online search (Underhill & McKeown, 2008).

In 2000 the Pew Internet and American Life Project conducted a national survey that looked at the health status of the Internet users. Princeton Survey Research Associates conducted 500 follow up phone interviews with Internet users age 18 and over. Analysis of these interviews suggests that individual online experiences differ by health status. Most of the Internet users in the survey consider themselves to be in either good or excellent health. Those with fair or poor health are relative newcomers to the Internet, but search for specific health information online with greater frequency than their healthier counterparts. People with apparent illnesses are also more likely to discuss the information they found online with their health care providers (Houston & Allison, 2002).

Golder (2005) conducted a multivariate analysis of the Pew (2002) telephone survey data. This research hypothesized that individuals in poorer health (as measured by both the presence of a disability, medical condition, or self-reported health status) will be more likely to search for all types of health information except exercise and fitness related subjects. It is important to note that individuals made a clear distinction between self-reported health status and presence of disease or disability. The result indicated that it was disease or disability that influenced searching, not self- reported health status

(Golder, 2005).

According to Fox (2006), 80% of American Internet users have searched for health information on at least one of 17 topics. Only 7% of them look for health information on a daily basis. One in four Americans (25%) search for drug and medication information online; though she found no difference across health issue with regards to who searchers for prescription drug information online. Despite the large number of Americans who are looking for medication information online, only 4% of those searching for information have gone so far as to purchase medication online as 62% think it is less safe than buying medication at the drug store (Fox, 2006; Madden & Fox, 2006).

Particular circumstances, such as a serious diagnosis, or an important medical decision can prompt further engagement. People who feel they have a lot at stake are more likely to engage intensely with online resources. Internet users living with a disability, or chronic disease are more likely than other Internet users to be wide-ranging online health researchers and to report significant impacts from those searches (Fox, 2008; Fox & Jones, 2009).

Three quarters (75%) of online health information searchers (e-patients), with a chronic condition say their last health search affected a decision about how to treat an illness or their condition compared with 55% of those without a chronic condition. Newly diagnosed e-patients and those who have experienced a health crisis in the past year are also particularly active as such 59% say the information they found online led them to ask a doctor new questions or get a second opinion, compared with 48% of those

who had not had a recent diagnosis or health crisis. Almost two thirds (57%) of recently challenged or diagnosed e-patients say they felt eager to share their new health or medical knowledge with others, compared with 45% of the other e-patients. Experienced e-patients are posting technical advice online about managing certain disease as well as advising people about how to communicate with health care providers

Surveying 3023 Parisians, Renahy et al (2008) found that 70% had Internet access and 49% of these had searched online for medical information. Their results showed that high income and education levels significantly predicted Internet access and use. Searching for health information is also linked with having Internet access. Those who reported the presence of a recent health issue and had Internet access where the most likely to search for health information online. However, those people having health issues, were more likely not to have Internet access at all. These results illustrate the complexity of predicting Internet use and health information seeking when a digital divide is present. While education and income are associated with Internet use and health information seeking, it is the presence of a health issue that most significantly predicts searching for health information online (Renahy, Parizot, & Chauvin, 2008).

3.1.5 The Role of the Internet

According to an early survey of American Internet users, 17% indicated they faced a major illness within the last 2 years and 24% stated that the Internet played an important or crucial role as they coped with their illness. Another group using the Internet to cope with an illness were the 39% of the population who have helped another person deal with a major illness in the past 2 years (Horrigan & Rainie, 2002). When

faced with a care-giving situation, 26% surveyed Internet users said the Internet played a crucial or important role, particularly for those between 50 and 64 years of age. Overall, the Internet plays a crucial or important role for women twice as often as for men (Horrigan & Rainie, 2002).

By 2006, eighty percent of American Internet users have searched for health information online (Fox, 2006, 2008). Madden and Fox (2006), further explored the notion of the Internet playing a role in the support and care for persons with a major illness. They found that 17 million people (12 %) said the Internet played a crucial role as they helped another person cope with a major illness (Madden & Fox, 2006).

In 2009, 57% of adults surveyed about the resources they turn to when needing information or assistance in dealing with a medical or health issue mentioned using the Internet. Eighty-six percent of those adults ask a health professional, and 68 % ask a friend or family member (Fox & Jones, 2009). Within this most recent Pew Internet and American Life report, 42% of all adults, or 60% of e-patients, say they or someone they know has been helped by following medical advice or health information found on the internet. This represents a significant increase since 2006 when 25% of all adults, or 31% of e-patients, said that.

Interestingly, 41% of people who go online for information and support are reading someone else's commentary or descriptions about health and medical issues in websites, news groups and blogs. This latest report suggests the Internet continues to play a role in health management as both an information source and source of emotional connection with others.

3.1.6 Non Internet users

Despite the attention and optimism directed at those who benefit from online health management experiences, there are those who do not search for health information online. Non-information seekers report more positive experiences with their health care providers than other groups. Non-seekers place most trust in their doctors as a source of information and trust other sources much less. Whereas online health information seekers trust a variety of information sources, including doctors, the non-information seeker is worth paying attention to, especially as information distribution becomes more assumed, and likely will eventually only be available online (Ramanadhan & Viswanath, 2006).

3.1.7 Summary

The strongest and most consistent influences on frequency of using the Internet to search for health information were: gender (female), employment (not full-time), engaging in more Internet activities, more specific health reasons (diagnosed with a health problem, on going medical condition, prescribed medication, or treatment) and membership in an targeted health issue online support group that shares health interests and helps others cope with an illness or major health conditions. Women, part-time workers and those with particular medical diagnoses were more likely to search the Internet for health related information (Rice, 2006).

These data are relevant to researchers and also hold cultural currency for mainstream media. The New York Times, a vanguard of newsworthy items responded to the 2008 Pew Internet and American Life reports and offered its interpretations. Swartz

(2008) a New York Times reporter posits that Google is the de facto second opinion. There is a change in the relationship between the public and the health care provider; patients are becoming full-fledged actors in the health care system, no longer bashful recipients of treatment plans. Additionally, Schwartz (2008) contends that information is becoming trustworthy, as the more people that are engaged in the conversation; the more likely the misinformation is going to be repudiated. Parker-Pope (2008) also a New York Times reporter, taking the perspective that information is power believes that doctors ought to be part of the conversation and coach their patients in how to conduct worthwhile research and need not be discouraged by the challenges to their authority. Similarly, the reporter Rabin (2008) responds more positively that not only are people looking for information but they are also looking for referrals to physicians. Thus, the Internet emerges as a resource for familiar connections once left to the realm of the somewhat close tie.

People are using the Internet to search for health information, a vital part of social support seeking and consequently health management. While commentary about the digital divide highlights the factors associated with not being able to get online health information. Ultimately, predicting who goes online is complicated. It is as much about the users' characteristics and relationships as it about the information they seek. While much of the reviewed literature does not assume a deterministic stance, that the Internet is causing behaviors, it similarly does not describe the complexity of managing one's health issues or accessing social support. Heath status, assuming the role of caregiver, broadband connections, and gender must be considered alongside Internet user style

when looking for the variables associated with online health information searching.

3.2 Engage with or avoid? Questions for the health information seeker

Gender and Internet connection speed influence the likelihood of accessing health information online. Once the information is acquired, how you interact with it, whether you perceive it to be believable and whether or not you actually understand it influences whether you will remain engaged with the information. Understanding the perceptions of the information seeker can help evolve health management strategies.

3.2.1 Trusting information sources

Clarke (2002) posits that most Internet health information seekers cannot tell good information from bad and are not aware of the websites that rate the credibility of information sources. In contrast, Dutta-Bergman (2003) argues that individuals looking online for health information can tell fact from fiction and do have the mechanisms for determining whether or not to trust and information source. For health information consumers, information received from a personal doctor is the most trustworthy; second are medical university websites, and third are federal government websites that offer health information. Trustworthiness of information is intrinsically linked to the source of the information. Consequently, Dutta-Bergman (2003), recommends that medical professionals guide their patients as to where to go searching for health information (Dutta-Bergman, 2003).

Nettleton (2005) found that Internet users rely on implicit rules to decide or

account for what is and what is not acceptable information. People draw on what the researchers refer to as "rhetorics of reliability", which are devices used to which articulate why they trust some online sources of information not others. This rhetoric of reliability people draw upon reinforces discourses of professionalism and biomedicine. Nettleton (2005) concludes that despite the cacophony and anarchy of the Internet, when it comes to deciphering Internet based health information, people's processes maintain a degree of social order. In the case of this research, the parents were motivated enough by wanting to get all of the information they could, that they found a way to make sense of the information they retrieved online.

3.2.2 Credibility

In response to growing concern about the credibility of online health information, Wang et al (2008), set out to investigate how Internet users judge credibility, how trustworthiness influences these users and how credibility operates on web sites and online discussion groups. Credibility pertains to the believability of the source. Homophily is the degree of perceived similarity a receiver ascribes to a message source. If the person receiving the information believes that the providers of the information are similar to themselves, homophily exists. When information is shared via a discussion group, the homophily or sameness across the group is created through sharing of similar stories and common experiences. The researchers hypothesize that i) credibility is positively associated with the evaluation and influence of information and ii) homophily within health information discussion groups is positively associated with the evaluation and influence of information. The 97 participants in their experiment were randomly

assigned to one of eight stimulus groups. Participants who perceived higher levels of credibility for the web site gave higher evaluations of the online health information the web site presented. For health information presented in a discussion group, participants who perceived higher levels of homophily gave higher evaluations of that information leading to greater likelihood to act on the advice offered in that particular posting. By concluding that it is homophily that grounds credibility and that credibility is not what differentiates influential from insignificant advice, the implications are that medical professionals need to question their drive to increase credibility, when it seems this is not the factor that most likely influences health management. Similarly, medical professionals need to temper the notion that information shared across peers is not viable.

Adams' (2010) inter-disciplinary literature review explored concerns about the reliability of online health information in light of the increasing popularity of web applications that enable more end-user-generated content ("web 2.0"). Her review explicitly considered: disclosure of authorship and information quality, anonymity and privacy, and the ability of individuals to apply information to their personal situation. She found that not all reliability issues are negative—social networking and the shift from text-based information to symbolic information, images or interactive information, are considered to enhance patient education and to provide opportunities to reach diverse groups of patients. However, the concerns about reliability must not be dismissed as outdated. Specific issues related to use of newly popular web applications for health purposes must be addressed.

3.2.3 Media Literacy

Skinner (2006) argues that online health information is only valuable if it is accessible and that media literacy is a barrier. There are six elements to literacy and generally people do not have the skills or competencies required to engage effectively with online information. While they are able to get online and they might be able to do basic searches, they are not necessarily applying appropriate levels of comprehension.

Adolescent girls reflect this lack of literacy, as they do not have the complex media literacy that is required for Internet health information comprehension. Their general Internet use does not appear to be affected by demographics, social location, ethnicity or age. However, despite their perception that Internet health information is immediately accessible, it is not where they begin their information quests. They seek health information from their mothers first, then their physicians and then the Internet (Gray, Klein, Noyce, Sesselberg, & Cantrill, 2005).

Low health literacy is not limited to people with low general literacy; even people with strong literacy skills may have difficulties understanding and using health information due to jargon and complicated language (Nielsen-Bohlman, Panzer, & Kindig, 2004).

3.2.4 Summary

A combination of information believability and comprehension inform the experience of health information research and retrieval. In a sense these factors frame the experience of information seeking. Similarly, the notion of media literacy predicts how one engages with information sought online.

Internet users want to trust health information intermediaries and have an internalized rhetoric of reliability. They evaluate websites and online discussion groups according to definitions of credibility and homophily. Believability, rather than accuracy of information defines the support component of this aspect of social support acquisition. The next phase of understanding how the Internet is influencing health management practices considers the effects of the experience. If the user is able to comprehend the information and deems it to be trustworthy, is the information changing behaviour? The following section considers the effects of going online for health information.

3.3 Considerations when using Internet based health information

The Internet offers links to both accurate and inaccurate information in almost equal measure. Consequently, Benigeri and Pluye (2003) suggest that while health information can be beneficial, it can also be harmful. Providing information online is effective only if the users understand it and use it responsibly.

Internet based health information is vulnerable to issues of comprehension and trustworthiness and is therefore not equally accessible to all who seek it. Some researchers argue the benefits of going online for health information, while others are critical and offer stern warnings. This section considers the consequences of using Internet based health information.

3.3.1 The effects of Interactivity

The interactivity of an Internet based environment accounts for some of the

appeal of seeking health information online, as does the potential for conducting one's own research about particular health issues. The Internet can be especially useful in relation to a number of health information needs and as a channel for interactive health communication (Eng, et al., 1998). It can be used to gather valuable information on the symptoms of diseases and new drugs identify alternative treatments; monitor current research; obtain full text of pamphlets and reports and enter in discussion in newsgroups and chat rooms (Rees & Bath, 2000; Sandvik, 1999). Internet based health information searches can help identify alternative treatments; monitor current research; find information where there is no ready access to health care providers (Levy & Strombeck, 2002; Rees & Bath, 2000; Sandvik, 1999; Song & Zahedi, 2007).

Researchers question why people access health information online and are captivated by online health information rather than seeking it from face-to-face sources. The perceived relative advantage of the Internet over other media is its cost-effectiveness and interactivity, which in turn contribute to its persuasive capabilities (Lustria, 2007). Interactivity is the ability to engage directly with the information and to create an information space that is personalized and responsive to the user's needs. Interactivity has been identified as one of the defining characteristics that set this new media apart from traditional media. An experimental research design was conducted by Lustria (2007) to examine the effects of Web interactivity on comprehension of and attitudes toward two health websites. This study asked the question: what can interactivity contribute to desired outcomes such as comprehension or attitudes? Two sites on skin cancer were designed with different levels of interactivity and randomly assigned to 441

undergraduate students with a mean age of 19 at a large Southeastern University. The findings suggest that interactivity can significantly affect comprehension as well as attitudes toward health websites. However, there is limited understanding as to how interactivity affects the processing of health information and its contribution in terms of health outcomes.

3.3.2 Considerations for health practitioners

In a critique of the availability of online health information written for public health practitioners, Benigeri and Pluye (2003) encourage other researchers to investigate the impact of the Internet by looking at health beliefs, health care services and population health measures. They maintain that while the Internet does offer information, it is not a panacea for health care management. Further, they argue that just as universal health care in Canada does not prevent disparities in access to health services, Internet connectivity does not prevent disparities in access to heath information.

As such, public health practitioners must see facilitating Internet use with their clients as a vital component of diffusing health information. Such engagement might change the role of the health promotion practitioner, but access to this information will also likely change the role of the patient and their relationships with medical professionals.

Neuhauser (2003) agrees that while e-health communication holds promise, there is limited evidence to secure the role of Internet based health information in behavioral change programs. There is considerable optimism however, of the long-term effects of exposure to online health information.

Anderson and Klemm (2007) argue that health related Internet surfing is driven by health service providers' attempts to save money. They contend that the Internet's advantages of providing current and comprehensive information, and alternative education tools, creates feelings of empowerment and support to balance its disadvantages of excessive and inaccurate information provision and compromising access, security and privacy.

Valimaki (2007) looked at 1666 patients discharged from a Finnish hospital and found that most people would rather get their information from their doctors. Patients would rather receive health information from their healthcare practitioners in a face-to-face exchange. When patients were discharged from surgical units they want to use e-mail to receive follow up information, especially the younger and well educated. Receiving health information via email is preferential to searching online. The aged and less educated patients were averse to using e-mail in information delivery.

3.3.3 The effects of health information for Internet users

At its best, health information leads to better health outcomes and stronger physician / patient relationships. Information that is misleading or misinterpreted may compromise health behaviors and health outcomes or can lead to inappropriate requests for clinical interventions. As such, individuals need timely and affordable access to information to be aware of health issues and to recognize warning signals is illness and disease. A predictor of living a healthy lifestyle is being knowledgeable about nutrition and fitness issues (Song & Zahedi, 2007).

The Internet offers people convenient, constant access to information, with interactive formats that promote understanding and retention. In conditions where there is no ready access to health care providers or health and fitness assessments, the Internet fills the gap.

According to Madden and Fox (2006) e-caregivers (those who find the Internet to be crucial or important during a loved one's recent health crisis) indicate that during a health crisis the Internet helped them to find advice or support from other people, find professional or expert services, and find information or compare options that would have been challenging without the availability of online information.

When patients themselves are Internet users, they report that various aspects of health care decision-making are affected by online health information. For example seeking online health information i) affected a decision about how to treat an illness or condition for 58%; ii) changed an overall approach to maintaining one's personal health, or the health of someone they care for 55%; iii) led them to ask a doctor new questions or to get a second opinion for 54%; iv) changed they way they think about diet, exercise, or stress management for 44%; v) changed the way they cope with chronic condition or manage pain for 39%; vi) affected a decision about whether to see a doctor for 35%; vii) significantly helped by following medical advice or information found on the Internet for 31% (Madden & Fox, 2006).

In a follow up to the 2006 study, where she found that confidence was bolstered by health information, Fox (2008) concludes that the impact of an online information search is more likely to be helpful than harmful. One third (33%) of e-patients say they or

someone they know has been significantly helped by following medical advice or health information found on the Internet. By contrast, only 3% of health seekers say following the advice or using information they found online has seriously harmed them or someone they know. In addition to these concrete reports of doing something different, they also report feeling better and having more confidence about their health care decisions.

3.3.3.1 How Internet based health information affects relationships with medical professionals

Recall from Chapter Two that today's medical encounter reflects personal and political shifts of the last fifty years. From the passive patient of the 1960's (Segal, 2009), to the Internet informed e-patient of today, knowledge and information continues to provoke and reveal constant developments to the doctor patient relationship (Buckland & Gann, 1997; Hardey, 1999; Loader, Muncer, Burrows, Pleace, & Nettleton, 2002).

Alternately, Parr (2002) argues that evolution towards a socially normative expectation about the balance of power within the doctor patient relationship may account for the changes, rather than the information itself.

Internet based information searching, access and overload can change the nature of the patient/physician relationship, where shared understanding and power differentials have numerous long term outcomes, including altered expectations of care, increased demands on over-worked medical professionals, and the creation of expert patients (Ahmad, Hudak, Bercovitz, Hollenberg, & Levinson, 2006; Kalichman, et al., 2000).

Medical information, no longer being bound to medical institutions, has "e-scaped" into society at large by means of new media (Nettleton, 2004). Now it is being

disseminated, and can disrupt the expert status and professional autonomy of the biomedical community (Hardey, 1999). As well, the very act of the patient seeking such information independent of the expert, contests the traditional biomedical assumption of the patient as recipient of knowledge and expertise (Broom, 2005a, 2005b).

Levy and Strombeck (2002) reviewed literature related to the benefits and risks of the Internet and concluded that new levels of knowledge among Internet users is transforming health care and the patient–provider relationship. Initially these changes were seen as negative, but the long term implications may have favorable outcomes for health promotion and disease prevention. Their negative review indicated that physicians are slow to embrace the Internet as a tool for collaboration and do not seem themselves as prepared to deal with patients bringing e-health information into medical appointments. With the patients becoming more proactive in their care management, the outcome often strains the relationship, as doctors fear they are losing control. Despite pessimism, many researchers recognize the advantages of creating strong partnerships between patients and clinicians.

Nettleton et al (2005) suggest that research about the effects of Internet information on the doctor patient relationship tends to either praise the influence of technology, or offer warnings of harmful effects. As such, the following review represents both perspectives and ends with a perspective that perhaps the context for how the medical encounter is framed needs some expansion thus shielding the patient from unwanted and unwarranted harm.

In the United Kingdom, 85% of physicians experienced a patient bringing Internet

based health information to their appointments. When information is brought to the session, 8% of the doctors think it makes the session less time efficient, 38% believe it is beneficial to their practice and 54% expressed neutral feelings about the presence of Internet based health information brought into appointments by patients. In light of these positive reactions, it is not surprising that three quarters (75%) of the doctors believe the information made no difference on the patients' health outcomes (Murray, 2003).

Bosely (2000) argues:

> The Internet has proved itself the ultimate democratizing tool, steering away the old medical culture which said that although we own our own bodies we are not competent to understand how they go wrong and what options there are for fixing them (Bosely, 2000, p8).

Similarly, by providing individuals with knowledge and support, the Internet potentially empowers patients and increases their sense of control over disease (Broom, 2005b). As such, thinking of the Internet as a challenge or threat may misrepresent the significant variation in how medical specialists are experiencing and responding to the infiltration of health information (Broom, 2005a).

Alternately, despite greater access to health information, consumers still invest trust in expert systems and the face-to-face consultation with a medical professional remains central to this (Hardey, 2010). In his review of websites where health consumers can rate, review and comment on medical professionals Hardey (2010) highlights a recent development in the doctor / patient relationship where patients construct user-generated content about their doctors to inform other patients of personal experiences. The use of user-review sites may therefore further change the nature of the medical profession and

the doctor–patient relationship, by further encouraging patients to think of themselves as consumers with health and health care professionals becoming products of consumption.

How one frames the doctor patient relationship ultimately affects the interpretation of the influence of information. Lupton (1995) asks us to expand our thinking about power beyond a Weberian perspective where power is about oppression and patients are empowered by removing power from doctors and bestowing it on themselves. This limited view according to Lupton restricts the medical encounter to its individualistic dimensions. This restriction views power as an object, or a product of a capitalistic and patriarchal enterprise. Instead, Lupton encourages us to consider a Foucauldian perspective of power where power is non-economic, and non-repressive; where power is not a property, it is instead a strategy.

By considering this alternate view of power, the roles of the medical encounter can benefit both the patient and the doctor because sometimes patients want to experience medical dominance and expertise. When power is thought to be a strategy, it can be beneficial. Power does not have to be oppressive, but new thinking can calibrate expectations and interactions.

3.3.3.2 Relationship with oneself

In the same way that using the Internet in health management produces and reveals changes to the doctor patient relationship, it also reflects and reinforces the relationship we have with ourselves in the context of understanding our own health and health care practices.

Deborah Lupton, an Australian sociologist with a history of integrating

Foucauldian critique into the sociology of health and illness, invites researchers to continually analyze assumptions about health from multiple perspectives. Within the doctor patient relationship, she proposes re-consideration of conceptualizations of power and when thinking about personal health and health care, she reminds us that personal issues reflect social norms (see, Peterson and Burton, 1997). According to Lupton (1997, 1999), health and health care of a population is a public and political issue. When people take individual responsibility for matters of public interest, the needs of the person are influenced by social norms.

> Citizens are urged to turn the medical gaze upon themselves, and engage in such technologies of the self as monitoring their own bodies and health states and taking preventative action in accordance with medical and public health directives. (Lupton, 1999, p57)

This self-monitoring is in Lupton's view evidence of personally engaging with medical gaze, a strong social norm. By assuming this external drive in our personal practices, we in turn reflect and perpetuate dominant discourses.

Lupton's views on this assumption of individual responsibility for health and health care practices are similar to the notion of Healthism. This term was first coined by Crawford (1980) and refers to an ideology overemphasizing the need and individual obligation to keep healthy. Healthism refers to the belief that achievement of good health and the avoidance of illness is the burden of every individual. As such, illness is often considered a failure to comply with health-promoting lifestyle.

> Individual responsibility is highly problematic. It risks the myopia of classical individualism. It risks fostering the illusion that individual

> responsibility is sufficient. It exacerbates a prevalent sense of powerlessness about social forces (Crawford, 1980, p377).

Ultimately healthism undermines social and collective efforts to improve health and well-being. Crawford (1980) believes that the health of a population is the responsibility of the collective, not just the individual. Becoming pre-occupied with controlling the manageable health factors like smoking and diet mediates feelings of powerlessness about larger personal and social uncertainties.

Healthism is an expression of medicalization, or the expansion of professional power over wider spheres of life, especially deviant behaviors: in this case medical professionals presuming to tell people what is good and right for the individual and for society at large (Crawford, 1980).

This moral obligation to live a health-promoting lifestyle has become increasingly pronounced in North America (Richmond, 1999). An example of such adherence to health oriented social norms is found in English-Canadian magazines. These texts instruct their female readers to take individual responsibility for their health and the health of their families (Roy, 2008). Using various techniques to encourage readers to actively pursue healthy behaviors, magazines reflect and reinforce a "discourse of healthism" and a moral imperative for women to be in charge of their own health. Roy (2008) concludes that such messages reflect a dominant discourse of health and promote a particular understanding of health.

Similarly, researchers in Australia conducted a study using a constructivist, inductive approach to explore how and why midlife women think about health in general,

being healthy and the factors that influence engaging in health behaviors (Smith-DiJulio, Windsor, & Anderson, 2010). They found that every woman in this study was, at the time of interview, fully conscious of persistent messages to actively promote health with behaviors focused on smoking cessation, exercise, and diet.

The women indicated it was difficult to pass a day without being reminded by acquaintances, the media, and health professionals that health is fragile and at risk. As individuals these women are expected to safeguard, control, and care for health or accept the consequences—at the very least social disapproval, and possibly illness. This focus reflects the value that modern society places on health and the continued emergence and consolidation of health as one of the guiding mantras of both governments and individuals (Adam & Loon, 2000; Cheek, 2009). At the same time that people are generally living longer lives, health is seen as precarious, problematic, and at risk (Furedi, 2004).

Although information about how to maintain one's health might originate with health care providers, the requisite surveillance is transferred to individuals to govern themselves. The data illustrate the inherent tension between the expectation to acquiesce to expert wisdom about necessary conditions for risk reduction and the expectation that maintaining one's health is an individual obligation (Biggs & Daatland, 2004; Clarke, Shim, Mamo, Fosket, & Fishman, 2003 ; Furedi, 2004). In conclusion, women in this study either implicitly or explicitly communicated a perspective that health and health behaviors are shaped by a complex interaction of social expectations and individual roles and relationships.

The integration of new information into daily practice leads to changes in perceptions of the experience of health and our relationships with our bodies and ourselves. As information distribution increases with Internet use for health management, the exposure a medicalized view of health also increases. As such, the ideals of healthism proliferate and our relationship with ourselves changes as we assume individual responsibility for the maintenance of our health and well-being.

While healthism may be fraught with negative connotations, empowerment is often viewed as a positive consequence of information, knowledge and power. Lemire (2010) wanted to understand the effects of information and communication technologies for personal empowerment in health management. He acknowledges that empowerment's multiple meanings makes empirical analysis challenging. As such, he constructed four unique definitions of empowerment according to four paradigms. He differentiates between i) professional empowerment, when one applies expert knowledge to act efficiently regarding heath, ii) technocratic empowerment, the adoption of behaviors that lead to risk reduction, iii) consumerist empowerment, referring to personal assertiveness in health related decision making and iv) personal empowerment, the taking of individual action with the intention of social change. From his comprehensive and measurable conceptualization of the facets of empowerment, he analyzed four case studies looking for the effects of ICT use, on his identified realms of empowerment. The four cases were: consulting health information online, online drug purchases, remote electronic patient monitoring and electronic health records. Lemire concluded that different expressions of empowerment are evoked by different uses of technology. In

each case, the user can be called to act as a patient, consumer, citizen or client. Consequently, he argues specificity is essential when discussing empowerment and information and communication technologies. While his research calls for more rigorous operationalization of the term empowerment, what he is remiss in emphasizing is the breadth of empowerment that happens as a result of including Internet technologies into health management practices.

3.3.3.3 The emergence of new relationships

The Internet has become an important location where health information is stored and accessed. The ubiquity and constant availability of online health information affects the users engaged with the information repository. As such there is vast potential regarding the impact of the online health information for those who go searching for it (Parr, 2002).

This impact could be considered through the lens of technological determinism that assumes technology directly affects human behaviors and social outcomes ergo, the Internet and its online information is directly affecting the health information seeker. However, this perspective neglects the complexity of both the Internet and how it is directly connected to the human interacting with it.

Actor Network Theory (ANT) brings together technological determinism, where technological artifacts change and influence social acts with social constructivism, which emphasizes the social interaction aspect of human engagement present when using technology (Latour, 1999, 2005). Prout (1996), suggests that ANT can articulate the relationships between non-human and human actors to understand the competencies they

create together. Using these same principles to consider the relationship between health and health information allows us to see the relationship between humans and the Internet. It is within this relationship where new ideas about health are being created and potentially new health discourses will emerge. The Internet does not itself impact or change the social relationships or the notions of health. It is the interaction *with* the Internet. The information acts as a catalyst that creates a new and visible outcome.

Given the influence of technology on health management practices, Greenhalgh and Stone (2010) wanted to figure out how to best look at large scale technologically based health care programs to examine the interplay between technological innovations and social order. They propose developing a theoretical perspective that brings ANT and Strong Structuration theory together to find out what happens when attempts are made to modernize health care. Within this perspective, technology (in some cases the Internet) can have material properties and interactive functionality. Their theoretical argument allows for technology to be many things simultaneously, or at least able to transition from one mode to another within the same analysis. They present that the breadth of such a theoretical perspective will help conceptualize the many roles technology enacts and the ensuing influences, thus inspiring more comprehensive research regarding the interplay of technology with its users.

Mager (2009) considered the mediated relationship between health information providers and health information users using Actor Network Theory as the grounding framework. This allowed her to systematically analyze the human and non-human actors involved in the enactment of online health information as equally important measures.

The study looked at how health information website providers and users differently practice and conceptualize online health information. The results followed a grounded theory analysis of seven websites providing information regarding diabetes and interviews with 41 participants who searched for information on chronic health conditions according to fictional scenarios presented to them.

When researching chronic disease information, all of the participants in the study started with Google making it a central actor in their search strategies. More than just the initial point to travel from, Google is also seen as the place to return to in case of confusion or trouble within health information websites. The participants' reliance on Google positions it as an actor in the information search process. Using ANT, Mager interprets Google as a mediator and translator acting as a passage between Internet users and information providers (websites). Google is inadvertently and critically influencing how information is represented and shaped on the World Wide Web. It could be argued that the users' relationship with this actor is both affecting the searcher, the information provider and as such changing health management practices

By considering Internet mediated health management as an interaction between human and non-human actors, it is possible to look for a relationship between the Internet and the Internet users. As such it is possible to conceptualize the emergence of a new relationship, a new form of social relation that ultimately influences the process of health management by influencing experience of information seeking and support acquisition.

3.3.4 Summary

Research to date articulates the process whereby people are coming to their doctors

with information and in turn disrupting the power previously taken for granted within the patient physician relationship. The expertise that was once solely in the hands of the medical profession is now in the hands of the health service consumer. In some ways however, medical dominance prevails. Health achievement is medicalized and in so doing, the pressure for health service consumers to take charge of their own health gains strength. The ease of health information distribution and the contents of pervasive health messages promote the sentiment that health is an individual matter and people must take care of themselves.

3.4 Finding support for health issues online

> Social support communication is traditionally considered to be the exchange of verbal and non-verbal messages conveying emotion, information or referral, to help reduce someone's uncertainty or stress, and whether directly or indirectly, communicate to an individual that she or he is valued and cared for by others (Walther & Boyd, 2002).

A premise of this dissertation is that people use the Internet as if it were a database of information and also as a tool of communication. Communication refers to both asynchronous and synchronous exchanges with both social network members and strangers.

The facility of the Internet allows for great ease and prevalence of certain forms of group communication originating in discussion boards and phone trees. There are implications or consequences for health care strategies if these online discussion, message boards and self-help style groups can actually provide social support.

Research questioning the provision of online social support asks: if online support is possible, what happens in online support groups? Why do people use them, and why do people drop out? It does not identify whether gender, age, health issue, or social network characteristics are associated with going online for an emotional connection. However, the results to date do indicate that people who go online looking for support benefit from the exchange.

3.4.1 Why do people go online for social support?

In a study conducted in Norway, the users of one of the four major national online discussion forums tended to be women who, based on self-perception based questions, derived satisfaction from online chatting and activities (McKenna & Bargh, 1998). While this survey did not investigate if participants had other sources of social support, the findings nevertheless enhanced prevalent understanding of the effects of Internet use.

In a review of online support literature, Wright (2003) recommends three theoretical perspectives to explain going online to solicit support. These models are: (1) social support is a perceived shield protecting an individual from the harms of life, as in the stress-buffering model; (2) it directly affects one's health as in the main effect model; (3) online support reflects the presence of a weak tie, congruent with the social network theory and offers individuals access to information and resources associated with such a tie. Rather than herald one theory, Wright (2003) presents several reasons why individuals seek support online: for a sense of community; to cope with a feeling of isolation; for an alternate source of information; preference for a narrative rather than a fact; going online is more convenient than face to face dialogue, and asynchronous

communication affords opportunities for editing dialogue.

3.4.2 For connection, support and social capital

Utilizing an archival analysis approach that examined the content of messages in an eating disorder discussion group, Winzelberg (1997) found that the most common message content involved self-disclosure (31%), requests for information (23%) and the direct provision of emotional support (16%). Winzelberg (1997) concludes that participation in online support groups is motivated by a basic need for connection, which is fulfilled by the availability of and access to such technologically based groups. Dunham (1988) provided an electronic bulletin board group for 42 young (18.5 year old) single mothers in Halifax and investigated the effects of participation in the online support environment. The women could post messages, exchange private emails and participate in real time teleconferences. The contents of the posts were mainly emotional support, information and tangible support. Close personal relationships and a sense of community developed in the online environment. The mothers who participated most consistently were more likely to report reduced levels of parenting stress following the intervention.

In a survey utilizing data from four major urban centers, Davison (2000) found that cancer, alcoholism and multiple sclerosis were diseases most likely to be associated with participation in an offline support group.

Reeves (2001) interviewed 10 individuals with HIV/AIDS and found they endorsed the Internet as a source of emotional support, information searching, social connections and intentional reprieve from their health issues.

Users of Norway's two major mental health related online discussion forums find discussion groups tend to supplement, rather than replace traditional mental health services, reporting no change in the amount of service used. According to 492 web-based surveys of users, most of whom are women (78%), find it easier to discuss personal problems online than face-to-face (75%). Similarly, in response to a different online survey, 63% of women with alcoholism reported using an online support program to supplement face-to-face support groups (Houston & Allison, 2002).

The Norwegian respondents indicated that the forums have an empowering and beneficial effect on their outcome, but not on their use of traditional mental health services (Kummervold, et al., 2002).

Loader (2002) performed an analysis of the contents of a week's worth of posts to a UseNet group for people with diabetes. The posts were identified as providing an exchange of information, companionship, self-esteem support, informational support, and meaningful emotional connection evidenced by friend chatting, unrelated to health issues. The group users placed greater emphasis on emotional connection than on the accuracy of information they obtained from the online support forum (Loader, et al., 2002).

Similarly, Fogel (2002) surveyed and assessed women diagnosed with breast cancer who go online for emotional connection and information. These women reported they experienced social support and much less loneliness. Additionally, Ziebland (2006) found that cancer patients utilized the Internet for support needs not met by conventional health care. For those diagnosed with cancer and referred to online support, there was information and emotional content available at each stage of diagnosis, treatment, and

follow-up more readily accessible than compared with traditional health care resources.

Building on Lin's (2001) argument that cybernetworks are forms of social capital, Drentea and Moren-Cross (2005) examined a mother specific discussion board on a popular parenting website, to consider whether virtual communities in cyberspace foster social capital and social support. Lin (2001) contends that social capital is the capital emerging from social relationships; however, other researchers disagree on whether the time spent on the internet leads to social isolation or social capital (DiMaggio, Hargittai, Neumann, & Robinson, 2001; Nie, Hillygus, & Erbring, 2002; Quan-Haase & Wellman, 2002; Barry Wellman & Haythornthwaite, 2002).

Drentea and Moren-Cross (2005) reflect that given the complexity of social capital conceptualization, it is challenging to precisely define what it comprises and how it works, particularly in relation to health. For the purposes of their research however, they operationalize social capital as being reflected in communication conveying emotional support, instrumental support (both informal and formal) and community building / protection.

Their examination of the mothering website discussion board indicated a created community for the mothers which provided the means for them to access emotional and instrumental support. The website became a place to enhance the social capital of those mothers who participated in the online discussions. The authors concluded that the site is an empowering source of feminine space where knowledge is reclaimed from the medical establishments. Similarly, the website played a role in the de-professionalization of medicine and the strength of self-help movements.

3.4.3 To avoid stigma while remaining anonymous

According to McKenna and Bargh (1998), individuals who have a "concealable stigmatized identity," experience a disproportionate degree of social anxiety and are therefore motivated to belong to groups whose members have similar issues. They are, however, less likely to engage in face to face communication within these groups on account of the stigma and their preference for anonymity. Online social support, with its potential for concealment and anonymity, is consequently the preferred means of social support acquisition for such individuals.

Teenagers use the Internet because they can be anonymous, and it easier to disclose personal details in a virtual world, because they can connect at home and because it is free (Klein, 2004).

3.4.4 Having high Self-Efficacy

Adults also tend to seek social support online because they believe it will help them. The notion of self-efficacy is the belief that an individual has the personal power to achieve a desired outcome. A person with high self-efficacy may engage in more health related activities when an illness occurs, whereas a person with low self-efficacy will harbour feelings of powerlessness. Self-efficacy determines what and how often a person engages in a given behavior. The amount of effort and the persistence put forth when faced with obstacles and the mastery of the behavior. Self-efficacy beliefs reflect confidence in one's ability to use the Internet to fulfill social support needs (Rains, 2008).

Eastin and LaRose (2004) also conclude that self-efficacy is related to online social support. In their analysis of people who seek online support, as opposed to those

who provide it, the more social efficacious people are, the more likely they are to view the Internet as an important social outlet. They also spend more time seeking support online and thus increase the size of their online support networks.

The result of the Eastin and LaRose (2004) study suggests that an individual may choose to move a typically offline contact to an online venue such as a discussion group when face-to-face dynamics are a potential hindrance to the support process. When current offline support connections lack the expertise of the content, they are not deemed suitable to provide support (Eastin & LaRose, 2004). Thus, online supports fill the support gap. Ultimately, the confidence that one's ability to use the Internet to fulfill social support needs is related to social support seeking activities, expressions of gaining support online, online support reliance and online social network size. Essentially, the more you believe the Internet can help you, the more you report it will.

3.4.5 Reasons for withdrawal from online social support

Despite the promise of online self-help groups to help people cope with health problems, people withdraw from these groups at high rates. Using data from Norway, the researchers investigated participation and non-participation of people in breast cancer self help groups. Sandaunet (2008) identifies five conditions for understanding non-participation or withdrawal from the group she studied. The conditions are: 1) The need to avoid painful details about breast cancer; 2) not being ill enough; 3) the challenge of finding a legitimate position in the group; 4) the organization of everyday life and 5) illness phases which do not motivate for self-help group participation. In conclusion, the researcher argues that these reasons illustrate how people's Internet use is often

contingent upon their health needs and pertains to particular conditions. As such, she argues that her research adds to the literature de-emphasizing the role of technology in health management.

3.4.6 Summary

A potential outcome of engaging with the Internet is experiencing social support. Those who are fortunate to connect with an online social support group tend to have better health outcomes, across a variety of health issues.

According to the research to date, knowledge about the impetus for getting involved with an online support group is limited. One researcher found that self-efficacy is the antecedent to going online (Rains, 2008). However, knowledge about the participants other sources of social support, or network composition is lacking.

Given that social networks are the location of social support, I think it is relevant to include a network analysis when researching sources of social support. As such, the next section outlines what my research questions are and how I look at health management within a general population. This dissertation offers a more comprehensive understanding of online social support seeking. By collecting narratives of those who go online for social support, I can describe their experience from multiple vantage points.

3.5 Research Questions of this dissertation

Within the concept of health management people use the internet like a database, they receive social support from the experience of going online, from the information that they receive, and from the emotional connections they make and the emotional content

they access. While the Internet may affect the outcomes of health management, previous research did not ask the kinds of questions that identify the subtleties of the relationship with the Internet; however, my research will.

My overarching research curiosity is about how people manage their health issues in the age of the Internet. Health management requires a relationship with a health professional, and a certain perspective on caring for the self, and popular notions of health and health care. To fully understand the issue, I need to be familiar with three theoretical perspectives and accompanying research. First, how people search for and access information. Second, how people obtain social support from their social networks and their online communities. Third, how interacting with information in online environments has consequences for relationships with oneself and ones health care providers and how these implications challenge personal definitions of health and well being.

This thesis takes a single question "how do people manage their health issues in the age of the Internet?" and approaches it from multiple levels of investigation. The first is that of the Internet as database, providing health information, the second that of the Internet providing a supportive encounter and the third layer investigates the impact of the Internet in the context of health management. At all three levels I will look at how people are using the Internet in relation to how they manage their health issues.

3.5.1 Q1: To what extent do people use the Internet as an information database?

Based on the literature reviewed earlier in this chapter, I expect searching for

health information to occupy a significant portion of users' time online. I want to find out what variables are associated with Internet use in addition to demographics. Consequently, I will consider health status, network characteristics and existing relationships with medical professionals. By questioning how the Internet fits within other health care practices, I will be able to describe the composition of health management strategies and the various components of how people manage their health issues.

My curiosities about using the Internet as database is about the complexity of Internet use, the interaction of health issue and Internet use, and attitude and expectations about the Internet for health information.

By questioning what predicts using the Internet as a database of information accessed for information retrieval, I want to learn what accounts for the fact that searching for health information is the second most popular online activity. I want to study if this new way of engaging with the Internet is predictive by health issues, are the people who are really sick or isolated engaging with the Internet is this way, or is it a socio demographic kind of situation, where a digital divide accounts for the differences in the ways and means that people are using the internet?

My analysis begins with an examination of how much time people spend using the Internet to search for health information. I will connect this data with what is more likely to predict using the internet as a database from a score of factors, including: socio-demographics, health issues, proficiency with computer and Internet use, and social network characteristics. I will also describe to what extent people in different social

positions vary their Internet use.

3.5.2 Q2: Does the Internet enable supportive encounters?

Literature to date addresses the benefits of online support seeking. Internet based social support does not burden social network members and the anonymity it offers alleviates the stresses traditionally associated with support sought from friends and family.

I am encouraged by the suggestion that those who engage in Internet health management strategies will glean the information and emotional connections ultimately encouraging beneficial health outcomes. However, the research does not identify personal factors that are associated with seeking emotional support online.

My research examines the prevalence of Internet based emotional support seeking and specifically examines if there in an association between using Internet mediated communication for health issues with identifying with a particular health status or having particular social network characteristics.

3.5.3 Q3: What are the health associated implications of using the Internet?

The availability of Internet based health information is changing some laypersons relationships with their medical professionals. Consequently, I will consider individual health management processes to identify any indication of a shift in these relationships. Specifically, I will address if there is evidence of empowerment in interaction with health care practitioners and medical institutions. When the Internet is a file-sharing database, it

is possible for users to "deepen their connections to the Internet" (Fox, 2006).

Within this layer of analysis, I will be looking specifically at how the Internet affects well-being and whether there are indications of patient empowerment in interactions with their medical professionals. I will identify if the Internet affects health status and where people fit the Internet into their health management processes. Through statistical and qualitative analysis, I will find out if the populations are self-diagnosing or if they are bringing their newly researched items into their conversations with medical professionals. My research will identify where in the sequence of health management strategies the Internet fits and if people are really acting in an engaged and empowered fashion when they are going online and when they are using the information afterwards.

3.5.4 Towards a theory of health management

My dissertation's aim is to profile the health management issues of the people of East York. I will tell a comprehensive story of how health management using all available means and strategies happens in everyday life. I want to apply theory beyond constructivist and technological determinism to understand how our interactions with Internet based health information is affecting us.

After examining all aspects of the health management stories of people with significant health issues and people with everyday concerns, I will present theory to understand health management in the age of the Internet. I will consolidate the narratives of Canadians going online for support and information. These stories together capture the influence of health issue, personal attributes, social network characteristics and Internet use patterns.

3.6 Relevance for Social Work practice

The social work profession is dedicated to the welfare and self-realization of all people (Canadian Association of Social Workers, 2005a, 2005b). Social workers play a key role in the provision of health services in Canada. The range of services they provide includes medical social work (such as social work with individuals, group work, discharge planning, family consultation, patient advocacy, counseling of terminally ill patients, training and policy analysis) as well as community-based and preventative services (such as health promotion and education, self-help group formation, community development and advocacy). In hospital care settings, social workers are often part of a multidisciplinary team that provides a unique holistic perspective to health care. This holistic perspective is not only concerned with the treatment of illness, but also with the promotion of wellness and the consideration of the social, economic, spiritual and cultural needs of the health services client (Auslander, 2001).

Social work policy and practice strives to assist clients with the navigation of health care systems, to provide service and support positive health outcomes. Optimal attention to and promotion of sound health care strategies necessitates exploration of the multidimensional processes associated with searching for health information. Researchers' investigations of health maintenance attest that there are connections between information and health outcomes; a relationship between information and social functioning and that information informs notions of health (Lupton, 1995a, Uchino, 2004).

With the presence of technology and the Internet in everyday life, it is timely for

social work professionals to consider the effect of computer-based technology on social functioning. Technology is now intertwined and relates specifically to the provision and access of health information and service (Geissbuhler & Boyer, 2006). As new communication patterns shift conventions of relationships, social workers must reconsider the formal and informal notions of personal connections. There are emerging possibilities for new relationships, social work interventions, service provision and work with individuals. When social workers care about social functioning, that implies they care about social relations.

Social relations, both new and old reflect the notion of social presence or a type of presence that is projected when a person is associating with others. In the case of new relations, social presence is not confined to face-to-face encounters but is necessarily relational. Interpreting the work of LaTour (2005), LaMendola (2010) argues that social work is interested in the process of assembling or reassembling human associations into different forms. Social work involves associating and reassembling social relations or creating new ones. Meaning, social work is involved not only with individuals but also with communities and organizations, assembling and reassembling their networks and associations.

This underlying understanding of the context and capability of social work is interesting and important now as there is an online environment created by the use of computer networks that facilitates human networked interaction across these digitally based networks.

As Wellman (2001) argues, these computer networks are inherently social

networks. "they are social institutions that should not be studied in isolation, but as integrated into everyday lives". Therefore it is important for social work to take up the task of developing new tools and new means to "help people navigate and find knowledge in complex, fragmented networked societies". LaMendola (2010) argues that social work must engage intimately with the practices of everyday life, where life flows.

The number of North Americans who go online to search for health information is increasing as it continues to be easier to get health information online (Fox, 2006; Underhill & McKeown, 2008). People are taking charge of their health, pursuing second-opinions with Internet based information, self-diagnosing and researching medical alternatives. This means that health information, once closely guarded by medical professionals, is now publicly available to those who know how to search for it. Researchers investigate the long-term implications of this.

There are opportunities and challenges presented by the advent of Internet based technology into the public and private spheres of clinical and policy-oriented practice. Therefore, it is time to critically examine the lived experiences of those who incorporate technology into their health management strategies, thus enabling social workers to fulfill their professional obligation to provide optimum support.

The Internet can act as a tool of empowerment and as such the act of searching for and accessing health information is changing the doctor patient relationship, and how people think about health and manage their health issues. As access to information changes, priorities emphasizing the need for and benefit of the information also change. Therefore it is important to recognize the emphasis on information acquisition within its

historical context. Similarly, it is important to be mindful of the relationship of information with power. As social work researchers it is important to recognize the connection between knowledge and power and how the availability and ease of access to information constructs this connection. In this way, social workers create the potential for new interpretations and construct evolving meanings about subjects of interest.

The intention of my research is to consider people living in an urban Canadian setting. Ultimately, researching health management will challenge social workers' assumptions about the Internet and about the kinds of roles the Internet can take. It is vital for social work practice to consider the inevitable implications of this information and connection. Social work practice will benefit from taking into account how Internet based information and communication constructs environments where empowerment is possible.

Chapter 4

Research Methods and Measures

4.0 Introduction

The purpose of this investigation is to look at the fit of personal Internet use within individual health management processes. To best address my overarching research questions and specific inquiries raised in the previous chapter, I needed to devise a comprehensive research strategy, a thorough methodology and meticulous tools of investigation. Several researchers sharing an interest in the examination of the Internet in everyday life came together to create the Connected Lives Project. Given the range of interests, the team decided the ideal place to investigate a diverse population is an urban setting known for its heterogeneity. Decades of immigrant migration and real estate development have transformed East York from its village like past to a cosmopolitan community where almost fifty percent of the population was born outside of Canada. Such population diversity would suit the research needs of each team member and met my requirement of looking at a large population of Internet users with diverse health issues and medical needs.

This chapter outlines the Connected Lives Project, describes the population of East York, Ontario and articulates the methods used to achieve my research objectives.

Furthermore, the tool development, data gathering techniques, sample selection of the project and how the team employed a mixed methods research design are explained.

The research tools comprise a thirty-two-page survey, interview guide, a social network name generator, and a participant observation guide to increase validity and reliability of the study. The large sample size and high response rate ensure the data's suitability for answering the research questions.

4.11 Connected Lives Project: East York, Ontario

The Connected Lives Project represents the work of a team of University of Toronto doctoral students working under the supervision of Professor Barry Wellman within NetLab[5] between November 2003 and April 2005. The team was comprised of one Principal Investigator; five student researchers, various assistants, and several support staff. Each researcher brought a unique perspective and interest regarding how the Internet and Internet based communication technology fit within the every day lives of Canadians.

My involvement with NetLab began in November 2003, when the collective first agreed to meet and discuss shared research interests. Given the common curiosity about the Internet and social networks, and the specific interests in communication, work at home, gender issues, travel, planning and scheduling negotiation demands, transportation, social activities and using the Internet to access health information, the Connected Lives survey and interview schedule became substantial tools. Creating and disseminating a

[5] NetLab is a research network directed by Professor Barry Wellman within the University of Toronto's Department of Sociology.

comprehensive tool to address our primary and cumulative research goals seemed feasible by building a multidisciplinary research team. The first months of meetings and negotiations were attempts to understand the presenting issues and robust theme.

My piece of research within the project focuses specifically on how the Internet fits into health management strategies. Consequently, I assessed rates of specific Internet use for information searching, frequency of Internet use for communication of health issues with others, and circumstances when people chose to go online, or use traditional information sources to answer health related questions. Additionally, I gathered a measure of subjective health status, to see its role in predicting Internet use and involvement in the experience of accessing health information.

All of the research for this project is set in East York, a residential area of Toronto that hosted NetLab's two previous community studies in pre-Internet days. East York was originally chosen for the first study in 1968 because of its convenient locale (30 minutes drive from the downtown core), atmosphere, cooperative government, and cultural homogeneity. Its selection for the second study (1978-1979) was for longitudinal continuity as 33 original respondents were re-interviewed (Barry Wellman, 1979, 1988b). While it would not be feasible to do a third wave of a longitudinal study 25 years later, East York retains its value for comparisons with our pre-internet data, and it provides a fair cross-section of the Canadian urban public.

East York sits squarely within the arterial highway system of Toronto. It is bounded on the west by an expressway, on the south by a subway line, and buses frequently travel main routes. Its population of 114,240 (Statistics Canada, 2003) is

ethnically and socio-economically mixed, residing in houses and apartment buildings. Mobile phone and broadband Internet service is widely available throughout Toronto, the largest metropolitan area of Canada. Computer access is good, with telephone and cable companies competing to provide broadband connectivity.

4.2 Mixed Methods

When addressing complex issues such as health management processes and posing health based research questions, construction of a mixed methods investigation is thought to be most appropriate (Sale, Lohfeld, & Brazil, 2002). As such, the complementary and cumulative effects of mixing methods suits the complexity of the question posed within this work (Hanson, Creswell, Plano Clark, & Creswell, 2005).

Mixing methods means designing both a quantitative and a qualitative study, and using them in combination. Therefore, this style of inquiry requires the researcher be mindful of the discourse associated with each ontological perspective and be skilled at both modalities.

The Connected Lives Project exemplifies a sequential design. Sequential design involves using quantitative data gathering methods first to describe a particular reality of the population, after which the population is considered through a qualitative lens that adds richness to the description of the phenomena. Within this dissertation, the quantitative data examines the Internet usage rates and the relevant predictive factors. The qualitative data is used to examine the lived experience of accessing health information and communicating about health issues. Using mixed methods design allows

for a description of the population in as many ways as possible in addition to analysis that will lead to an understanding not accomplished by previous research.

4.3 Research Integrity

A familiarity with both quantitative and qualitative methods is necessary for researchers using mixed-methods design (Hanson, et al., 2005). Mixed methods researchers using deeply probing experiential data must think in terms of trustworthiness and internal and external validity, reliability, and objectivity (Denzin & Lincoln, 2000; Denzin & Lincoln, 2002; Lincoln & Guba, 1985; Padgett, 1998). These strategies serve to protect both the researcher and the subjects. Being skilled at qualitative research also means being mindful of the role of the researcher while maintaining research integrity. While I did not gather deeply probing qualitative data, sensitive to reflexive interpretation as is required by grounded theory or phenomenological research, I do think it is important to locate myself within my interpretations, as researcher bias is a potential with any interpretation (McCracken, 1988). As such, the following presents my structured cultural review, thus situating myself within my work.

4.3.1 Cultural Review

My divergent roles of social worker and computer user influence my beliefs about service provision, clinical practice and the Internet. As a social worker, I learned to be a reflective practitioner, intent on providing comprehensive service within multidisciplinary teams. My generalist education and clinical practice allowed me to acknowledge my position of privilege with integrity. As such, I strive to be a reflexive

researcher in a manner complimenting my social work practice. Social workers acknowledge their belief systems, leaving their biases outside of their practice (McIntosh, 1989). By acknowledging my bias towards academic learning and contributing to the research community, I hope to keep it from infiltrating my work.

As an "early adopter" of computers and Internet based communication I participated in the utopian glee; as a clinician, working in addictions, the dystopian perspective was never far. Moving cross-country to pursue scholarly goals meant keeping in touch with social ties across time zones and learning to appreciate the asynchronous communication afforded by Internet based communication tools. Using the Internet for emotional connection and for information seeking came easily to me. However, during my doctoral work events changed my perspective about my Internet use and the influence of online communication. I was misdiagnosed with a health ailment and overwhelmed myself with misinformation. Now I am more cautious when accessing health information online. A poignant story influencing my research direction happened with the death of a friend's parent. When I found out the news of the death of a friend's mother online, rather than in person, I knew interpersonal communication had changed profoundly.

Knowing I am optimistic about the role the Internet plays in people's lives it was vital that throughout this study, I take extra care to examine the data with neutrality. I did discuss my biases with colleagues all the while being mindful that my research community are also tech savvy investigators who fully integrate Internet use into all aspects of their lives. Coping with bias is one of many challenges facing qualitative

researchers. For the work to be representative, it is essential to include measures to reduce a tendency towards skewed interpretations. Negative case analysis is one such tool.

4.3.2 Negative case analysis

Negative case analysis is the analysis of a case that does not fit an emerging pattern (Corbin & Strauss, 1990). Negative case analyses provide alternative explanations or themes that do not fit the emerging patterns (Charmaz, 2006). In qualitative research, negative case analysis enhances rigor and is used in the quest for verification (Corbin & Strauss, 1990; Padgett, 1998). There are no outliers in qualitative data. Each story has something to tell. Throughout data analysis, as codes emerged that seemed to resonate with the majority of cases, there would often be a case that was an example of the opposite kind of situation. These negative case examples are included throughout the thematic analysis within the qualitative data review.

4.4 Tool Design

Within this dissertation I define health management to be the composite of getting health information, gathering emotional support for health concerns and having a relationship with a medical professional. My research questions reflect my curiosity about the processes associated with health management, now that the Internet and Internet use affects each aspect of the management process.

Consequently, within the Connected Lives Project I prioritized gathering data about health management process and the associated potential factors of demographics,

network composition, Internet usage patterns and health issues.

The survey gathered specifics about health information searching, online support gathering, network support gathering and demographics. The interview provided an opportunity to ask about more private and personal details concerning health status, health information searching, online health information searching, online health support gathering and network based support gathering.

It was important to embed the material within the larger personal interview because I wanted the security of rapport building given I knew that five research team members were going to be delivering the same interview. The interview needed a natural flow and to be as scripted as possible while being open ended with opportunities for variation within the questioning as needed.

4.4.1 The Survey: design and delivery

The initial task of the Connected Lives Project involved collectively developing a 32-page self-administered survey to be distributed to a randomly selected sample in East York, Ontario. The specific instrument used is shown in Appendix A. Given the breadth of research objectives, and the constraints of the survey format, months of negotiations, revisions, group process sessions, and field-testing lead to the development of a satisfactory tool. The survey asks people about their jobs, the technology they use, how they are currently using the Internet, their families and social networks, their community involvement, social attitudes and general demographic information.

Raosoft[6] determined a sample size of 377 necessary for generalizable results. The

[6] www.raosoft.com/samplesize.html

sampling frame for the survey drop-off process was a list of 1000 names and corresponding addresses stratified by FSA (Forward Sorting Area, i.e. the first three letters of the postal address).

Members of the Connected Lives team personally contacted each individual from the original sampling frame. Formal letters of introduction were sent, follow-up phone calls were made and a member of the research team personally hand delivered each survey with an offer to pick up the completed survey in either a few hours or a few days. Monetary incentives (five dollar gift certificates for local coffee shop franchise) were delivered to each individual returning a completed survey.

Three hundred and fifty people (a 56% response rate) completed the one and a half hour survey that was hand delivered to their homes and picked up a week later. The sampling frame yielded 621 valid names of English speaking non-frail adults (18+) living within the boundary of East York Ontario of the original 1000. The remaining 379 names were removed dues to such factors as lack of English language skills, frailty, death or having moved. Given the large sample size and favorable response rate, the survey data provides statistical generalizability.

4.4.2 The Interview: design and delivery

The final page of the survey asked if the participant was interested in being contacted to complete a follow-up interviewed. Each potential interviewee was promptly phoned and an in-house interview was arranged.

The interview schedule afforded an opportunity to gather data not collected by the survey and to explore new topics relating to our thematic research interests. Within the

interviews, people told stories about their health issues, how they access health information and with whom they share it. The specific instrument used is shown in Appendix B.

Beginning with semi-structured questions on daily household and social routines, the interview continues by asking about computer and Internet use. Detailed information on social network composition, information seeking behaviour and health issue related questions were posed later in the interview. To systematically gather social network data a unique tool was developed specifically by the Connected Lives Project team to use during the interview process. This tool involved the interview participants to think about important people in their lives that they would consider *very* close and *somewhat* close ties. The lists of names were then transferred to large pieces of paper with concentric circles drawn on to represent rings of closeness. Complete details of this tool are described by members of the Connected Lives project within the Field Methods Journal (Hogan, Carrasco, & Wellman, 2007).

Participants were also asked what role the Internet plays in information gathering, decision making, and engaging in different activities.

Timing and sequence of the questions were my focus when writing the interview guide. Since each interview would be conducted by one of five research members, the questions needed to be written in such a way as to be open-ended, with the possibility of probes, yet specific enough to offer consistency across the interviews.

During the interview guide construction process, I was mindful of the private and personal nature of health (Radley & Billig, 1996). To that end, I wrote a detailed

interview administration guide in such a way as to gather information and meaningful stories in an empowering manner. This involved building rapport through active listening and gentle probing, while cultivating an affinity between the interviewer and the participant. The guide included prompts to get as complete a story about the process of gathering health information as possible. As I did not want to necessarily privilege the Internet, but wanted to ensure people spoke of all methods that they used to gather information, interviewees were asked people to describe the last time they went looking for health information.

Finally, the interviews ended with open and semi-structured observations of Internet search behaviors. If the participant had an Internet connection, the participants completed specific search tasks based on activities drawn from questions within the interview. I was particularly interested in having people show me how they use the Internet when looking for health information. For example, a participant was asked to indicate which of five potential health issues was most relevant to them and then they demonstrated how they would search for related information online. The intention of the observation was to find out if the search actual strategies reflected the described search strategies, or if social desirability bias was a work within the interviews. Although the questions were written to attempt to avoid assuming the respondents would be using the Internet to search for health information, the observation was an opportunity to identify if people were using the Internet in a manner similar to what they previously described. Those who completed the observations demonstrated fluency with using web-based search tools and often showed challenges with spelling various health issues. In the end,

the content of the observations did not differ enough from the interview content to warrant unique coding or analysis.

At the end of the interviews and observations the participants' computer station set-ups were photographed as this information was particularly relevant to one researcher curious about household technology space composition.

Of the 350 people surveyed, 87 (25%) agreed to participate to be interviewed. This represents an 85% response rate of those survey respondents who indicated they would be willing to be interviewed on the survey. Five doctoral students from the Connected Lives team conducted interviews between February and April 2005. Each interview took between two and four hours, usually completed within a single evening in the participants' home. Participants were compensated twenty dollars (Canadian funds) for their time.

4.5 Data Analysis

Survey questions and responses were coded into SPSS variables, entered into a secure database and cleaned by members of the Connected Lives Project. The 87 interviews were digitally recorded and transcribed by members of the Connected Lives team. After each interview, the interviewer wrote a cover sheet summarizing the experience and highlighting themes from every section of the interview.

Audio recordings of each interview were reviewed and memos of personal impressions and initial themes were written to accompany each interview. Only relevant sections where the participant spoke about health issues underwent coding; however, the

entire interviews were listened to for context and experiential knowledge of each interviewee. While each interview is unique, there is value in listening to the entire collection of interviews in succession to experience the entirety of the collective experience.

Four of the interviews were not recorded due to technical malfunctions. Interviewers field notes and observations were coded for content and themes for these missing transcripts. Six of the interviews did not include a full health section component. Best efforts were employed to include as much information about these individuals as possible.

Topic coding initially extracted the sections of the interviews of particular interest (Morse & Richards, 2002). A qualitative data analysis software package called NVIVO assisted with coding and organizing the sections of interest from the interviews. Many of the codes were also converted to SPSS variables for further analysis.

During the first phase of topic coding each response was coded into one of three unique variables: health score, health category and health issue priority. The subjective Health Scores were coded as numeric values from 0 - 10 and were specifically converted to an SPSS variable appropriate for descriptive statistics and correlation analysis. Health Category was coded as one of five different health issue types (lifestyle, mental health, chronic, acute, public health). These codes were also converted to an SPSS categorical variable in order to conduct both quantitative and qualitative analyses. During the interviews, the participants typically described a particular health issue of significance. These health issues were coded as the Health Issue Priority variable.

Throughout the second phase of coding I specifically analyzed the sections of the interview where the participants described the last time they looked for health information. I titled this coded section the "Health Story" code. Next, I created unique categories within this code to capture the place of Internet use within the health management process. Four categories described Internet use in the context of a health issue inquiry: 1) Internet use coming before a medical appointment, 2) Internet use after a medical appointment 3) Internet use instead of a medical appointment and 4) No Internet use at all. Also within the code of Health Story I created categories to describe the effect of Internet use for the participant when referring to their Internet use. These categories included 1) becoming informed, 2) becoming healthy, and 3) habitually using the Internet. A full summary of the coding process can be seen in Appendix D.

Coded data was managed and organized within Microsoft Excel spreadsheets, where it could be categorized and grouped more easily to look for patterns and sequences within the data. Field notes, codes, key words and summaries were recorded, indexed and filed for ongoing reference.

4.6 Participant Profile

People living in East York graciously gave of their time and opened their homes to the Connected Lives research team. I am honoured by their honesty and grateful for their illuminating responses to our team's curiosities.

4.6.1 Demographics

The Connected Lives Survey asked socio-demographic questions about age,

gender, marital status, the number of children, the place of birth, the year in which respondent migrated to Canada, citizenship status, occupation, the highest level of education, the country of origin, and income.

Fifty-eight percent of the *survey* respondents are women, with a median age of 45. Fifty-nine percent of the somewhat less representative *interview* sample are women, with a median age of 49.

When data were gathered in East York in 1968 and 1978-1979, almost all residents were Canadian born and had British-Canadian ethnicity. Over the past few decades with immigrant migration and high-rise apartment development, East York is becoming like metropolitan Toronto (and different from many other places in Canada) with its high percentage of foreign-born residents. No longer resembling its village-like past, 53% of East York residents were Canadian-born in 2001 (Statistics Canada, 2002), similar to the 51% Canadian-born survey respondents and 58% interview participants.

Despite changes, British-Canadians comprise nearly half (44 percent) of the survey sample. Visible minorities (i.e., non-white-Canadians) make up 27 percent of the survey sample: principally East Asians and South Asians, with Chinese-Canadians and Indian-Canadians being the largest groups. This is substantially lower than the 2001 Canadian census report that visible minorities represent 36 percent of the East York population. These ethnic groups are underrepresented in our survey (and subsequent interviews) because of language and cultural barriers. In most other respects, our data reflects census demographics, including gender, age, income, education, and family composition.

Nearly two-thirds (62%) of the survey respondents are married or stably partnered, as are 68% of the interview participants. Three-fifths (61%) of the survey respondents have children, as do a somewhat higher 66% of the interview participants. East Yorkers are educated. Forty-three percent of the survey respondents have a university degree, while 27 percent have a high school education or less. Most of the population is working-class and middle-class. Median personal income is between $30,000 and $40,000. With most adult household members doing paid work, median household income is substantially higher, between $50,000 and $75,000. Sixty-two percent of the survey respondents are doing paid work. Of the rest, a high percentage (37%) are retired, 16% are students, and 13% are full-time homemakers. The rest of the sample report that they are between jobs, on leave, or have other reasons for not working.

Sixty-two percent of the *survey* respondents are coupled: married, common-law, or in a long-term relationship. Twenty-three percent are single. Interview participants are more likely to be coupled (68%) and less likely to be single (15%), compared to the survey respondents. A higher percentage (51%) of interview participants than survey respondents have a university degree, while only 20% of the interview participants have a high school education or less.

4.7 Health Issues

Interviews are opportunities to build rapport, gather information in an empowering manner and collect meaningful stories. Interviews where participants are asked to share personal and private matters about their health need to reflect the potential

sensitivity of the subject matter while honouring and respecting the participants. To that end, the Connected Lives Project interview structure asked individuals several times about their health issues, how they take care of themselves and where they access health information.

Hunt and McEwan (1980) first started the subjective health indicator as a more successful measure of how patients feel. Asking someone to describe their health status, or the perceived level of health, grounds the individual in their own lived experience and reflects large social norms (Hydén, 1997; Lawton, 2003). In answering the research question, comfort is taken in assessing differences and similarities across health issues simultaneously. Since this research does not target a health issue specific population, yet was interested in differentiation, it is important to construct a baseline of health status (Pierret, 2003).

Personal health priorities are thought to reflect social mores and can be said to reflect the differences between those with information and those without (Foucault, 1975; Lupton, 1997). Asking individuals about their health priorities gives subtle entrée into what the social conventions of a particular time are. The subjective health question within the Connected Lives interview is a preliminary attempt to reflect the personal nature of health and thus the political nature of health management. To get a robust picture of each individuals dynamic health issues and health priorities, I asked every participant three times to talk about their health matters. Each response was coded into one of three unique variables: subjective health score, health issue priority and health issue category.

4.7.1 Subjective Health Score

During the health section of the interview (Interview Section 10), each participant rated his or her subjective health status on a scale from one to ten and said what would need to change to increase their health score by one point. Seventy-eight people (90%) answered the question. The mean score was 7.8 and the distribution of scores appears to be normal with a standard deviation of 1.9 and a range between 1 and 15. Health scores tend to be higher when a participant is between 18 and 30 (8.2) and then again, when they are over 65 (9.1).

4.7.2 Health Issue Priorities

After scoring their health, the interviewees mentioned what it would take to improve their subjective health score by one point on a ten point scale.
Asking people to talk about health produced a variety of responses reflecting attitudes and beliefs about health and wellness. Most people agree that some things construct good health (diet and exercise), while others articulate notions about what constitutes health (attitude and longevity) and what makes up a favorable health score.

An interesting finding is the conveyance of a moral obligation to take charge of one's own health (Roy, 2008). Perhaps the Internet reinforces notions of health and the emphasis on being healthy without explicitly defining what that means.

Saltonstall (1993) found that health, for both men and women, was allied closely to physical standards that conformed to the ideals of being in shape. Health was also something to be achieved by deliberate, intentional action involved the body, such as dieting, having enough sleep and physical exercise. The respondents moved back and

forth between being a body and having a body.

The individual health issues ranged from needing to lose ten pounds and start exercising, to managing diabetes or cancer. Arthritis, kidney disease and hepatitis also emerged as health issues faced by individuals in the population. Quitting smoking and coping with stress were also among the responses. Some with perfect scores indicated having no health issues worthy of discussion.

4.7.3 Health Issue Category

Prior to the observation component that followed the Connected Lives Project interview, participants were asked to consider the primary health issue they had discussed previously and choose from five categories that would best describe that issue. They could select one of the following five categories to classify their health issue: acute, chronic, lifestyle, mental health or public health. Examples of related issues were listed on the back of the cards to assist the interviewees with selecting the appropriate category (see Appendix C for more details). I chose these categories because they encompass the majority of popular health issues (Fox, 2006; Health Canada, Statistics Canada, & Canadian Institure for Health Information, 1999). The public health category was included because the Connected Lives Project took place following the SARS pandemic[7] that affected the Greater Toronto Area in 2003. While the survey and interview schedule were being produced public health information outlets were distributing information regarding SARS and measures for preventing the transmission and infection of the disease.

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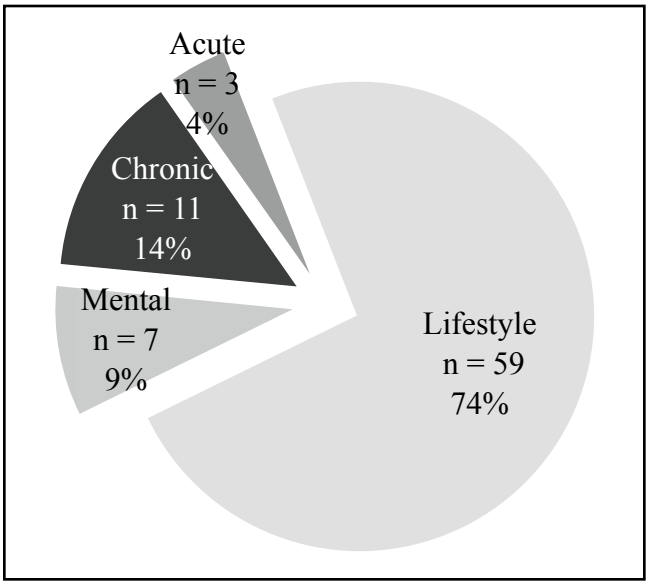
[7] SARS refers to Severe Acute Respiratory Syndrome and was declared a pandemic by WHO in 2003.

Eighty people completed this section of the interview. Their responses were coded from the interviews and converted to analyzable variables within SPSS. Seventy three percent consider lifestyle issues to be their health priority, chronic issues account for 14%, mental health issues are a priority for 9% of those interviewed and 4% chose acute to describe their health concerns. No one chose public health to describe their most recent health issue inquiry likely because the SARS epidemic had been declared over at the time of the Connected Lives interview. Arguably some of the health issues described by the participants could be classified as public health issues. Quitting smoking, exercise and community nutrition are all issues addressed by public health organizations; however, individual responsibility for health care permeated the responses of the interviewees. Since the health categories were subjective and chosen at the discretion of the participant, their classifications were recorded at face value and not corrected for accuracy.

Figure 4.1 Health Issue Category distribution



4.7.3.1 Lifestyle Health Issues

Fifty-nine people chose the Lifestyle health card to reflect their area of primary interest. Fifty-six (95%) of them specifically indicated weight loss and exercise as the focus of their inquiries. The mean health score is 7.9. It would take losing 10 pounds to increase many individual ratings by one point. People choosing this category have a mean number of 16 very close ties and 25 somewhat close ties.

Looking for lifestyle information includes going online for recipes, diet and exercise tips and items described as "coming up" during the day. The majority of persons who chose Lifestyle as their health priority go online to research both their own health issues and those of friends and family. Occasionally they would discuss an instance of looking for health information for someone else that would not fall within the Lifestyle health issue category. I did not code these cases within the other categories. It is important to note that while none of the individuals who chose the Acute health category indicated using the Internet to search for health information, people within the Lifestyle category did look for information to cope with immediate concerns for other people.

Four out of 59 people use a medical professional, rather than going online. Some used a free phone service offered by the Ontario government, while others used books, CD ROMS, or their friends.

Most do not have serious issues; they are mindful of their health and value information as a way to maintain good health. It appears the act of looking for information is reassuring, even though it does not change existing behaviors or invite new modalities of health maintenance.

Curious about prevention of serious concerns while maintaining good health, adopting the role of researcher allows people to pursue a variety of subjects. Since the Internet facilitates the information seeking, people tend to offer details about looking for information. Those who rely on books or other sources for information tend not to describe doing any ongoing research.

4.7.3.2 Acute Health Issues

For the purpose of the interview examples of acute health issues included but were not limited to fever, injury, cancer. Three people chose this health card, one man over 65 and two women between the ages of 50 and 64. Heart surgery, cancer, and dental issues are their respective health concerns. The mean health score is 9.3 for these three interviewees.

These individuals categorize their health issues as acute have a mean of 4.5 very close ties and a mean of 10.5 somewhat close ties. Exchanging health information within networks was common. Those who help with health matters are the same people with whom they discuss the contents of their days . In particular, one interviewee consults with her sister for all health issues, when others are looking to health books or specialists.

They get information from a doctor, or from someone else who has Internet access and shares it with them. Although the Internet did not fit in the process of accessing information or emotional support for health concerns, people did receive information from medical professionals and support from network members. One individual researches health issues using books, one involves specialists and one asks her sister to look for information online on her behalf.

4.7.3.3 Chronic Health Issues

The Chronic health issue card included arthritis, diabetes and high blood pressure. The 11 people classifying their issues as chronic are older than the average age of the the sample, and have a lower subjective health score with a mean of 6.6. A mean network size of 24 social ties for this group is larger than the mean number of ties for the rest of the sample. People in this category have 18 very close ties and 22 somewhat close ties. The number of network members ranged from 3 to 66 persons.

Going online to research conditions and treatment modalities was observed, as was an avoidance of information gathering, either due to information overload, or not wanting to inconvenience network members. Keeping up to date with medical news and preparing for medical appointments are reasons to go online. Four out of nine people using the Internet look for information in relation to recommendations made by their doctors. For the remaining 56%, for whom the Internet does not fit within the strategy at all, they access their physicians only, either because they do not have Internet access, or they do not want to address their health issues in an active way. Those not going online seek information when something arises, rather than in an ongoing manner.

4.7.3.4 Mental Health Issues

Mental health issues include but are not limited to depression, attention deficit disorder and anxiety.

During the interview development stage, it was deemed important to include mental health to enable the choice of psychological issues in addition to physical ailments. Rather than asking people directly about mental health concerns, the interview

provided the innocuous selection of the mental health card. Placement of the health card selection piece towards the end of the interview anticipated the development of rapport with the interviewer. Some who chose mental health indicated other types of issues when first asked to tell what their health concerns included. They included such issues as needing more sleeping, coping with stress, building self-confidence and improving home conditions.

The Internet fits in a similar manner to the other sources of information for these seven people. Their mean health score is 8. The average network size and composition 11 very close ties and 10 somewhat close ties. One interviewee has three network members and become visibly upset by the interview drawing attention to the number of ties she has.

There are no striking differences between those who use the Internet and those who do not. Each source of information is articulated with the same kind of rapid response and the same kind of intensity. Three of five people use the Internet for health information with two people obtaining their information from offline sources. Those going online, research their prescribed medication or their diagnoses. One interviewee consulted the Internet to find out about a surgical procedure. Another person only used websites written in Spanish and expressed confusion about Canada's healthcare system.

4.8 Social Support Acquisition

The Connected Lives survey asked people to indicate if they had ever used the Internet to communicate about health issues, and if they had ever given or received

support from people they only know online. I wanted to see if people in East York were engaging with online support realms and if they were exploring the support available for health issues online. I wanted to find out the prevalence of going online for emotional support within a general population. I was curious if people were reaching out only their strong ties networks, or if people were communicating with strangers and people they might have met online. Within the interview, this concept was explored further.

4.9 Social Network Composition

A social network is a framework for thinking about the people in your life with whom you share time and communicate with. Recording a version of a social network depends on the language of description and the method of capture. An important aspect determining who is included with an individual's personal social network is the notion of closeness.

The Connected Lives survey asked each person to calculate how many very close and somewhat close ties they have in their social networks and to estimate how many of those ties were friends, family, neighbours and workmates. Measures of closeness were defined within the survey for the participants. Very close ties are those persons with whom one is likely to share intimate details of their lives, discuss important matters with, have frequent contact, and from whom they seek help. Whereas somewhat close ties are those persons with whom one is close, but not as close as the very close ties, have less frequent contact, and is less apt to seek help from, but more so than with acquaintances (Boase, Horrigan, Wellman, & Rainie, 2006; Granovetter, 1973; Barry Wellman, 1988a).

The survey states:

> Please think about the people in your life who do not live with you. We would like you to consider those who you are VERY close to and those who you are SOMEWHAT close to.
>
> VERY close:
>
> - Those that you regularly discuss important matters with,
> - Those that you regularly keep in touch with, or
> - Those that are there for you when you need help.
>
> SOMEWHAT close:
>
> - More than just 'casual acquaintances', but not 'very close'.

The survey participants have diverse networks and there is a lot of variation across the networks. On average, people have 13.4 very close ties and 21.1 somewhat close ties. Most ties are either family or extended kin. Typically, the population has 6 immediate ties, 7 extended kin, 5 work mates, and 3 neighbours. As the population ages the number of ties decreases. The number of ties for women appears to be different then from the men in the sample; however this difference is visually interesting without being statistically significant.

To collect social network data, during the Connected Lives interview (completed by 87 of the original 350 survey participants), each individual completed a personal network map using a modified name generator method (Hogan, et al., 2007). The interviewers asked participants to list the names of people in their lives. Then they placed the tags with the names on them onto a large piece of paper representing their network. This task was time consuming, however the participants seemed to enjoy the experience. There were many novel responses and some people wanted assurance that no

one would see their network maps. After the maps were made, the interviewers asked a variety of questions about whom in the network provided certain things, and who requested certain things.

As the interview progressed, the participants could refer to their network maps. This was particularly helpful during the part of the interview where the participants described whom they provide health care for and whom they go to for health information and emotional support.

These unique social network maps have been translated into data files to be read by GUESS, a social network visualization tool. By translating the data into readable files and processing them into computer program generated output, the creation of consistent imaging to compare details of network profiles is possible. These GUESS generated files provide tangible and consistent visualizations of which the interviewees are receiving, giving and exchanging health information with and how they are connected to each other.

4.10 Rates of Engagement, attitudes of use

Within the survey, participants were asked to indicate if they have a computer, if / how often they use the Internet, and what activities they pursue. Additionally, participants were asked to indicate their attitudes towards computer and Internet use.

4.10.1 Computer Usage

Eighty percent of the survey respondents have computers in their homes, and 75% of those computers are connected to the Internet with a high-speed (broadband) connection service. Not only do people have the Internet in their homes, 65% of

respondents go online at home everyday.

Computers are precise technical machines requiring a certain skill set to use and another skill set to maintain. Within the survey, a series of questions addresses the issue of maintenance. Respondents chose one of various scenarios to best describe the person who performs maintenance on their computers. The options included, themselves, other family members, spouses, neighbours, friends or technicians. Seventy-five percent of respondents maintain their own computers. Of those who ask others to perform maintenance, 33% ask their spouse, 15% ask their male children and 10% ask their female children perform routine maintenance. Less than 10% of the sample relies on technicians for maintenance.

The survey asked people to consider what skills they had to perform certain tasks on their own computers. The questions were ordered from easy tasks to more challenging. As computer based tasks get more complicated, fewer people can perform them; however, most people can easily use a word processor (80%) and use Internet browsers (86.5%).

4.10.2 Internet Usage

Technically, the Internet is a network of linked computers; metaphorically, the Internet is a communication device, an information-seeking tool and a recreational activity. Given the multiple definitions and interpretations associated with the Internet, the survey remained intentionally ambiguous with its definition of the Internet and Internet based activities, thus allowing the respondents to decide for themselves what the Internet represents. When the Connected Lives survey respondents were asked to

estimate how much they would miss the Internet should it no longer be available to them, 79% would miss the Internet somewhat or very much.

Respondents commented on whether or not the Internet makes various everyday tasks easier or more difficult, or whether the Internet has no effect on task completion. Tasks included such things as communicating, searching for information, shopping, learning new things or meeting new people.

The Internet is rarely perceived to make tasks more difficult. Instead, it is believed to make things easier. One percent of respondents believe the Internet has made searching for health information more difficult, while 84% indicate they think it has made it easier. Fourteen percent believe the Internet has no effect at all on searching for health information. Ninety five percent indicate a belief that the Internet made it easier to learn new things. With regards to communicating, not one person in the sample suggested that the Internet makes communication more difficult. Generally, the belief is held that the Internet facilitates communicating with household members, other relatives and friends.

The respondents were asked to indicate within the survey what year they first started using the Internet. The mean number of years online is 8.4, suggesting, given the time of the survey, that most people in East York went online in 1996. People who have been online over 10 years account for 21% of the sample, divided equally among men and women.

Of the people who have a computer in the home, less than 2% of them never use it. For ease of interpretation, I constructed a categorical variable for user style. Non-users do not access the Internet. Light users go online 1-2 hours per week. Moderate

users are online 3-7 hours per week and heavy users are online for 8 or more hours per week. The majority of people (78%) are either moderate users, using the computer 3-7 hours per week, or heavy users, who use the computer more than eight hours per week. Gender is not related to style of user, meaning a significantly similar number of men and women are divided across the style of user groupings.

4.11 Summary

According to my analysis of the Connected Lives survey data, East Yorkers consider themselves to be healthy. They are culturally diverse, educated and are likely to be married and have children. They tend to use the Internet from their homes, schools, and places of work. Researching and communicating online are typical tasks for the majority of the population. Ultimately, they have integrated Internet based tools of health management into their daily activities. Further details of this analysis will follow in next chapters.

In keeping with the sequential design, after I analyzed the quantitative data from the surveys, I looked to the interviews for insights to address my research inquiries. I specifically addressed how people fit Internet use into their health management strategies and the effects of that integration on their supportive relationships and definitions of health.

During the thematic analysis, I noticed how people referred to the Internet, the language they used when describing search engines and their discourse about the Internet. To further my investigation, I reviewed my codes and saw that for some the Internet is a

database, for some it is a reassuring communication device and for others it empowers them to take fuller charge of their own health. People refer to the Internet with familiarity and derive support from interacting with it. This emerging relationship with the Internet and the influence the Internet has on both the individual engaged in managing their health issues and the process itself will affect therapeutic social work practice and health policy development.

In the following chapters I will expand on these preliminary findings. Chapter Five describes the relationship between personal factors and use of the Internet to search for health information. Chapter Six specifically addresses who is using the Internet to communicate about their health issues. Finally, Chapter Seven relies on the qualitative analysis of the interviews to describe the implications of Internet use on definitions of health, supportive relationships and the interaction between use of the Internet and communication with medical professionals.

Chapter 5

Findings I: Gathering Health Information

5.0 Introduction

My privileged position of being a web savvy computer user leads me to use many online resources throughout each day. Consequently, when I am sick my health research begins on Google's home page where I am directed to links providing medical information, treatment options and prescription medication definitions. Gone is my routine of using the medical book's index to satisfy my curiosities.

What piques my research curiosities is influenced by my attitudes about health and health management, which in turn affects my health management strategies. Taking charge of personal health research, rather than relying on medical professionals to provide information, allows me to feel more informed and more in control of my health outcomes. Not burdening my spouse or friends with endless questions is good for my relationships, as Google does not judge my propensity for ongoing research.

When I can find out what is wrong with me, how to care for it and how to take personal responsibility for the health of my body and my mind, I am empowered to do so. I am no longer as reliant on medical professionals to control my health outcomes as I begin to take charge of my own health management strategies.

My experiences reflect the overall changes to the information seeking and emotional support aspects of health management change in the age of the Internet. Understanding how the Internet use is integrated into the search for health information will prepare researchers and medical professionals for the inevitable changes to the overall experience of health and to health care practices.

The practice of social work in the context of health care has a rich history spanning more than one hundred years (Auslander, 2001). In recent years, the gradual introduction of new concepts of health and wellness, systems and ecological theories and holistic biopsychosocial frameworks into the health care system gives evidence to a paradigm shift initiated by the ethos of social work being reflected in the context of health care (Auslander, 2001). Social work strives to understand and incorporate the needs of clients and health service users into its practice. Therefore the results of this chapter that considers the experience of looking for health information, both on and off line, and assesses how patterns of Internet use, health status and network composition contribute to this aspect of health management hold relevance for social work practice and policy.

5.1 Previous Research

As Canadian rates of Internet use increase and government policy improves the population's access to the Internet via broadband connection, both early adopters and those affected by the digital divide are now online in almost equal measure (Underhill & McKeown, 2008). To date however, online health information gathering or functional

support acquisition is influenced by web user style, gender, and health status among those who have access to the Internet at all (Underhill & McKeown, 2008).

According to the research reviewed in Chapter Three, what increases the likelihood of using the Internet to search for health information can broadly be categorized in four ways. First is a broadband connection; people with faster Internet connections are more likely to perform more tasks with the Internet if they can connect quickly (Fox, 2008; Rains, 2008). Second is the category of gender, if a person is female; they are more likely to look for health information (Cotten & Gupta, 2004; Warner & Procaccino, 2007). Third, if people are computer savvy they are also more likely to perform more tasks (Rains, 2008). Finally, if people have a pressing health concern, they are more likely to go online to look for health information (Fox, 2008).

Consequently, within my research, I anticipated three general findings: (a) searching for health information will occupy a significant portion of users' time online; (b) that searching for health information will vary depending on health issue; and (c) that people's expectations about the Internet will influence their usage.

Given that information flows through networks, it is surprising that research to date has not considered the relationship between network characteristics and searching for health information. Aside from Wellman's (2003) work describing the pathways to health information, little work describes the relationship between network characteristics and time spent searching for health information.

In addition to Internet competence and health status, I also consider the relationship between network composition and how much time is spent searching for health information online.

5.2 Research Questions

This chapter describes how the amount of time people spend using the Internet to search for health information is influenced by socio-demographics, health issues, proficiency with computer and Internet use, and social network characteristics.

In order to assess the relationship between personal characteristics and the information searching aspect of health management, I propose several specific investigations. Firstly, the chapter describes how much time people spend looking for health information. Second, the relationship between age and gender and searching for health information is assessed. Next, with regard to a persons' degree of web competence, I explore how Internet user style is related to searching for health information, and whether a person's efficacy about the Internet predicts how they search for health information. Fourth, I analyze if how a person categorizes their health issues is related to the way they search for health information. Finally, I examine the relationship between the number of ties contained within the interviewees' social network with the time they spend searching for health information.

5.3 Methods and Measures

To address the aforementioned research questions, I used data gathered by both the Connected Lives Survey and the Interview schedule.

The Connected Lives Survey respondents gave an estimate for three variables: (a) how much time they spend online overall; (b) how much time they spend looking for general information; and (c) how much time they spend looking for health information from home, work or school.

In this chapter, the dependent variable is the amount of time spent searching for health information from work/school and home. The five independent variables are: (a) having a broadband Internet connection, (b) gender, (c) health status, (d) Internet savvy, and (e) network characteristics.

To answer the research questions and test the corresponding hypotheses, the survey data were converted into SPSS variables. This was done in order to measure time spent information searching, demographics, health status and network composition.

Particular sections of the qualitative data collected during the Connected Lives interviews were also converted in to SPSS variables for the purpose of analysis. Other data from the interviews were coded where appropriate.

Each interview participant was given a pseudonym to assure their anonymity and to improve the memorability of the person for the reader. Pseudonyms were chosen randomly and do not attempt to reflect ethnicity or age of the interviewee.

5.4 Findings

5.4.1 Time spent online

The Connected Lives survey respondents spend a mean of 9.9 hours per week online at home and 11.4 hours per week at either school or work. The group spending the

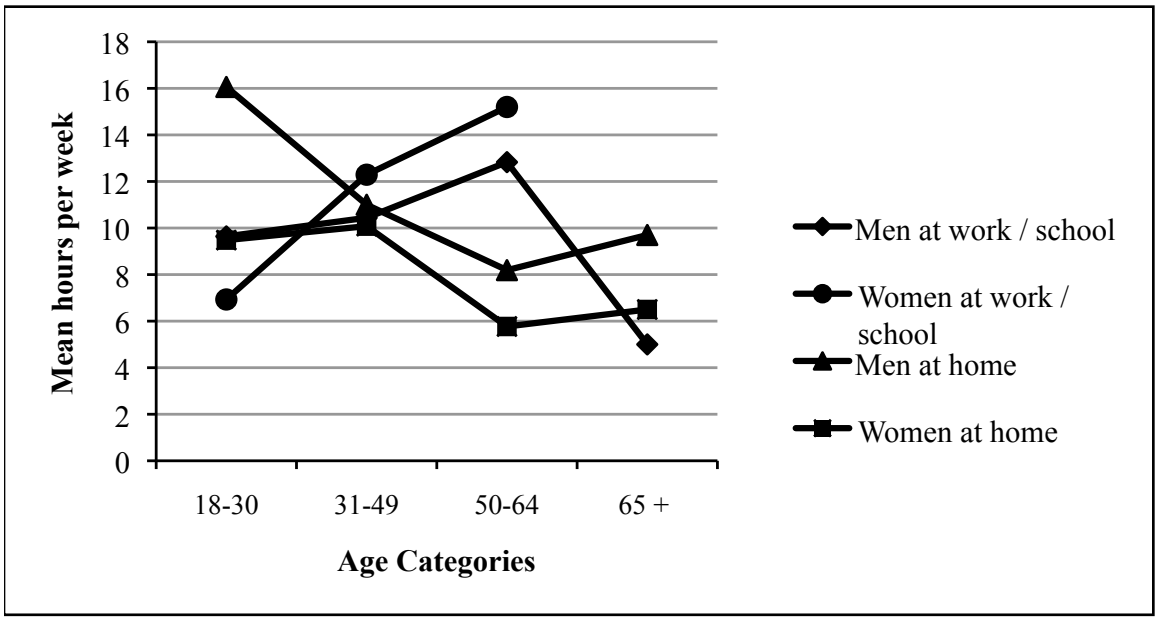
most amount of time online at home is 18 to 30-year-old men, who spend an average of 16.1 hours per week. Women between 31 and 49 spend 10.1 hours online at home per week. Men between 50 and 64 spend the most amount of time online at work, with a mean of 12.8 hours per week. 50 to 64-year-old women spend 15.2 hours per week online at work.

Table 5.1

Number of men and women going online at home or work / school by age category

	Home		Work / school		Total
	male	female	male	female	
18 - 30	18	23	14	15	70
31 - 49	56	78	32	57	223
50 - 64	26	30	18	10	84
65 +	10	2	2	0	14
Total	110	133	66	82	

Figure 5.1 Time spent online per week by gender and age



5.4.1.1 Searching for General Information online

Of the overall time spent online, a mean of 3.0 hours per week is spent at home searching for general information. 1.7 hours per week are spent at work or school. Men spend the most amount of time searching for general information at home. 18-30-year-old men spend 6.6 hours. Women in the 31 – 49 age category spend 2.5 hours per week searching for general information online at home. At work, men aged 18-30 and aged 31-49 spend 2.1 hours per week searching for general information. Women aged 31-49 spend the most amount of time at work searching for general information and average 1.8 hours.

Figure 5.2 Time spent online per week searching for general information

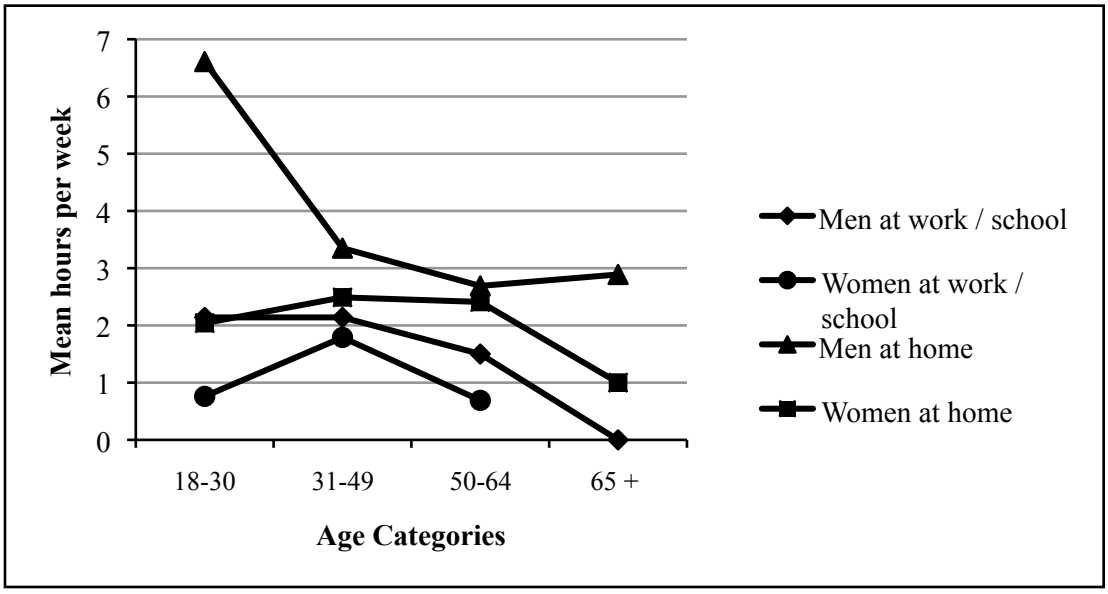
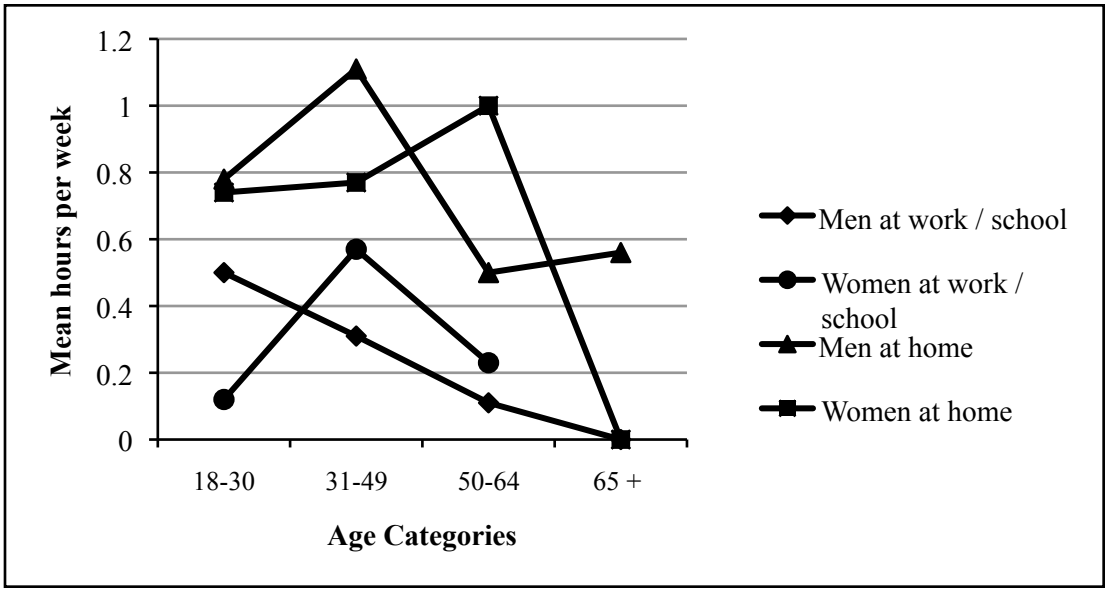


Figure 5.3 Time spent online per week searching for health information



5.4.1.2 Searching for Health Information online

The 0.8 hours (48 minutes) the survey respondents spend searching for health information online at home represents 27.6% of the time spent searching for general information. For those survey respondents searching for general information at work, 22.3% of that time (0.4 hours) is spent searching for health information.

Men, aged 31-49, spend the most amount of time online at home searching for health information, with a mean of 1.1 hours per week. Women aged 31-49 spend 1 hour per week searching for health information from home. At work, women aged 31-49 spend the most amount of time searching for health information and spend 0.6 hours per week. Men ages 18-30 spend the next most amount of time searching for health information from work, averaging 0.5 hours per week.

5.4.2 How Internet user-style is related to searching online for health information

I have previously hypothesized that the amount of time spent online in general is related to the amount of time spent searching for health information. Classifying General Internet use or "Internet User-style" according to a how much time a person spends online is not a new convention within this research, rather it is a standard adopted by Internet researchers, and other members of the Connected Lives Research Team (Hogan, 2009; Hogan, Carrasco, & Wellman, 2007).

The Internet user-style categories are: (a) Non-users do not access the Internet and never go online, (b) light Internet users go online 1-2 hours per week, (c) moderate Internet users are online 3-7 hours per week, and (d) heavy Internet users are online for 8 or more hours per week.

Non-users, those individuals who indicate they spend 0 hours online at home, report spending 45 minutes at school or work researching health information.

Those who spend more than 8 hours per week online and are considered heavy Internet users average 1.4 hours per week looking for health information from home.

A one-way analysis of variance was conducted to evaluate the relationship between using the Internet to search for health information and user-style. The dependent variable was the time spent online searching for health information at home.

Table 5.2

Hours spent online searching for health information by User Style

	N	Mean	SD
Non-Users (0 hours)	5	0.00	0.00
Light Users (1-2 hours)	42	0.38	0.54
Moderate Users (3-7 hours)	75	0.43	0.70
Heavy Users (8+ hours)	107	1.35	2.18

Table 5.3

Summary of ANOVA: Hours spent online searching for health information by User Style

	Sum of Squares	df	Mean Square	F	*p*
Regression	52.56	3	17.52	7.14**	0.00
Residual	552.46	225	2.46		
Total	605.02	228			

**p < 0.01

Internet user style is related to searching for health information online [$F(225, 3) = 7.14$, $p = 0.00$]. Those who spend more time online overall are also spending more time searching for health information.

5.4.3 How self-efficacy is related to searching for health information

Rather than asking people if they believed the Internet would help them in the abstract, the Connected Lives Project asked people if they believed that the Internet helped them to perform certain tasks. People who believe the Internet will help them perform certain tasks are more likely to use the Internet to help them perform those tasks

(Barcy & Barcy, 2008; Smith, Dixon, Trevena, Nutbeam, & McCaffery, 2009). The Connected Lives Survey respondents chose between whether the Internet makes various everyday tasks easier or more difficult, and whether the Internet has an effect on the completion of tasks such as communication, searching for information, shopping, learning new things or meeting new people.

The Internet rarely makes tasks more difficult. Instead, it is believed to facilitate task completion. Approximately four fifths (83.8%) of respondents believe the Internet has helped them search for health information. Fourteen percent indicated the Internet has no effect at all on searching for health information. Only 1.8% of the survey respondents believe the Internet has made the task of searching for health information more difficult.

5.4.4 How health issue category related to searching for health information

During the Connected Lives interview, participants were asked to choose from one of five categories that would best describe their primary health issue. I created series of health issue cards to capture a broad spectrum of health issues, without overwhelming the interview and subsequent data coding process. The categories offered to them were: (a) acute, (b) chronic, (c) lifestyle, (d) mental health, or (e) public health. The categories and their affiliated health issues were chosen to represent popular groupings of health issues according to Statistics Canada and the Pew Internet and American Life Project (Canada, 2002; Fox & Fallows, 2003; Health Canada, Statistics Canada, & Canadian Institute for Health Information, 1999).

Seventy three percent of respondents consider lifestyle issues to be their health priority. Chronic issues account for 14% of the sample's responses. Mental health issues are a priority for 9% of those interviewed, and 4% chose acute to describe their health concerns. No respondents chose Public Health issues to describe their primary health concerns.

Those who classify their health concerns as being lifestyle issues spend 0.7 hours (42 minutes) at home and 0.4 hours (24 minutes) at school or work searching for health information online. People with chronic health conditions spend 3.7 hours at home and 0.5 hours (30 minutes) at work or school searching for health information online. People with mental health issues spend 0.8 hours (48 minutes) at home and zero hours at school or work searching for health information. Finally, those individuals who regard their health issues as acute spend zero hours searching online for health information at both home and at school or work.

A one-way analysis of variance was conducted to evaluate the relationship between hours spent online at home searching for health information and health category. The independent variable, health category was reduced from the original four value variables to two categories: Lifestyle health issue and Medical issue. Medical issue is a consolidation of Chronic health issues and Acute health issues. This consolidation was created to increase the sample size and strengthen the analysis of variance. People with Acute health issues do not spend any time using the Internet to search for health information. By adding them to the Medical issue category, it is now possible to observe the difference in number of hours spent online by those with Chronic health issues.

Table 5.4

Hours spent online searching for health information by Health Category

	N	Mean	SD
Lifestyle Issues	44	0.66	1.27
Medical Issues	8	1.88	3.36

Table 5.5

Summary of ANOVA: Hours spent online searching for health information by Health Category

	Sum of Squares	df	Mean Square	F	*p*
Regression	10.01	1.00	10.01	3.36	0.07
Residual	552.46	225.00	2.46		
Total	605.02	228.00			

The results of the statistical analysis indicate a relationship between the kind of health issue one has and how much time is spent online searching for health information [$F(225, 1) = 3.364$, $p = 0.07$]. Specifically, people with Medical concerns spend more time online searching for health information. Arguably, the amount of time spent online searching for health information by those with Chronic health issues is greater than those with other health issues.

Thematic differences emerged during the analysis when the interview data were organized according to the health category. The following sections address the qualitative variances and describes how the experience of looking for health information differs across health issue, by considering the following questions: (a) What types of

information are people looking for within their specific health category, (b) what meanings are people ascribing to the experience of looking for health information, and (c) what novel experiences are being expressed when they describe their search for health information?

5.4.5.1 Searching for chronic medical issue information

Six interview participants chose the chronic category to describe their health issues, which included multiple sclerosis, hepatitis C, kidney disease, sinusitis, heel spurs, and rheumatoid arthritis.

Everyone in this group is seeking to either: (a) find information online about his or her specific conditions, (b) independently research treatment options, or (c) research treatment options in response to a medical diagnosis. These respondents spent 3.7 hours at home and 0.5 hours at work or school searching for health information online, which is the most amount of time spent by any health issue category.

People with chronic medical issues are searching for information about personal ailments and innovative treatments. They are interested in learning about treatments and cures for their own issues. Since most of them have received a specific diagnosis, they are able to follow up medical appointments with online research about treatments and pharmaceuticals as part of coping with their persistent conditions. The following two interview excerpts are typical examples of people who integrate Internet use within their health management strategies.

Isaac is a 34-year-old married civil engineer with two young children. He moved to Canada three months prior to the Connected Lives interview. He has been online

since 1994 and uses his Internet-based home computer on a weekly basis. He does use the Internet to search for health information. He gives himself a health score of 8 out of 10. In the following quote, he refers to searching online for a specific diabetic treatment:

> Because I'm diabetic, so I've visited seven or eight times Google. Then I write down the diabetic treatment. So there are so many websites I have gone to with that. Yes, I have got health information from the Internet. (343)

In this quotation, Isaac says that because he has diabetes, he uses Google to search for treatment options. This is interesting, as it seems to connect having a chronic health issue with wanting to conduct research. For Isaac, Google is a viable source of treatment options for someone managing a chronic health condition.

Eunice is a 57-year-old widow who uses the Internet to search for health information. She gives herself a health score of 7 and her health complaints are arthritis, obesity and a desire to quit smoking. An interviewer's field notes suggest this individual satisfies her curiosity by beginning with a familiar search engine and using a unique set of guidelines when determining the usefulness of various information sources:

> She starts with Google but there are so many sites that are listed. She has to make a decision on which ones to choose – she uses hospital sites, certain people or ones that seem legitimate. Some sites are helpful, while others are bad. (008)

People with significant medical issues tend to be interested in their medical concerns rather than health issues in general (Fox, 2008). The research conducted by this

group is intentional in its focus. Rather than general information browsing, people are looking up specific issues with the intention of acting on what they find.

5.4.5.2 Searching for lifestyle issue information

The 32 people who categorize their health issues as lifestyle oriented do not have significant medical concerns. Instead, they are interested in achieving optimal health and well-being by striving for proper nutrition, good eating habits and regular exercise programs. They gather information regarding personal habits they can include in their daily routines. They spend an average of 40 minutes at home and 22 minutes at school or work searching for health information online every week. They want to stay informed with current trends in health care and enjoy researching subjects related to their own bodies and their own lives. The forthcoming interview quotations highlight the topics and circumstances when people look for Lifestyle information. Some of the interviewees also looked for chronic or acute information for other people in their networks.

Hannah is 41-year-old student who uses her Internet-connected home computer on a daily basis. She uses the Internet to search for health information, and is interested in diet and exercise. She has been online since 1998. She gave herself a health score of 7 out of ten. According to her, she is interested in:

> How to eat and feed a family properly. How to maintain optimum health. What foods harm you, what foods heal you. Current trends in science and technology. (110)

Hannah is someone without a specific medical concern who is interested in general health issues. Rather than researching specific topics, Hannah gathers a variety of information about food and nutrition as part of her strategy to stay well.

Rihanna is 57-year-old woman who has been online since 1997 and uses her Internet connected home computer on a daily basis. She uses the Internet to search for health information and is mainly interested in diet and exercise. She gives herself a health score of 8 out of 10. She says:

> I search the Internet. I look up a lot of health things. I'm really into being healthy and trying to find out about the latest things. I'm getting a little into the raw food thing. I like spirituality and I look up Zen and different spirituality things… (274)

Rihanna wants to stay abreast of current health trends, as that is part of her health management strategy. For her, well being encompasses topics such as diet and spirituality. Being up to date with new information is as important to her sense of well being as is following through with particular eating regimes like a raw diet.

Theresa is a 33-year-old married mother of three who uses the Internet to search for health information. She gave herself a health score of 10 out of ten. She connects to the Internet through her home computer on a daily basis. She was born in and has always lived in Canada. She says:

> I'll look up health information. So a few weeks ago one of our daughters was suspected of having mono so I went on Healthy Ontario.com and went "oh yeah, those symptoms, blah blah blah" so I looked up that sort of thing…I have things like - sometimes recipes. I'll think, what can I do

> with this whatever. So I'll go and work out something. I'll type in keyword "asparagus" and 5,000 things come up. So I do that. I get emails from things like a parenting website, Parent Stages, it was something that I signed up for, I think it's put on by Pampers or something like that. So on a weekly or biweekly basis, they send an email with some interesting things, often it's linked to other child development related sites. So I'll go and do that. It's not really for research purposes as much as for interest or it's there, let me see what this is all about. Or HPTV, I get things from HPTV. I get things like "How to Conquer Clutter" and I'll go into the link and see what that's all about. I've also entered contests online. I've done that. (421)

Theresa's quote exemplifies a typical lifestyle issue information seeker, who is curious about multiple topics. Unlike the majority of people with Lifestyle health interests, Theresa researches information about topics other than diet and exercise information.

Sally is a 49-year-old married teacher with 3 children. She uses her Internet connected home computer daily and searches for health information. She mostly researches health information about her children. She gives herself a health score of 3 and is mostly concerned about her weight:

> Well it could be anything. It could be online because I could have seen something to deal with weight on a television show, like a Dr. Phil show or it could have been. I mean it could be anything. I mean it depends on the situation. If I'm near a bookstore or there's a book or if I'm near a computer that's online, that's where I can find the information. (432)

Sally's curiosity is not limited to online research. She is content to look up information using any available means. The Internet offers a convenience and information in combination, but the Internet is not the default choice. For Sally, the research process is the vital component of her health management, and that is not exclusive to the Internet.

Clay is a 27-year-old student in a long-term relationship. He has always lived in Canada. He uses his Internet connected home computer daily. He also uses the Internet to search for health information. He gave himself an 8.5 out of 10 for a health score.

> Umm.. as vain as it sounds, it actually goes hand in hand with looking good. Unfortunately in the gay community you are more umm socially accepted if you're not overweight. So I probably pay attention more to the fact that I don't wanna be overweight. Rather than a health issue. Maybe I am confusing it a little bit too much. I think it has more to do with umm… a vanity type thing for why I am going to the gym and why I am eating healthier. I think that in order to take care of my health better, I should probably do it for better reasons other than umm looking good and you know, having more energy. But a lot of it is to do umm with visual… how you look. (601)

Clay's path from curiosity to research with slight confusion as to personal motivations and questioning health topic inclusion drives him to examine a diversity of subjects. For some respondents, weight is a health issue. For Clay weight is a vanity issue and it drives him to spend time researching diets online.

The majority of people with Lifestyle health issues are researching how to keep themselves healthy and take care of their bodies rather than looking for medical

information about specific medical issues, diagnoses and treatments. Pursuing health issues, rather than medical issues, is an important distinction that warrants attention. Health issues include such things as staying current with diet and exercise trends and with preventative sexual health behaviors. When their concerns are not medical, or medically related, they could instead be considered preventative measures. People who are looking for medical information are going through a different process and are spending more time online.

The people interested in Lifestyle oriented information want to take charge of their health and connect their behaviors to their health outcomes. By applying research regarding diet and exercise to one's daily life, these interviewees view health as something that can be achieved through research and action. Their comments appear to reflect the ideology of "healthism", a term coined by Robert Crawford (1980). Healthism, according to Crawford, is "the preoccupation with personal health as a primary focus for the definition of well-being; a goal which is to be obtained primarily through the modification of lifestyles, with or without therapeutic help (p. 398).

5.4.5.3 Searching for mental health information

Those who chose the Mental Health category define stress and transitioning to a new life in a new country as mental health issues rather than specific diagnoses. Their issues include: (a) how to keep a healthy home; (b) how to have a happy family; (c) how to cope with nervous anxiety; and (d) how to get enough sleep.

When the Mental Health category classifies a person's health concerns, they spend 0.80 hours at home and zero hours at school or work searching for health information using the Internet.

Lisa is a 39-year-old married homemaker who, at the time of the interview, had lived in Canada for one year. (She had recently moved from Argentina). She is online on a daily basis, using the Internet-connected computer she has in her home. She has been online since 1998 and gets most of her health information from the Internet before going to the doctor. She is interested in diet, dental hygiene and mental health issues. The following two quotes articulate her definite ideas about what kinds of issues are mental stressors for her and her family:

> I think I'm fragile…Because the momentous stress for me and my family when we came here because we don't know the environment, we don't know the realities of the language.. so, it's stressful. My priority is to maintain healthy the roof. (280)

> …because Canadian health system is so different than the others, so we try to learn about Canadian system either by Internet of by the… I go to exhibition, I go to the health exhibition in Toronto to learn about Canadian health. Yes. My first step. I have to know about health, it's by the Internet. (280)

Lisa's interview illustrates how valuable the Internet can be for someone with the specific concerns of a recent newcomer to Canada. Lisa wants to learn about the Canadian health care system and Canadian health issues. She has institutional,

organizational and personal health issue curiosities. She looks to the Internet for answers to her breadth of questions, and to orient her to her new locale. The Internet affords a quality of exploration, that does not require orientation to a new country or living situation.

For this group, the Internet is used to research their pressing issues and to help find strategies to alleviate the stressors in their lives. Stress has recently come to be considered more of a health rather than a medical issue, something that people are encouraged to take care of on their own. People are trying to be healthy and pursue their own topics, rather than following up on a diagnosis or on a medical appointment.

5.4.5.4 Searching for acute medical issue information

The medical situations faced by the three people with acute issues are: (a) heart surgery, (b) sinusitis, and (c) dental issues. People who classify their health issues as acute are not using the Internet to search for health information. Instead, they rely on their family doctors for any information needs.

Darla is a 51-year-old student who recently had heart surgery. Her medical information comes from her physician and from books. She has an Internet-connected computer in her home and indicates she goes online about once per week. She uses her Internet connection for email and to read news of her native Trinidad and Tobago. She does not have a history of using the Internet for medical or health information, and consequently does not consider it to be a viable source to consider in the future. According to her:

> I wouldn't go on the Internet, like I haven't in the past so I don't know if I will in the future… (310)

Darla's interview gives insight as to how a person who does not use the Internet thinks about researching health issues. She has not performed this behavior previously and cannot imagine actually doing it; therefore she is unlikely to do it. She had an acute health issue and likely received health information, medication advice and follow-up treatment options from her physician and is satisfied with the information she received. She states previously in her interview that she prefers to speak only with her doctor.

When an acute issue presents itself, people are not interested in researching what is happening, or satisfying their curiosity. They are instead looking for immediate assistance for the crisis.

5.4.6 How network composition is related to searching for health information

While network parameters are excellent for describing network features, these same conventions are not always good at predicting what kinds of information will flow within a network, or who within the network will initiate the transmission of new information. For example, if an individual has a network of 23 ties, divided equally among very close and somewhat close ties, it is difficult to predict with any certainty which person in the network will offer the central person either information or emotional support for their health concern.

The Connected Lives Project gathered data about the interviewees' social networks. Once this information was represented in a large interactive network map,

created by the participant representing all of their very close and somewhat close ties, each interviewer asked the participant a series of questions. These included questions such as, "whom in your network do you go to for health information and for care with a serious health condition?"

Most of the respondents reported having at least one person in their network to whom they go for health information. Many of them have at least two people to go to for health information. The mean number of people each individual had to go to for health information is 2.6 with a standard deviation of 4.2 and a range of 0-31.

Ten percent (26) of those interviewed did not mention having anyone to go to in their social networks for health information or care for a serious health concern. When forty-two percent of those with no one in their network are considered as a unique group, two different responses emerge. They either go to their doctors, whom they put into their networks, or they refer to Google as their source of health information and support for health concerns. These responses highlight the value of relationships and ties for providing information. Twenty five percent of the entire sample mentioned either someone outside of the network or the Internet.

5.5 Summary

Maintaining one's health is a complex process comprised of information searching and emotion support gathering. People in East York conduct health information research online as part of their health management strategies because they believe the Internet helps makes tasks easier, which is related to how much time is spent

searching for health information. The majority of them also have both home computers and high-speed broadband Internet connections increasing the likelihood of performing online research.

East Yorkers spend about fifty minutes per week searching for health information, but this is not influenced by their age or gender. In fact, there is limited evidence linking personal factors with using the Internet to search for health information. Evidence of a digital divide is not present in the Connected Lives data. Predicting whether someone will look for health information has more to do with their other online habits. Those who spend more time overall online, spend more time searching for health information.

How you classify your health issue also influences how much time is spent searching for health information. People with Chronic issues spend more time online looking for information about their conditions and the treatment options. A thematic analysis indicated differences across the experience of searching for information depending on the health issue. People with lifestyle health issues are interested in achieving optimal health and learning about their bodies in relation to diet and exercise issues. People with mental health issues are looking for how to cope with anxiety, how to create happy home environments. People who identify as having acute health issues do not look online.

Individuals who are not online and do not use the Internet to access health information tend to refer directly to a medical professional, or printed resource to satisfy their information needs.

People who do not have anyone in his or her social network to offer them health

information or emotional support for health concerns describe a relationship with the Internet that can provide the social support they need. How this relationship with the Internet is empowering East Yorkers to participate more fully in their role as patient and in their role of champion of their health issues will be explored further in a forthcoming chapter.

Chapter 6

Findings II: Garnering Emotional Support for Health Issues Online

6.0 Introduction

Most of *my* health queries are minor and only require a supportive telephone call to my Grandmother, Violet. Our communication often involves a description of health ailments and reassurance that a family member suffered a similar affliction and survived. Her kind words are the social support that buffer me from getting ill and help me to heal more quickly. If Violet used email, this content could also be conveyed in an electronic message, not just over the phone.

When I do not get enough information from Violet, my broadband connection enabled laptop computer ensures constant Internet access and instantaneous satisfaction of my health issue queries. As such, the medical book remains unused on the bookshelf, no longer my research companion when I am ill or curious.

Despite my online researcher tendencies, having a strong relationship with Violet and my supportive network of friends means I tend not to look online for emotional connections. However, when I was misdiagnosed with Morton's Neuroma I read numerous testimonials and personal accounts of surgery and recovery. I could have

easily joined an online community for information and emotional support had my diagnosis turned out to be accurate.

My likelihood of accessing support online for health concerns has more to do with my being web savvy, my ease with using Internet based communication tools and having particular health issues. Additionally, I am drawn to out of network support when I do not want to burden my friends and family.

This chapter considers the three factors of technical aptitude, health issue and network composition and assesses how predictive they are for whether or not the people of East York are using the Internet to communicate about health issues with others online.

6.1 Previous Research

It is well established that accessing emotional support for health issues online is not only possible; it is beneficial for those who seek it. As reviewed in Chapter Three, the benefits can vary from experiencing the full range of social support to building social capital (Davison, Pennebaker, & Dickerson, 2000; Drentea & Moren-Cross, 2005; Dunham, Hurshman, & Litwin, 1998; Fogel, Albert, Schnabel, Ditkoff, & Neugut, 2002; Houston & Allison, 2002; Loader, et al., 2002; Winzelberg, 1997).

People with targeted health issues (cancer, HIV, Diabetes) who engage in online social support glean information and emotional connections, which encourage more beneficial health outcomes. By offering a means of connecting with people who share medical concerns in an anonymous, non-stigmatized environment, online social support offers emotional connection and the benefits of social support without burdening a social

network, primary care providers or friends (Eastin & LaRose, 2004; Klein, 2004; McKenna & Bargh, 1998).

Twenty-four adolescents with chronic kidney disease chosen from a health service database were invited to participate in a six-month online peer support group intervention. Transcripts of the online network dialogue were analysed as was the content of post-intervention interviews. Overall the teens reported gaining knowledge of their disease, having their health experiences normalized and being empowered to be more fully engaged in their care management processes. Ultimately, these teens reported benefiting from online support (Nicholas, et al., 2009).

Social workers also benefit from online emotional support. Meier (2002) analyzed the message content of facilitated online listserv designed to specifically support social workers vulnerable to burn out. Initially the social workers resisted the support format because of their perceived lack of Internet skills, and their fears of exposing vulnerability to peers. After the ten-week program, the 43 people who participated in the group reported feeling supported and found the experience to be beneficial.

Peer support is a positive precursor to successful weight loss efforts. Online support in the form of informal web-based communities like Sparkpeople.com is becoming more popular and available. Hwang et al (2010) surveyed 193 people and performed follow-up interviews on 13 of them who used the public weight loss support community. The support exchanged in this community is primarily in the form of encouragement and motivation, information and shared experiences. While the support

resembles that available in face-to-face contexts, online environments offer convenience, anonymity and non-judgmental interactions.

Research investigating the content and outcome of online social support seeking typically reports positive results. What tends to be missing from this research is an analysis of the precursors that lead individuals to pursue online support. While users may indicate they appreciate the maintenance of their anonymity while not burdening their peers and support networks, we do no know if that is the significant cause for people looking online for support. This chapter intends to consider the relationships between personal factors with seeking social support for health issues online.

6.2 Research Questions

To build a clear account of health management in the age of the Internet, Chapter Five described the amount of time people spend using the Internet to search for health information and this chapter considers the predictive and associated factors of going online for emotional support for health concerns.

This chapter adheres to my overarching research questions about health management strategies, by answering several specific investigations that relate both to the amount of time people spend communicating online in general and the prevalence of communicating about health issues online.

The research questions this chapter addresses are: 1) How much time do people spend communicating online? 2) What is the predictive relationship between age and gender and health communication? 3) How is Internet user style related to health

communication? 4) Does how one categorizes his/her health issues relate to communicating online about health issues? 5) What is the relationship between ego network composition and communicating about health issues?

6.3 Methods and Measures

To answer the five previous research questions, I rely on qualitative and quantitative data derived from the Connected Lives Project.

The Connected Lives Survey respondents estimated the number of hours spent online communicating about health. The respondents also indicated if they ever used the Internet to communicate about their physical or mental health issues with either a) a doctor or health care professionals, b) friends or family members, or c) other people with similar health care issues. Chi-square tests were performed to measure differences in proportions across groups.

Section 10 of the Connect Lives Interview Guide addressed whether people used the Internet to communicate about health issues the questions are as follows:

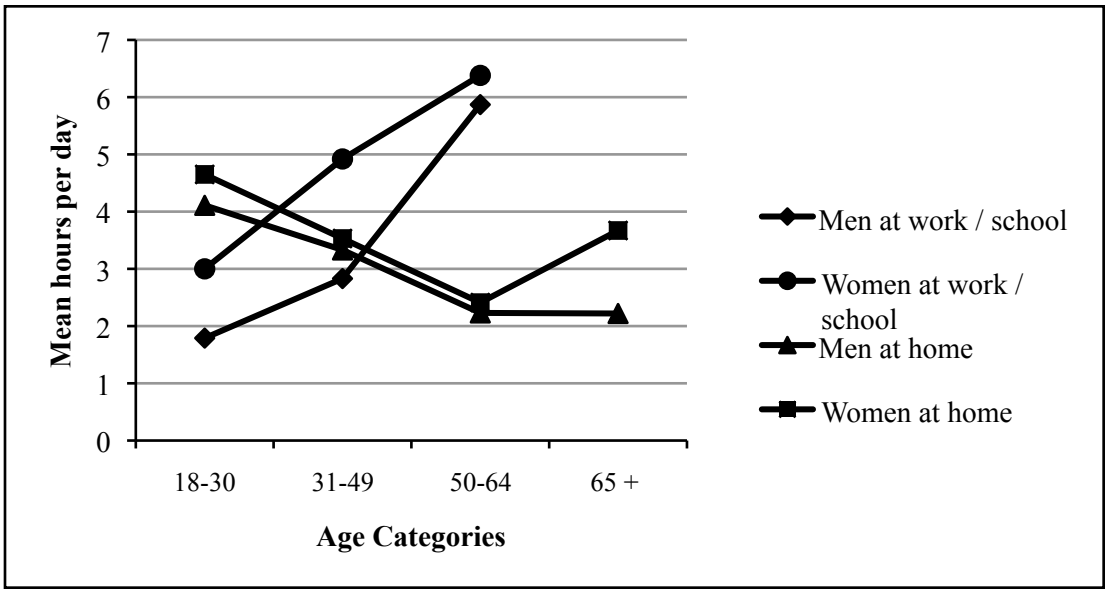
> Have you ever wanted to talk to someone who has a similar health matter?
> Did you connect with them online?
> If yes,
> - How would you describe your relationship or connection to that person?
> - Where did you first meet them?
> - Please tell me about the experience of finding them online
> - What kinds of support did you receive?
> - How successful was your experience (probe for advantages and disadvantages of each source of support mentioned)

The qualitative data gathered in response to these questions was analyzed for patterns that

might suggest commonalities across those people who do use the Internet to access emotional support from strangers. The three individual cases are presented in a subsequent section of this chapter.

6.4 Findings

Figure 6.1 Hours spent online per day at home or school/work



6.4.1 General Online Communication

The Connected Lives survey respondents use the Internet at home for a mean of 9.9 hours per week and 11.4 hours per week at either school or work. Most of their time is spent communicating, with an average of 3.3 hours (33%) at home and 4.1 hours (36%) at work or school.

Men and women between 50 and 64 communicate the most overall and are doing it at work or school. Regardless of location, women communicate the most overall.

Interesting to note the increase in communication at home for women after they turn 65. This might have something to do with wanting to keep in touch with grandchildren, or having tech savvy offspring interested in keeping them technologically current.

6.4.1.2 Communicating about health issues online

More than one third (35.5%) of the survey respondents communicate with friends or family about health issues online. Thirteen percent (13.1%) use the Internet to communicate with people with people with similar health care issues. Slightly more than ten percent of the respondents (11.1%) use the Internet to communicate about health issues with a health care professional.

The proportion of men who communicate online with health care professionals is 30.3% whereas the proportion of women was 69.7%. The differences across gender are not significant, $\chi^2 = 2.35$, $df = 1$, $N = 264$, $p = 0.09$.

The proportion of men who communicate online with friends or family members is 40.2% whereas the proportion of women was 59.8%. The differences across gender are not significant, $\chi^2 = 0.45$, $df = 1$, $N = 297$, $p = 0.29$.

The proportion of men who communicate online with people with similar health care issues is 35.9% whereas the proportion of women was 64.1%. The differences across gender are not significant, $\chi^2 = 0.86$, $df = 1$, $N = 258$, $p = 0.23$.

When age is combined with gender as a predictive variable in relation to online health communication, a stronger relationship appears. Of the men who are using the Internet to communicate about health issues online with friends or family, 53.5% of them

are between the ages of 31-49. This larger proportion across the other age categories is significant, χ^2= 7.21, *df* = 3, *N* = 126, *p* = 0.07. This may reflect the age when medical concerns first appear in concert with being tech savvy. Or this could be evidence of an age group that care simultaneously for the younger generation of their children and the older generation of their parents.

There is no significant difference across men of different ages who communicate with health care professionals, χ^2= 2.94, *df* = 3, *N* = 126, *p* = 0.40. There is no significant difference across men of different ages who communicate with people with similar health issues, χ^2= 1.39, *df* = 3, *N* = 126, *p* = 0.71. There are no significant differences across women of different ages who communicate with either medical professionals (χ^2= 3.20, *df* = 3, *N* = 168, *p* = 0.36); friends or family members (χ^2= 2.25, *df* = 3, *N* = 168, *p* = 0.52); or people with similar health issues (χ^2= 0.69, *df* = 3, *N* = 168, *p* = 0.88).

6.4.2 How Internet user-style relates to communicating about health issues online?

Moderate and heavy Internet users are more likely to communicate about their health issues online.[8] Of the people who are using the Internet to who communicate with *friends and family* about their health issues 79% are at least moderate Internet users. Eighty-four percent (84.3%) of those who communicate with *people with similar health care issues* online are at least moderate Internet users. Not surprisingly, 82.1% of those who communicate online with *doctors and health care professionals* are at least moderate

[8] Recall that in section 5.4.2 describes the categorical distinctions that comprise Internet user-style. Moderate Internet users are online between 3-7 hours per week. Heavy Internet users are online more than 8 hours per week.

Internet users.

6.4.3 How Health Category relates to communicating about health issues online?

During the Interviews, some participants would describe various health information searches that could be categorized into different health issue categories. A few participants shared narratives that fit into a mix of categories. During the observation section of the Interview, participants were asked to choose the one category that best described their most recent experience of searching for health information. These results are based on that one category.

Thirty-nine percent (39.1%) of the Connected Lives interview respondents communicate with friends or family about health issues online. Seventeen percent (17.4%) use the Internet to communicate with people with similar health care issues. Eleven percent (11.6%) uses the Internet to communicate about health issues with a health care professional.

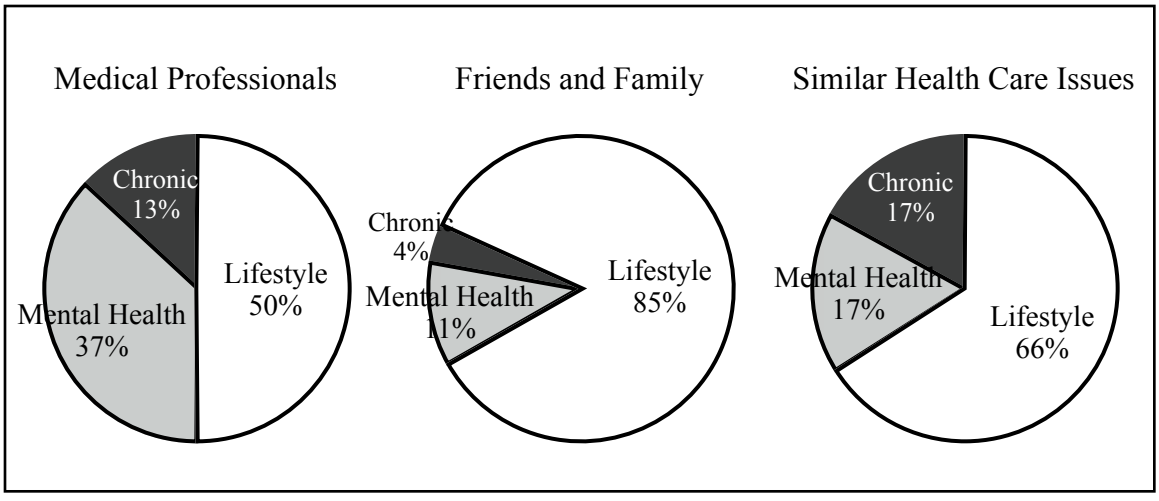
Of those interviewed who are using the Internet to communicate about health issues online, seventy-five percent (74.5%) of them also chose the Lifestyle health category to classify their health issues. Seventeen percent of the interviewees who communicate about health issues online classify their health issues as Mental Health issue related. People who classify their health issues as Acute do not communicate online about health issues. While the respondents were offered a Public Health category to define their recent health issues, no one chose this category and consequently no one who uses the Internet to communicate about health issues presents with a Public Health issue

of interest.

Those who classify their health issues as Lifestyle account for eighty-five percent (85.2%) of those who communicate online with friends or family, sixty-seven percent (66.7%) of those who communicate with people with similar health care issues and fifty percent (50%) of those who communicate with a medical professional online.
People who regard their health issues as Mental Health related account for eleven percent (11.1%) of those who communicate online with friends or family, seventeen percent (16.7%) of those who communicate with people with similar health care issues and thirty-eight percent (37.5%) of those who communicate with a medical professional online.

Interviewees with Chronic health issues account for four percent (3.7%) of those who communicate online with friends or family, seventeen percent (16.7%) of those who communicate with people with similar health care issues and thirteen percent (12.5%) of those who communicate with a medical professional online.

Figure 6.2 Online health issue communication by health status across audience



As seen in Figure 6.2 those individuals who are communicating online about

health issues with friends and family, the majority indicate having Lifestyle health issues. This might reflect that most people with Lifestyle health issues are interested in losing weight and exercise and are communicating with family or friends for support or companionship. People who communicate with someone with a Similar Health care issue online are as likely to have either Chronic health issue interests or Mental health issues. Perhaps these individuals are looking for support outside of their networks, as they do now want to burden their somewhat or very close ties. People who classify their health interests as Mental Health issue oriented represent 37% of those who communicate online with Medical Professionals. People with Chronic Health issue interests account for 13% of this group. Perhaps the increase in representation of these two health categories in this communication grouping has to do with wanting to avoid stigma. Mental health issues and some chronic conditions are laden with social stigma. Using the Internet for supportive communication may ease that burden for these people (Berg, 2008).

6.4.4 How network size predicts communicating online about health issues

Social networks provide the context to describe the people in our lives and for thinking about the source of social support. Models of social support acquisition suggest that emotional support from the people in our networks benefits recipients by offering protection from harm and negative health outcomes. However, it is not the number of ties that matters, because not all of our friends are good for us (Barry Wellman & Gulia, 1999). Not everyone in our networks is someone available to discuss health issues with.

Boase et al (2006) divides networks into thirds and differentiates core and significant ties into two types of networks. Here the number of ties were combined and networks were were categorized as either being small (containing 0-10 ties), medium (containing 11-48 ties), and large (49 + ties).

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Network work size does not have a strong influence on whether someone goes online to communicate about health issues, except for women communicating online with people with similar health concerns. Within this grouping of the women, 19.0% have a small network, 38.1% have a medium network and 42.9% have a large network. The proportion of difference is significant, $\chi^2 = 6.56$, $df = 2$, $N = 145$, $p = 0.04$. Perhaps they appreciate the anonymity of online support rather than the scrutiny of gathering support

only from those they consider to be network ties.

6.4.5 Three examples of online health issues communicators

This section describes three interviewees who have ongoing use the Internet to communicate with and make connections to people who share their unique health concerns. Each interviewee is looking for people that might be able to offer insight and information about their common health issues. The interviewees are not concerned that with whom they might be communicating with are strangers and are unknown to them.

Each of the three respondents is similar to the others in that they all mention being affected by a significant health issue, they all identify as being web savvy and they all have fewer social ties than the rest of the interviewees.

The following descriptions and corresponding quotations illustrate how the experience of going online for support is both possible and beneficial.

Isaac is a 34-year-old man from Pakistan who moved to Canada a few months before he agreed to participate in the Connected Lives Interview. He started using the Internet in 1994 and goes online at least weekly. Other than having diabetes, he thinks of himself as healthy and keeps active by running five times a week. He uses the Internet to search for information about treatments for diabetes and he shares this information with his brother, who lives in Pakistan. He also communicates via email with other people that he only knows online. While he describes them as strangers, he finds the information and support they share to be helpful. This respondent has twenty people in his network, one of whom (his brother) he goes to for support for his health concerns.

P: Yeah, because I'm a diabetic. So I have visited seven or eight times Google. Then I write down the diabetic treatment. So there are so many websites I have gone to with that. Yes, I have got health information from the Internet.

I: And have you ever shared that health information with anyone else?

P: Yes, because my elder brother, he has got the same problem. So I make a link and I send that information to my brother.

I: Great, that's very interesting. We'll probably talk a little bit more about health later on. Ok, alright, we've kind of already talked about this.

I: Can you tell me a little bit more about that? Like, about how that started, and maybe how you found them?

P: Actually, a friend, he guided me that this is the guy who knows how to control diabetes. So I mailed him once, he's in Pakistan.

I: You emailed him?

P: And I called him.

I: You called him.

P: Yeah. I emailed him, and then he asked me about my program for using MSN. So I was here, and he was in Pakistan, and we shared so many things together. Because he's also a diabetic. But he's about sixty, and you can't say that he's sixty. He looks like he's forty-five, or forty-six. So, that's what he has controlled his diabetes. So yeah -???-

I: And are there other people that you maybe get information or support from, that you've never met, but you know on the internet?

P: Yeah, more guys. I didn't know about them, but I just emailed them, and then-

I: How did you find out about them to begin with?

P: One of my friends, Nawaz. He's very social here. So he just told me that this guy -???-

I: And maybe you should talk to him. Ok. Interesting. That's what I'm very curious about, when people are getting- and how do you find the support? Is it helpful?

P: No doubt about it. Because one of the friends, (says name), I never met him. Nawaz gave me his address. So he told me several things. And then once I- because I was taking my food, you know? Once, I was taking food- I finish my food, and then when I feel, you know, it's ok now- but he told me, don't do it like this. You know, you take your lunch in two or three hours.

I: Oh, interesting. Ok.

P: You eat something, and then you leave it. After fifteen minutes, you go and take something. So there are so many very good advice that he gives me.

I: Right. If you were to describe your relationship with these people, how would you describe these, maybe, ten people that you write back and forth about diabetes with? Like, are you friends with them? How do you think about them?

P: No, -???-

I: Someone that gives you advice, or that maybe you say, "I'm worried about this, or I'm curious about this." Do you think of these people as your friends? These people that you write to? Or are they just strangers?

P: They're just strangers, yeah.

I: And do you feel like the information that they give you, is it supportive?

P: Yes, of course.

I: So you sort of feel like they're there for you, but they're strangers.

P: Yeah, this is what I told you. I didn't know (name), but he gave me very good advice -???- So, of course it is supportive.

I: Yes, but they're strangers.

P: They're strangers, yes.

I: That's the thing that I'm interested in-

P: Even my- you know, I was taking my admission in -???-. So one of my friends, he told me that he's the guy, and he'll tell you that, you can just email him. I just, you know, emailed him, and then he guided me, you know. So many things there. Because I was very new there, I had only two or three months there. And then he guided me, and I got all the documents, and initially when I applied, my application was approved. Otherwise, and there are so many people, two or three guys, they face problems. They didn't have the documents, you know?

I: So they were very helpful, and-

P: Yes of course, no doubt. It gives you everything. It gives you contacts, communication. I use it whenever I feel I need it. I use it.

Isaac begins by looking online for treatments for his diabetes. He uses electronic mail to connect with others to discuss successes they may have had. Communicating with strangers online is facilitated by the anonymity and distance of on online encounter. It is also easy to be linked to new people once one online connection is made. Isaac describes the support he receives from the strangers and because of the trust, he is able to follow the advice he receives online and integrates their suggestions into his health management strategy. As a newcomer to Canada, Isaac is neither familiar with nor using the local medical system. He has a critical need for access to Canada's institutional medical system. Isaac is able to receive vital information and support from a community of

people, who because of their online status are always available whenever he needs them.

Wanda is a 55-year-old single woman from the United States who moved to Canada nine years ago. She has Hepatitis C and came to Canada for the medical services that would be available to her here. She describes her mental health as being a 10, but her physical health is much worse. She has been using the Internet since 1994 and goes online about daily to read about current treatments and research about Hepatitis C. Her research focus is non-FDA approved medication accessible in Canada. She does not have anyone in her network (n=5) that she communicates about health with, except her doctor. Her doctor is the person for health information and for health care and no one else. She does glean emotional support online from her communications with medical professionals, but does not seek social support from other people who have contracted Hepatitis C.

The following quotation tells the story of a woman who uses a combination of the Internet and medical doctors, both those that she knows and those she has found online. This interviewee actively maintains her health and uses all of the resources available to her for support. Her management of a chronic health care issue is exceptional in that she not only conducts a large amount of research online, she also contributes her knowledge to an international database. She wants to know as much as she can about her condition, she has professional mechanisms for trusting the available information and has become familiar with a variety of information sources over the course of her treatment program.

I: have you ever accessed the Internet for personal health information?

P: Yes, for Hepatitis C.

I: How did you start looking for that information?

> P: I originally because the reason I'm up here was because you have Dr. Fineman (?) and he's well known in Nephrology (?) and Hepatitis. Through conversations that we've had of different new drugs and we'd look up that new research pilot program I would go to any FDA site where they're doing research and start in clinical trials and then from there you get your key words again.
>
> I: So you'd stay mostly within – like health specific related sites and you kind of have the different journals and the FDA where you would go?
>
> P: Yes.
>
> I: Ok, and did you share this information with anyone?
>
> P: Definitely.
>
> I: Who are the kinds of people that you share this information with?
>
> P: My colleagues who are doing research on this particular subject and if I happen to see something that might be related for some reason and I would call someone that I know that might be in that field. (608)

For Wanda, accessing information and doing research online comes easily as she is a tech savvy Internet user who is motivated to connect with others because of her small social network. Her circumstance of having a chronic health issue to manage, but needing information leads her to the Internet for both information and support. This mediated interaction and online research is part of her health management plan. Having a Hepatitis C diagnosis gave her something to research and the Internet gives her constant access to the people and the resources she wants.

Chico is a 42-year-old man from Jamaica who has lived in Toronto less than one year. He and his wife live with their cat and dog in an apartment in East York. This interviewee is web savvy and goes online daily from home and from work. He works in

the field of tech support.

> I: Oh, that's too bad. Now you did mention that you have used the Internet to access health information. Can you tell me a little bit more about that? What kinds of-
>
> P: Yeah, for the latest one, with winter skin conditions. I'm like, "What's happening?"
>
> I: (laughs) Exactly. You wake up in the morning and you think, "What is this?"
>
> P: Yeah one time I'm pretty sure I got something that that may have been very close to frostbite. The coldest day that we had, when it went to -23 or something like that. I actually ended up being outside; had a jacket but no gloves on. And I couldn't stick my hand in the jacket, because it was cold as ice and I was trying to find the scarf. -???- And it was slippery inside here, and you don't have -???- for balance. They told me the scarf was this -???- colour; I could not find it. And I was walking right through -???- looking for the thing, my hands exposed. And it was -???-, and my hands were -???. And you know-
>
> I: What is this?
>
> P: How to stop?
>
> I: So, what did you do? How did you get information or find out what was wrong?
>
> P: Using -???- eventually. I phoned like around six, went to some forums and stuff, and looked and saw what people, you know, -???- with my condition.
>
> I: So you wanted to find other people that had it. So you were looking for other people?
>
> I: So how did you find them? How did you find the forums?

> P: I was just clicking on the condition, a search, and then I was narrowing the search, until I found a forum. Really sometimes, forums with people -???-, because you find that a professional or a doctor, his terminology aren't the type of terms I might use. Misdiagnosed, or something. So -???-
>
> I: Oh, interesting. And did you post any questions yourself, or did you just read other people's?
>
> P: No, I could barely type! (laughs)
>
> I: Oh right, of course. With your elbows! Right. That's interesting. So, did you find that helpful? Did you figure out what was wrong?
>
> P: Yeah well, it got better within a day or so. It was pretty much- I had one interesting one which was, the first impulse was to stick it in hot water. -???- was still frozen. (laughs) So I managed to resist the temptation to put boiling water on it. (561)

Chico has an immediate health concern, is web savvy and has few friends he can go to for support as he recently moved to Canada. As such, he goes online when there is no one else to ask for help. When he was looking specifically for how to cope with frostbite, he ended up reading information posted on forum, content created by other sufferers of this winter ailment. He incorporated their suggestions into his personal management of his condition. His use of the forums reflected his lack of understanding of the medical language used on professional websites and his preference for lay language and personal accounts of health issues. In this case, the Internet gave him the kind of information and emotional components of social support and lead to a positive health outcome, rather than the potential harm that may have resulted from him doing what he wanted to do. Chico is an exemplar of the conditions that drive a person to look online for informational and

emotional support and the benefits of such an encounter.

6.5 Summary

Participants in the Connected Lives Survey spend one third of their time online communicating with others. In this chapter I looked specifically at the people who are using the Internet to communicate about their health issues with friends and family, medical professionals and people with similar health care issues. Less than thirty percent of the population use mediated communication tools to discuss their health issues with others.

Being web savvy and not having a serious health condition may influence using the Internet as a means of health issue communication. The characteristics of one's social network are not strongly related to using the Internet to discuss your health issues.

Those who report being online for more hours per week at either school or work or at home also tend to spend more time online communicating in general and are most likely to be the ones who use the Internet to communicate about their health issues. Survey respondents who report discussing health issues online tend not to describe serious health issues. Lifestyle health issues are popular information pursuits for the majority of the people living in East York and are the typical health category for those who are using the Internet to access emotional support for their health issues.

While I critiqued previous research for not analyzing the relationship between network characteristics with a propensity for seeking support online, within my own research, I found network size does not appear to predict whether someone will

communicate with others online about their health issues.

Despite the descriptive relationships between my outcome variable of communicating with others about health issues online, the analysis of the Connected Lives survey data did not show a statistically significant relationship between Internet competence, health status and network composition. Likely these results reflect the small sample of users who were engaging with a new (in 2005) behaviour.

Fortunately the qualitative analysis of the interviews offered insight as to what is related to using the Internet to glean emotional support. I found an interaction or a set or relationships between the variables of use of technology, subjective health status and participants' network characteristics. When I looked explicitly at three case studies, I found people who went online for emotional support and were able to obtain it from the encounters with the Internet. Being a heavy Internet user, having a serious health concern and a smaller than average network size creates the optimal condition for using the Internet to access emotional support for their health concerns. While the analysis of the narratives revealed relevant patterns for thinking about who is going online for emotional support, the findings are not explicitly generalizable. However, their stories show places for further inquiry and the values of both qualitative and sequential methodology.

Chapter 7

Findings III: Using the Internet for personal health management: implications and transformations

7.0 Introduction

My 95-year-old Grandmother exemplifies how using the Internet is influencing relationships with medical professionals and others. Over the last five years, whenever Violet receives a new prescription from her doctor, she calls me to "have a look in my computer" and research her medication. At ninety-five, her conceptualization of what the Internet is might not be accurate; but having seen me use my laptop, she is aware of its potential. While Violet's doctor informs her of the side effects and interactions of her medications, she does not retain everything he says. She wants to stay current and informed about what she is ingesting and she likes to keep me apprised of her health issues. My research skills and ability to search online for information empower me to participate in her health management. She in turn values the extra information I can offer her and appreciates that our conversations are not rushed. By the end of our discussions she understands what her new medication is doing for her and will carry this understanding into her next medical appointment. For the two of us, the Internet is as embedded in her health management process as a call to me.

Evidence of further transformations brought about through Internet use in the health management process is the timing of Internet use within my health management sequence. Violet calls me (for my Internet connection) after seeing the doctor, and I go to the Internet before I do anything else. As such, the Internet is transforming my relationship with both Violet and myself. I know more about my health, my body and disease prevention than I ever learned with the medical book.

This chapter considers the health management scenarios of the Connected Lives Interview sample in terms of how these individuals are including the Internet within their everyday health maintenance strategies and how that Internet use is transforming their relationships both with medical professionals, themselves and the Internet.

7.1 Previous Research

Chapter Five articulated the place of information searching with an individual's processes of health management. This chapter expands on these findings and considers the effects of embedding the Internet for information research and retrieval within health management strategies. Such effects are evident in changes to the doctor / patient relationship, the process of health management and definitions of health.

Traditionally, within the doctor patient relationship, one person held the technical information the body and disease, while the other had information regarding the experience (Lupton, 1995b). Together the doctor and patient created a model of health and treatment. Today medical information is readily available and people with the ailments can access information about disease and medicine and about their own bodies

as healthy objects they are required to take care of (Ahmad, et al., 2006; Kalichman, et al., 2000).

Research examining the doctor patient relationship uses satisfaction surveys to consider commonalities and outcomes across various relationship styles. The research questions tend to be about efficiency and time in relation to medical appointments and the doctors' use of time. Critiques of the literature often involve an either / or stance. Either the information is benefiting the relationship, or it is harming it. Physicians are often assumed to take the stance that the information is harming the encounter, while patients experience a sense of empowered and an improved relationship (Broom, 2005a).

I am looking for evidence of shifting health management practices that are influenced by the availability of information and emotional support online. By looking at the processes people are engaged with as their manage their own health issues I will see if patients are becoming their own diagnosticians, or if that realm remains in the hands of medical professionals. Additionally, I want to identify how using the Internet is transforming not only the physician-patient relationship, but also our relationships with our own health and our relationship with the Internet itself.

7.2 Research Questions

Up to this point within this dissertation I have described how much time people spend searching for health information and how much time people spend communicating about their health issues while using the Internet. Analysis of the survey data identifies that people who are online at least 3 hours per week are more likely to both search for

health information and communicate about their health issues. Interview extracts illustrate both the kinds of information people are looking for online and the possibilities of garnering emotional support for their health issues. Now I can identify who is more likely to use the Internet as a part of their health management process.

I remain curious as to what the implications of using the Internet are. More specifically, my overarching research question for this chapter is: *how is using the Internet to gather health information transforming the relationships embedded within a health management process*? To extract an answer, I use an integrative approach to understand the dimensions of impact, rather than a cause effect model of most other research. I approach the question in three parts.

First, I look at where Internet use fits in relation to identifying a health issue and / or seeking medical attention. This gives insight as to how Internet retrieved health information is transforming the doctor patient relationship. Secondly, I describe qualitative data depicting how using the Internet is transforming our sense of well-being. Not only are people using the Internet because they want to be healthier and the experience of gathering information is facilitating this, people express feeling healthier, empowered and informed as a result of going online. Third, I analyze the language used when people refer to using the Internet as a source of health information. This review of associated discourse offers insight as to the interaction between human user and the non-human machine. Within this intersection of information provider and information seeker, I illustrate the emergence of a new style of social relation built on confidence in the encounter and certainty about the outcome.

7.3 Methods and Measures

This chapter examines the consequences of using the Internet in the context of managing personal health issues. Qualitative data for this chapter was gathered during the Connected Lives Interviews. The qualitative analysis took the form of transcription review, line-by-line coding, thematic analysis, creation of categorical divisions and quotation review (Lincoln & Guba, 1985). For details of the coding process, please see Appendix D.

To identify where the Internet use fits within the process of health management I tracked when people mentioned using the Internet in relation to discovering a health issue and interacting with a medical professional. I categorized the participants according to when they used the Internet in their health management sequence. Here I was looking for confirmation of people using the Internet to self-diagnose and what I noticed instead is that people tend to look for information in relation to a medical appointment or because of Lifestyle oriented health issues.

Second, I look at how using the Internet to access health information, regardless of where in the process, is affecting the Connected Lives interviewees. Being able to conduct online searches facilitates the research process and people are engaged in learning about health issues and are striving to be healthy.

In the third section, I coded for how people refer to the Internet. Many respondents are using language of familiarity and trustworthiness when talking about their online experiences. People are going online without a second thought, as the Internet is

becoming integral and habitual to a personalized health management strategy.

This chapter describes the fit of the Internet in health management strategies. To that end, I focused my analysis on those who are using the Internet to search for health information. The majority of my sample integrates Internet use within their health management strategies and express positive experiences with the process. Certainly Internet use can have adverse consequences, especially when health issues are involved; however, I did not encounter narratives depicting overt harm or difficulties.

These findings may be perceived as optimistic, as they describe an assurance in the beneficial effects of Internet use. To reduce the impression of researcher bias, I include the descriptions of negative experiences of using the Internet that provide insight as to why people would avoid the Internet when managing a health issue.

7.4 Results

7.4.1 Accessing health information online in relation to medical appointments

Chapter Five indicated that the process of searching for and accessing medical and health information is possible and popular for people with Internet connections. When this kind of information was not as easy to access, people relied solely on their doctors to learn about their bodies or their medical conditions. Information flowed from doctor to patient and the relationship was unidirectional (Lupton, 1995b, Lupton, 1997).

Now that information retrieval is simplified and accessible, anyone with Internet access can research topics based on their own curiosity, wanting to be informed and

desiring to know more. People can learn about how their bodies work, how to describe what is wrong with them and what kinds of options exist when choosing treatment interventions. The next step for many of those people is to bring that information into their medical appointments, or to use the medical appointment as a prompt for more detailed online research.

Arguably, using information gleaned from online sources within and outside of a medical appointment is transforming the doctor/patient relationship. People are taking it upon themselves to look things up before they go to the doctor as they become more involved in their health management. As such, this section addresses the research question: where does the Internet fit within the doctor / patient relationship?

In the Connected Lives Project the participants are not bound within unidirectional doctor / patient relationships as some participants refer to an evolution from researching their symptoms to discussing that research with their doctors during their medical appointments, while others would rather wait until after an appointment and use the Internet in direct relation to the medical or diagnosis they may have received. Fifty-three people specifically refer to integrating Internet use into the health management strategies. Of those people, nine directly refer to using the Internet before a medical appointment. Eight people make reference to using the Internet following a medical appointment. Of the remaining thirty-six people who are using the Internet in the health management strategies, three people refer to using the Internet rather than making a medical appointment.

7.4.1.1 Researching health issues online before a medical appointment

Nine people specifically refer to performing their own online health information research in advance of their medical appointments. Their motivation is to either to be a) actively involved in their own treatment planning and discussions with their physicians by being prepared and doing their own research to start the conversation, preparing questions and verifying and corroborating within their own treatment planning and discussions with their physicians or b) by gathering information to form an opinion on their own, not necessarily with the intention of sharing or discussing the information with their health care practitioners.

Forbes is a retired 68-year-old married man. He uses the Internet daily from home and has been online since 1994. He is concerned about his weight, blood pressure and stress management and categorizes his health issues within the Lifestyle classification. The following quotation exemplifies the theme of wanting to be informed about health issues and shows how someone uses the information they gathered online to assist with their dialogue in a medical encounter.

> I don't do anything or take any action without consulting my doctor. So I basically just use it as a resource. To start the conversation with the doctor... (815)

Forbes would not act on information alone, but he would take his online research to a doctor as a means of initiating and improving the doctor patient communication.

Beth is a 54-year-old married woman who has been online at home since 1997. She uses the Internet daily from home and is online all day at work. She describes herself

as being in perfect health and gave herself a health score of ten. She also classifies her health interests as Lifestyle oriented.

As with Forbes, Beth's quotation gives evidence of how having a background understanding of a health issue can facilitate communication with a physician. Beth is mindful of her relationship with her doctor and is doing her part to make it better.

> I: Did you take that knowledge that you had gained from the Internet with you into the office – did you mention and talk about it to the doctor?
>
> P: Yeah I did. I found it kind of gave me like a background understanding, so that we could communicate a little bit more easily about it (439)

Beth is keen to improve her communication with her doctor by having more common understanding of her situation. She is also interested in increasing her specific understanding of her personal health issues.

Clay is 27-year-old student in long-term relationship. He has been online since 1994 and uses the Internet daily from home and daily from school. He includes diet and exercise as his Lifestyle oriented health issues. Most of his queries are answered online; however, this quotation illustrates how he will use his online research to not only educate himself, but also to initiate a conversation with a medical professional.

> Ok. So, I'd just… I typed into Google uhh Chlamydia. So the very first thing that comes up is July 2004 - What Is Chlamydia? Well perfect, it's a fact sheet. Very first entry is a definition. What are the symptoms? Boom. How is it diagnosed? How is Chlamydia treated? I mean can it be prevented… complications. I mean, this page here to

> me, gives me everything I could possibly ever think of to know about what Chlamydia is, and should I be worried about it and blah blah blah. Well I took some of this information and then obviously through my tests at a real clinic, umm I said "Look, I found this on the Internet. Is this true and what else should I be thinking about?" That kind of thing. (601)

Clay likes being knowledgeable of his health issues in advance of a medical appointment. However, he still relies on his physician for action and intervention once he has gathered information about his issues on his own.

Grace is a 43-year-old single Senior Planner. She has been using the Internet since 1990 and uses it daily at work and is online at home weekly. Her health issues concern diet, fitness and nutrition and she gave herself an eight for her health score.
In the following quotation, she describes doing her research in advance of a doctor's visit, but would likely only discuss what she found at a convenient time, rather than making an intentional appointment.

> Usually I read what they have to say, and form an opinion of what I need to do. Or need to talk about to my doctor, or need to talk about to friends. You know, it's a source of information, but I usually check out the sites by trust.
>
> Yeah, some of them I would not put as much or sometimes I crosscheck the site to see if they say the same information. Or sometimes I go to another site, because one site doesn't have enough details and another one might be more detailed…
>
> Well, I just found out I have iron deficiency right now, so I just wanted to know how that works. What's influencing that, what's the

> treatments, how long does it takes, what's recommended. So it's something I could discuss with my doctor when I saw her… (191)

Her health topic research reflects the interplay between the Internet, a physician and herself as a researcher. For Grace, her doctor provides a level of accuracy that she does not perceive from the Internet. For her own benefit, she plays each information source off the other to feel the most engaged in her health management.

Zowie is a 32-year-old married recent immigrant to Canada who has lived in Toronto for one year. She began accessing the Internet in 1993 and now uses it only from home going online daily. Her health issues are lifestyle oriented and she is concerned about weight loss and gave herself a health score of nine. In the following excerpt, she describes using the Internet to gather information and then waits to see if her doctor corroborates what she found out.

> I: Is there anywhere other then the Internet that you would go for health information?
>
> P: Well, I have the Ontario Nurses hotline number. I've used that a couple times. But no, because with this kind of information you want to get immediately. I don't have time to go to the library and look around and stuff because if I'm concerned about something I want to know right away. Because a concern would like, because that thing is happening right here and then.
>
> I: What makes you like a site, or stay at the site? You said you read the blurb that Google gives you and you go. What kinds of things would attract you to go to a site?
>
> P: The less number of ads it has the better. The way they set out their copy and stuff because graphic design makes all the difference to me.

> I: The visual.
>
> P: Yeah, the visual and then how fast they get that information across. Do I have to read a lot of stuff before I get to what I'm looking for? Or are they to the point, in your face data.
>
> I: That is what you want.
>
> P: Exactly. Even how easy to access on the page.
>
> I: Once you find that information, do you go and find a second opinion?
>
> P: I will go find a second opinion; I probably keep the information to myself and then check with the doctor to see if he collaborates with it without my prompting him. (341)

Zowie uses the Internet because of its immediacy. When she wants to know 'right away', she goes online. She also wants to make sure her doctor is aware of the information she learned online. She will not confront him with her findings. She would rather assess the accuracy of the information on her own and wait to see if her doctor's information is consistent. Unlike the other recent immigrants who connected to information sources in their countries of origin, Zowie is looking for Canadian resources. Using local services becomes a strategy for her integration into her new Canadian way of life.

Parnell is a 49-year-old married accountant who has been online since 1999. He uses the Internet at home daily and is able to be online at work. He gave himself a health score of seven, classifies his health issues as Lifestyle and would like to lose some weight. This man wants to gain an understanding of his issues before meeting with the doctor and uses his research to form questions for his doctor. Within the following quotation the respondent can sense that his doctor was challenged by the questions as the doctor attempted to maintain control of the appointment.

> I went to Google and I said "injured shoulder" and then I knew it was SC joints and just put in AC joints, and then it brought me down to the different – all the different things; who was injured; what the severities were – so when I went to the doctor the next day, the specialist, I was talking to him and he was saying certain things too, I had wrote a bunch, about 30 questions to ask him. So I went to the doctor – what about this… and he was like oh jeez, you know – who's the doctor here? You can tell they don't like that sometimes…Of course they don't like that. They don't like, you know – knowledge is power. They don't want people asking them different questions because you're entering into their realm. But there was a lot of good questions on the site. I researched it the whole night so I went through. I had about 30 questions. (455)

In this quotation Parnell describes talking to his doctor about alternative medicine and various treatment modalities. Despite his attempts to create collaboration, there is the appearance of resistance from his doctor to an evolution in their relationship.

> So, when I was researching my cholesterol, I was asking the different drugs, I was asking my doctor about the different blockers – like I researched that a bit to ask him questions. When he gave me the stuff for – this guy was giving me VIOX for my back – injured back – anti-inflammatory… I asked what the hell are you giving my VIOX for man? He said, well how as I supposed to know – and the other guy gives me Celebrex. I mean it's all the same – you take that shit. And now I have some other stuff which is naturopathic – and works like shit – it doesn't do anything -. It comes and goes…. (455)

Parnell uses Internet research as expertise to question his doctor and has different results than some of the other interviewees. He comes to his physician with questions,

rather than just information and it seems to arouse a negative reaction from his doctor. The following interviewees prefer to gather information on their own, not necessarily with the intention of sharing with medical professionals. They want enough information to formulate an opinion, but they do not want to discuss their issues.

Hilary is a 39-year-old married woman who has a computer at home. She never goes online at home but is online all day at work. She would like to quit smoking, lose weight and exercise more. She gives herself a health score of seven and considers her health issues to be Lifestyle oriented. As the following quotation indicates, when she has a specific problem, she goes to the doctor and appreciates all of the information pamphlets she is provided with. Her doctor is able to dispense information in manageable increments.

> Um, it would probably be – I could see me looking for stuff like Public health and Lifestyle, again going along with the losing weight stuff. I wouldn't see me looking up anything for either of these, I would deal directly with the doctor and if it were something like this it would have to be something like – either I had just found out I had this or somebody I knew – so I wanted to learn more about it. Like my mother had Alzheimer's disease and when we first found out she had Alzheimer disease I got all the information that I could about it and read up on it as much as I could and that was probably the only time I ever looked up anything on the Internet – I did, I checked everything I found to find out everything that I could about it. (690)

Hilary wants to learn and wants to know about health issues, but she only researches medical issues for her mother, whereby the Internet is the resource of information after a

medical appointment. For herself, she is content to use the Internet to learn about losing weight.

This next quotation illustrates how conflicted Hilary is about using the Internet. She wants to be informed about certain topics, but is vulnerable to being overwhelmed; a negative consequence of online research. While she prefers to get information from her physician, she also recognizes that the Internet can offer much more information.

> In all honestly kind of after I really got going, I kind of felt almost inundated by it. There was so much of it there. At least with the little pamphlets the Doctor have you it was limited information on each one. (690)

Becoming a researcher is not without risk for the people conducting research on their own. Ultimately, Hilary benefited from the experience of gathering health information online and helped her to feel more prepared for her medical encounter.

> But I did find that it that the information that I found on the Internet made me feel more prepared the next time when I would go to see the doctor with specific questions on you know how do we do this, or how do we handle this or what can we do and yah. (690)

Feeling prepared in advance offers Hilary more control on the outcome of the doctor patient interaction and possibly the relationship.

Each one of these six interviewees exemplifies the experience of looking for health information online before a medical appointment. Everyone is interested in conducting research to increase their knowledge and awareness of personal health issues. Internet health information searches are seen as a means of enhancing communication

with medical professionals and in turn strengthening relationships. The need for a medical encounter is not likely to be replaced by online research in these cases.

7.4.1.2 Researching health issues online after a medical appointment

Unlike the previous grouping of people who take information to their doctors for verification, the next eight interview respondents described specifically following up a doctor's visit with Internet based research. Mostly they classify their health issues within the Lifestyle issues category. These interviews are more likely to trust their doctors, but do want additional information to satisfy lingering curiosities or be reassured of treatment plans. They appreciate the Internet as it offers an opportunity to learn about medical issues, diagnoses and treatment options on your own.

Alex is a 74-year-old married and retired man. He started using the Internet in 1997 and goes online about daily from both work and home. He gave himself a perfect ten for his health score and is interested in Lifestyle health issues. The following quotation illustrates how Internet research can enhance a doctor patient relationship while empowering this individual to take charge of his own health issues.

> I would never come in from the doctor's office without heading to the Internet to find out more about the problem. And my doctor normally says I know more than he does. It's because I have the time to check things out; he doesn't. And so I was just recently told, for example, that I have a chronic kidney disease. And that's serious. So I'm not going to sit around and not do anything about it. And the doctors weren't quite sure what was going on, but I think I figured it out. You

> spend enough time on there and go to the right sites, don't read all the 2500 listings, but go to the medical schools, and you can find out anything you want. So looking at some data I got from the doctor, which they couldn't make sense out of, because I was going to three different doctors who don't talk to each other…I was able to pull it together and get a focus on what the problem is. So that would be a major use; I should have mentioned that…(848)

Alex conducts his research in collaboration with his doctor. He is not content to do nothing, but is more comfortable to do something in relation to the medical professionals surrounding his chronic health issue.

Eunice is a 59-year-old woman who is both retired and widowed. She classifies her health issues as "chronic" and is concerned about arthritis, quitting smoking and losing weight. She has a home Internet connection and goes online about daily. Unfortunately a transcript of her interview is not available. The field notes emphasized Eunice's curiosity and the advice received from a medical professional regarding self-diagnosis. Both the Internet and a medical professional are consulted in response to person query.

> She starts with Google but there are so many sites that are listed. She has to make a decision on which ones to choose – she uses hospital sites, certain people or one that seem legitimate. Some sites are helpful, while others are bad. She will speak to her doctor about these issues, but found the Internet helpful once she has been diagnosed with something…(008)

Eunice goes online before and after a medical appointment, but she does think that going

online afterwards is ultimately more helpful. Being able to research an identified topic is easier than searching from scratch.

Unlike those who attempt to self-diagnose health conditions and medical concerns, Alex and Eunice prefer to perform their health based research following a medical appointment. For them there is value in having a specific topic to research, rather than looking aimlessly for unspecified information.

7.4.1.3 Researching health issues online instead of making a medical appointment

Three people are integrating online research about health and medical topics into their health management processes, they do not necessarily need to get the information in relation to a doctors' visit, rather they are looking things up online to a) supplement the doctors' information or b) for definitions and health information, rather than procedural or medication issues.

Nora is a 36-year-old married woman who volunteers full time. She uses the Internet from home about daily and from work about weekly. She classifies her health issues as "mental health" oriented and is concerned with getting enough sleep. During her interview she describes looking online for information relevant to an upcoming surgery. She could have gleaned this from her doctor, but chose to conduct her research using the Internet instead.

> I think it was 5 years ago, after my second child was born. I had to go for laparoscopic surgery. There was a small cyst, so they had to operate. So it was nothing serious, but I just got some information –

> what is that and how they did the procedure…Just to see how long is the procedure, and is it safe, and what is laparoscopic surgery. (842)

Nora's search strategy resembles those who look for information following a medical appointment, however she was looking for the procedural information and other kinds of information that she did not get it from her MD. Nora does not mention asking her doctor for the information, instead she performed her research on her own.

Terry is a 48-year-old married executive assistant. She does not have a home Internet connection and only goes online at work about weekly. Increasing her fitness and quitting smoking are her health concerns that she classifies as Lifestyle oriented. The following quotations shows how she is empowered to research on her own and has filters for determining what kind of information she is interested in and what she is willing to follow up on. No longer is the doctor the only source of information.

> P: I would type in the condition or the subject matter… I would go to Google… Like back pain – and what to do to alleviate back pain or elbow pain, that sort of thing –
>
> I: and then Google will give you 12 million sites then what do you do
>
> P: I click on what ever I think will be informative and read about it (179)

Peter is a 57-year-old retired married man. His home computer is connected to the Internet and he goes online about daily. He is a colon cancer survivor and gave himself a health score of nine. Today he would like to lose some weight. He never researchers health information online for himself, but does look for things concerning his wife. He thinks the Internet is more up to date than his old medical book.

P: Yeah it was for my wife and that was only one instance. Otherwise I'd just go to the doctor, unless there is something that I was not to familiar with like some disease or a word I'm not sure of if it's not in the dictionary downstairs, then I might come up here and look it up as to what it is on the net. (He then describes a word he once looked up) On the Internet it would be more up to date then in some nursing book which is twenty years old.

I: And how would you look at that?

P: (Shows interviewer where he would go on the computer)

I: Ok so you would go to the search in the browser….

P: (Shows how he looked up the car he purchased)

I: Thinking in health, would you go to a more questions and answers or would you skim definitions? How would you pick up the website for example because sometimes you have a lot of lists?

P: Well I would see which one is more pertinent to what I want to see and after about half an hour I'd get fed up and shut it down.

I: So basically you'd go one by one…

P: Yeah cause you know there is so much stuff, just pictures to make it look good.

I: Ok and let me come back to the health cause that's an important thing for us. The Psoriasis, so how would you do that?

P: First I'd go to the dictionary and see how its spelt.

I: And then you go one by one and you basically read a little bit?

P: It depends on my time and how interested I am in it. (663)

While Peter acknowledges that information found online is likely quite current, it does require patience and good spelling to be able to research effectively. For actual health concerns, Peter would ask a doctor, but to learn more about something, the Internet is the

best source.

Nora, Terry and Peter describe an efficiency of moving from posing a specific health question and having it answered immediately by their online quest. Their experiences are generally positive. Peter however, is often left feeling overwhelmed by the amount of information available.

7.4.2 How accessing health information on the Internet affects individuals

Internet use is a part of the health management process for many now, an adjunct to the existing process for some and an extremely new element for others. The incentive for accessing health information is often to improve communication with medical professionals by learning about health issues. The participants of the Connected Lives interviews gather health information online because they are curious; they want to know more and they like being informed. The information they glean through their Internet use empowers them to take charge of their own health by getting the information to help them strive for good health.

7.4.2.1 Internet users become health information researchers

The following individuals share a common goal of learning more about specific conditions, or health issues in general. They are curious, engaged, interested and want to know more about themselves, their loved ones and about health issues in general. Using the Internet is a mechanism for satisfying their curiosity and teaching them more about health issues.

Patty is a 26 year-old married woman who has an Internet connected computer in her home that she accesses about daily. She gave herself a health score of 10 and does not describe any health issues or concerns. Her online research is motivated by general curiosity and a desire to know more and keep up to date regarding current trends.

> Just my own education, my own interest. And I'll, often on the dietitians of Canada website. Cause that's kind of like our website, and so they're always posting different things and so I like to go on and just keep up with what's happening. (207)

Patty's excerpt does not suggest an external pressure to learn, rather a sense of self-satisfaction from being engaged and up to date with current information.

James is a 36-year-old single man who works as a web developer. He has been online since 1996 and is online all day at either home or work. He moved to Canada eight years ago. He gave himself a health score of eight and is concerned with lifestyle health issues including diet and exercise. The following quotation demonstrates value of supplementing doctor's information with online research.

> My mom has this condition that she recently discovered. She told me about it when one of the doctors told her about it, and so basically, I just went on the Internet and did a little bit of research on it…and in that way it was very helpful because that way she received more information than she actually received from the doctor. (258)

Sally is a 49-year-old married woman who works as a teacher. She has been online since 1997 and uses the Internet at home and work about daily. She gave herself a health score of three and considers her health issues to be Lifestyle oriented. She would

like to lose some weight. During her interview she self-identifies as a researcher who describes the Internet as an accessible source of information.

> You know probably Google or Merck Manual or something like that. You know if I have a medical condition that I know about and I just want more information about it I would look online…Well it might be a medical condition that one of my kids have. My son at one point had this rare disease and my daughter had, was diagnosed with a bicuspid aortic valve and I wanted to find out more information on that. Or I have heart arrhythmia and I'm just trying to find out a test, you know what do these tests mean, why is the doctor ordering it. So I'm a person who likes to have lots of information. (432)

Sally's identifies herself as someone who appreciates having information. Being a researcher with access to the Internet allows her to pursue this pleasurable activity.

Marcus is a 47-year-old single man. He has been online since 2004 and uses the Internet from home about daily. He gave himself a health score of nine and thinks he is in perfect health. He is interested in lifestyle health issues and uses the Internet to research his mother's ailments. Any Internet research he does involves learning more about his mother's symptoms and health issues.

> Last time I looked was 2 weeks ago, regarding my mother's health…I started with the pain that she was feeling. She was feeing stomach pain, so I just typed in stomach pain on the Internet and went from there…I went to several different sites to get the general overview of what was being said or written. (584)

Marcus refers to wanting a "general overview" of the meaning of her symptoms and as such takes on the role of researcher, striving to learn more.

Tanya is a 43-year-old woman married who started using the Internet in 1993. She reports being online all day at home and all day at work. She gave herself a health score of seven and a half and classifies her health issues within the lifestyle category. Generally she is interested in weigh loss.

> P: When it comes to health information, it depends on what health information. So for example when you're looking at public health Meningitis vaccine, if you're looking to see if it's paid for by the Ontario government, funded and you're on the Ontario government site, you kind of know. If it's something really more specific, it might be through – depends on the kind of data you're looking at right? To do that, something like that if you're looking at symptoms, usually there's two or three different websites that'll have it – the same thing. It would be the one.
>
> I: By and large you trust the information that you get?
>
> P: I wouldn't say that, I would say that by and large I know how to pick sites that are good versus sites that aren't (383)

Tanya is wary of non-governmental health information sites and the commercialization of information. She indicates having a way of knowing what online health information is reliable based on who is funding the information provision. She seems to be confident that she can identify accurate information online.

Theresa is a 33 -year-old married woman. Online since 1997 and uses the Internet about daily from home and work. She is on disability leave from work and gives herself a perfect ten health score. Her health issues are lifestyle and she would like to get more exercise. She opts for government websites when searching for health information.

> My first point of reference would always be Healthy Ontario.com because I know that it exists and I know that sort of government. (421)

Donald is a 62-year-old married man working as a lab manager. He's been online since 1992 and uses the Internet about daily from home and is online all day at work. He gave himself a health score of 8 and describes his interest in weight loss as a lifestyle health issue. As his quotation suggests, having a diagnosis can initiate research; however when that diagnosis is false, it does not matter the quality of the information, because the research strategy is misguided.

> Yeah, only to understand a specific problem, I'm trying to remember what it was. Marlene was diagnosed with something just a few years ago and it turned out that she was falsely diagnosed. So I went upon to find out what it is and so I used the web to search. (844)

7.4.2.2 Internet users strive to be healthy and in charge of own health

The following individuals are pursing and taking charge of their personal health matters. They each express personal responsibility for their health and are active engaging in behaviors they define to be healthy.

Rhianna is a 57 -year-old retired married woman. She started using the Internet in 1997 and is online at home about daily. She classifies her health issues as Lifestyle oriented and scored her health as an eight out of ten. Today she would like to lose some weight. During her interview she expresses an ongoing curiosity regarding health topics and seems to connect her sense of self with being healthy and being up to date with health trends.

> I search the Internet; I look up a lot of health things. I'm really into being healthy and trying to find out about the latest things (274)

For Rhianna there is a connection between having current health information and pursuing new knowledge with being health and achieving positive health outcomes.

Clay a 27 year-old student, profiled in a previous section 7.4.1.1, exemplifies how internal and external pressures to acquire knowledge can lead to a person searching for health information online.

> Oh yeah, for sure. Umm finding out where clinics are. For example I mean it's umm it's very important in the gay culture that you are aware of everything that's going on. Whether you are monogamous like myself or not, you have gotta know what your health status is. Not just on a HIV or AIDS like a typical what you would worry about but things like Chlamydia or you know Gonorrhea, Gonorrhea, you have symptoms for example, But I would never have known that without looking it up on the Internet. Whereas Chlamydia sometimes there is not symptoms that you normally see. Sometimes you can be a carrier and you can pass that on to your partner or whatever. So I think for me that's umm something that's been recently added. For health reasons. (601)

Community pressures to be healthy and informed implicitly encourage an individual to act on health messages and be active in their own health management.

John is a 55 -year-old retired, married man. He has been online since 1994 and uses the Internet about daily at home. He gave himself a health score of six and is interested in Lifestyle health issues. He would like to get more exercise.

> I hunt every diet plan on the Internet that I see. (827)

During his interview, John expresses interest in gathering diet related information to satisfy his inclination to be informed. It is likely he is responding to a social pressure to maintain a healthy weight that can be achieved with proper diet and exercise. Interestingly, information acquisition does not guarantee taking action.

7.4.3 Accessing health information on the Internet affects the relationship with the Internet

The previous section considered how the process of conducting online health information research could empower an individual to take responsibility for their own health. As much as the ability to access information can strengthen ones' confidence regarding personal care, it is not simply the information that produces this result, it the interaction with the source of information that contributes to the effect. It is within the interaction between the human and the non-human actor that the effect of health information can been seen.

The answer gives evidence of a rapport with the Internet. The interviewees use confident language to describe their interactions with the Internet. Their online searching is a habit or common practice within their health management routines. The familiarity of language used to describe their interactions with the Internet, a non-human actor, could account for the increasing rates of online health information searching.

During the analysis, two of the themes that emerged were a) the habitual use of the Internet as it becomes embedded in everyday lives and daily routines and b) the description and attribution of location to the Internet, as if it where a place one could visit or go to in times of need.

Each of these themes contribute to sense of rapport and confidence that appears to be an emerging aspect of Internet use and provides insight as to why Internet use gains both popularity and influence for its users.

Steve is a 60-year-old divorced man from Chile who moved to Canada 31 years previously. He has been online since 1995, and goes online at home about daily. He gave himself a health score of one and classifies his health issues as Chronic. He takes great interest in managing chronic kidney disease. Online research is a part of the daily routine and strategy for coping with an ongoing medical condition. The following quotations are exemplar of someone who makes no hesitation about using the Internet for health management, who uses definitive language describe his use and clearly has a routine for his online search strategies. Each of the four following quotations establishes the confidence Steve has with the interactions he has with the Internet.

> "I always start with a search engine."

Always is the language of routine and habit. Whenever Steve needs health information he starts online. He has a pattern that he follows from health query to research strategy.

> "Oh I look at… I open Internet, go to Netscape, I have Netscape. Then look at the search, metasearch engines, Google, Yahoo! and others. Docfind, Exfind???? There's so many of them"

This quotation was taken from the observation portion of the Interview. Steve is describing the last time he looked for health information online. He has a routine for his information searching, based on extensive time spent researching his medical issues.

> "I spend one hour on the Internet looking for news for kidney disease, healing, cure, therapy, alternative approaches. "

Steve's willingness to interact with the Internet for an hour at a time on a daily basis reflects his confidence that he will find what he is looking forward that deems helpful for his health management.

> I: and how do you decide, where you go?
>
> P: Oh, I go down on the search engine. The particular topic, then I click and if the topics there then I read it. (773)

Steve is actively engaged in his health management process. Steve is now a researcher, taking charge of his own health care plan and learning to cope with kidney disease. Steve's use of the Internet affirms that he can get what he wants and needs with enough time spent navigating search engines and reading online material.

Sheena is a 21-year-old mother living with her baby and common law husband in a home without the Internet. She uses her mother's computer almost every day. She is interested in losing the weight she gained during pregnancy and quitting smoking. She classifies her health issues as Lifestyle in nature and gave herself a health score of eight.

> "I always go to yahoo." (263)

Sheena does not go to a physician or friends, or family first, she goes to the Internet. Like Steve, she "always" uses the Internet. Without hesitation, Sheena goes online, confident that her routine of looking for health information online will lead to satisfactory results. Her response reflects the importance of the Internet and the place it holds in her health management routine.

Tanya who was mentioned in a previous section is a 43-year-old married woman.

She is interested in mental health topics as well as diet and exercise. In this quotation she describes her health information searches as habitually beginning with an online search engine.

> "Yeah, always start with Google." (383)

Like Sheena, Tanya does not go to a medical professional, or her friends and family; instead she chooses Google. Internet searches are her usual practice. Invariably and without hesitation, Sheena begins her health research with an online search engine.

Hannah is a 41-year-old separated woman currently in school as a full time student. She started using the Internet in 1998 and goes online about daily. She uses the Internet to research her lifestyle oriented health issues, including diet, exercise and mental health issues. She gave herself a health score of seven and would like to lose some weight. In this quote, her use of the word always shows how the Internet is her definite and consistent starting point for health information searching. By referring to looking to the Internet all the time suggests an ongoing curiosity and interest in health management.

> I: Do you ever use the Internet to look for mental health and lifestyle issues?
>
> P: Lifestyle issues all the time. Always. (110)

Hannah, like the others uses definitive language and indicates a habitual practice with her Internet use.

Felicia is a 43-year-old divorced woman employed as an account executive who started using the Internet in 1991. She has an Internet connected computer in her home

that she uses about daily and reports using the Internet at work all day. She gave herself a health score of eight and a half and is primarily interested in her diet, her irritable bowel syndrome and her knee issues. She classifies these within the Lifestyle category. She uses Google as her starting point for all information searches and trusts Google and the sources it links to. While Google is a proprietary name, not a unique source of information her quotation offer insight as to a perception of the service Google offers to its users.

> P: Yeah, I've – nutrition a little bit. Um, just trying to find some information on food contents and what's in food and fiber – that kind of stuff.
>
> I: So when you are curious about that, how did you go about looking for that information?
>
> P: I'm sure I Googled it, cause that's become a verb now. I usually type in Canada; I would've put nutrition. Let's see, sometimes you can link through the magazines though – Chatelaine and those kinds of magazines – I know I've done that. So, their recommended sites. I think – I remember searching for nutritionist information once and finding Ontario Canadian Website – I think Ontario Nutritionists…. (880)

Felicia is striving to be healthy and there is an implied expectation that being aware of nutritional information, flowing social pressures in many instances leads to healthy outcomes.

Chico was mentioned in a previous chapter. He is a recent immigrant to Canada who went online to seek emotional support for his frostbite. This 42-year-old married man started using the Internet in 1996 before he moved to Canada which he did month prior to the Connected Lives interview. Today he goes online daily at both home and at

work. Chico is interested in quitting smoking and other lifestyle health issues. He gave himself a health score of six and would like to get more exercise. Embedded within this quotation is reference to searching for health information which has become part of his routine as he frequently uses Internet to satisfy numerous curiosities.

> The only thing I haven't done with it is- on it, but I do use it to- for example, -???-. I will Google, which is my favorite search tool. I will Google my recipes, based on what is in the -???- Directions, -???- if we are visiting people sometimes, just put Mapquest and stuff like that. Get around. Pretty much everywhere I go has a website, so easy to research where we're doing shopping, and what deals are, and what activities in that place. For healthcare as well. Health issues. We'll research like that. I'm a big user of Messenger. I also use, there's a program that's on it, a program that has, let's see, Skype. (561)

This quotation was taken from the beginning of the interview when the research team asked the participants to describe what they did online, rather than to describe a time when they may have searched for health information. Chico's reference to Google as a verb and a location demonstrates his confidence with the search tool and his integration of Internet use into his daily activities. Google is the starting point for many tasks of this self-identified researcher.

Kent is a 54-year-old married man who is online all day at work and uses his Internet connected home computer about weekly. He only rated his health as six and a half out of ten because he would like to lose some weight. He thinks his health issues fall within the Lifestyle health issue category.

The following quotation demonstrates how Kent attributes location to the Internet.

> For me it's the Internet. I do. I go for recipes and for health information. (097)

Kent has confidence that the Internet will have what he needs. He is optimistic the experience will deliver helpful results. The confidence is built from repeated exposure to the Internet. He has used it enough to know it to be a place that will offer information support.

Petra is a 33-year-old married woman who moved to Canada three years prior to her interview. She started using the Internet once she moved to East York and has an Internet connected computer in her home. Her Internet use is daily from home and less than once a month at work. Her Internet health research tends to involve looking for home remedies for particular issues. She gave herself a health score of ten and considers herself to be in perfect health. The following quotation exemplifies the notion of the Internet being a place where someone can go. As a location, the Internet holds familiarity and with that familiarity it is possible to develop a relationship. In this case, the relationship is with something that has everything.

> In Google, they have everything. (810)

Petra, like Kent *goes* to the Internet. The Internet is an abundant resource that she is confident will provide her with everything she will wants and/or needs. Petra does not doubt the experience she will have with the Internet.

Dorothy is a 45-year-old married woman who works as a consultant. She started using the Internet in 1995 and goes online at home about daily. She gave herself a health score of ten and considers her health issues to be lifestyle oriented. She has researched

migraine headaches and cholesterol. The following quotation exemplifies how the Internet can offer information while refraining from judgment thus the Internet becomes more trusted than one's friends.

> Medical things I tend to look up myself, you don't want your friends to think you're a hypochondriac. (366)

For Dorothy, the Internet is somewhere you can research in private without judgement or questioning from friends. The Internet will not question your actions, it will answer your questions.

Miliania is a 58-year-old single woman who started using the Internet in 1989. She reports being online all day at work, where she is a manager and all day at home. Quitting smoking is her primary health issue, which she classifies within the Lifestyle category. She gave herself a health score of eight and reports feeling quite healthy. In contrast to the previous example, the following quotation suggests that using the Internet can have a direct effect on the user in terms of making them feel something and in this case, the Internet creates a sense of hypochondria, rather than dissuading such a reaction as it did for Participant 366.

> I: Have you ever used the Internet to look up health information?
>
> P: Yes, not very much because then I feel that I have all the sicknesses you can think of. (206)

Miliania offers the negative case example from the interview sample. Her fears about exposure to Internet based information sounds like a version of "cyberchondria" one of the warned against responses to online health information where exposure to

information changes your relationship with health in a negative fashion (Harris Poll, 2006).

7.5 Summary

An effect of the evolution of integrating the Internet into health management is patient empowerment and improved communication with medical professionals. People's relationships with themselves, their doctors and the Internet are transforming. As such, the context of information and emotional connections comprising social support, vital to positive health outcomes, is also changing.

Being a researcher, looking for information about health topics without medical prompting and taking charge of personal health issues influences one's conceptions and definitions of health. Positive health outcomes are thought to be achievable ends, given the right information and behavioral adaptations. Health outcomes are becoming something that can be controlled and health information is becoming something to be consumed. East Yorkers are assuming responsibility for their own health now that information retrieval is easier. They are engaged with that information as it empowers them to learn, know and do more health-oriented activities. They are thinking about ways to take charge of their own health and are reflecting on the ability of health information to change how they think about themselves and the health management choices they make. Several interviewees make specific reference to clearly integrated health information search strategies. They thoughtfully discriminate between information provided by commercial sources and that which is offered by medical or governmental

websites. For the newcomers to Canada, the institutional knowledge they are lacking is an important area of information support that they are seeking online. Their cases exemplify an increasing media literacy among Internet users and an emergence of the health information consumer.

Despite a curiosity about health topics, people in East York do not self-diagnose. While they look up health information on their own, when they are searching for medical information it tends to be in relation to a medical appointment either as a preparatory investigation or as a follow up. People research before medical appointments to be prepared and improve communication during their appointments. As patients become more engaged in their health care processes by being prepared to ask questions and conduct their own follow up their interactions with doctors are affected. Although fears remain that the Internet is negatively affecting the doctor patient relationship, this population value and wants to improve their relationships with their health care professionals. They see an increase in communication and discussion as a positive means of achieving this end.

Some East Yorkers go online after a medical appointment to learn about a diagnosis, or increase their knowledge and involvement in treatment planning and follow-up. Using the Internet for health information affects individuals by getting them engaged in their health by becoming more informed and more empowered to act on the information.

Not only are people learning more about themselves, they are in turn learning more about the Internet. Now there is a confidence and optimism about going online

immediately for information. The language describing their online experiences and the precursors to Internet searches shows a new relationship, one that is reassuring, interactive and familiar. People are not longing for the days of their medical books; very few people mentioned having alternate static resources. The conceptualization of the Internet is extending from connectivity tool, to familiar a resource that is used habitually as it integrates into the health management process.

Chapter 8

Discussion

8.0 Managing Health Issues Online

This dissertation grew from an intention of finding out how Internet use is incorporated into health management practices. To that end I examined the ways people use Internet technologies to search for and access information and glean social support. Given the complexity of health management, I constructed my analysis to consider the intertwining aspects of i) how and where people look for health information and ii) how and where they access emotional support for health issues. In the age of the Internet, use of online resources is now entwined within each of these layers. Not only did I assume the Internet to be an information database and a mechanism for accessing social support, I presupposed that the Internet can play a significant role in the health management process and the intersection of human and non-human machine will influence both the process and the outcome of engagement.

As a result of my analysis, this chapter offers a way of understanding health management by revisiting my three research questions: To what extent do people use the Internet as an information database? Does the Internet enable supportive encounters? What are the implications of using the Internet for health management? In addition to

answering these questions, this chapter offers implications for social workers, strengths and limitations of the research and my final thoughts regarding the evolution of health management.

8.1 Using the Internet as an information database

Most East Yorkers have home computers, high-speed connections and a positive attitude about Internet use. They think the Internet makes tasks like searching for information much easier. When medical and health information curiosities arise, it is not surprising that the majority of the population goes online. The information they retrieve will either sufficiently satisfy their needs or will be used to promote communication with a medical professional. People in East York are taking their health issues into their own hands as they assume individual responsibility in their quest to be healthy and informed.

If you are a *moderate* Internet user, you have a *Chronic* health condition or are curious about *Lifestyle* health issues and your social network is smaller than average then the Internet has become part of how you manage your health issues. Searching for health information is a part of everyday Internet use for people accustomed to being online for general information searches and those who are online more than 3 hours a day. People with chronic health care issues, having a specific health diagnosis that want to inquire about treatment options and long-term care spend the most amount of time online looking for health information.

Despite my expectations that women would be online longer than men looking for health information, in East York performing online information searches is not related to

gender. Internet use and communication is a domesticated task, meaning it is performed in the home, but it is taken up in equal measure by men and women. The care of self and family is no longer the task of the mother or wife, rather it is becoming the personal responsibility of every individual.

Previous research about the information seeking process indicates that an individual's situation and context will determine their information needs (Sonnenwald, 1999). After which, people seek information from people like themselves. People either follow habitual patterns when seeking information and use search strategies that were successful in the past or they seek the most accessible information (Faibisoff & Ely, 1976; Pettigrew, 1998). Additionally, people will seek information from formal and institutional sources as a last resort (Chatman, 1991; Harris & Dewdney, 1994). Information is typically acquired from other people, like influential friends and family members. These "opinion leaders" influence those around them by passing on information (Katz, 1957; Katz & Lazarsfeld, 1955). Interpersonal relations affect health information diffusion, as health information continues to flow primarily through friendship networks (Katz, 1957).

Results from my research indicate that information flow does not necessarily rely on relationships or social networks as the context for diffusion now. Health information seeking for many relies primarily on having a broadband Internet connection.

People in East York tend to have high-speed Internet connections and this gives them a technical advantage which prevents them from experiencing the repercussions of a digital divide. As the Internet establishes itself as an information repository, the sharing

of and access to information reflects societal priorities. Not being able to access information is seen as a significant disadvantage creating chasms between those with information and those without.

Having never used the Internet at all or self-identifying a vulnerability to information overload will likely result in refraining from going online to research personal health issues. Those people who do not go online at all are not likely to use the Internet to search for health information. People who do use the Internet for some things, but are apprehensive about accessing too much information are not likely to use the Internet to search for health information as they express fear at being overwhelmed by too many resources. When a close relationship with one's physician is present, and the physician is considered to be a member of the social network people will generally access all of their health information from that medical professional rather than going online to search for it.

8.2 How the Internet enables supportive encounters

In Chapter Six, I analyzed how much time people spent communicating online, and whether or not they used the Internet to specifically communicate about health issues with others. The residents of East York look online for answers to their health questions. They do not look to each other for information about health issues, but they do however look within and outside of their social networks for emotional support for health issues. These results were somewhat surprising given what Chapter Two described about information flowing through networks and relationships. Keep in mind however, that

many respondents did indicate gathering information they did intend to share with others.

Communicating online for the sole purpose of managing a specific health care issue is a new way of gleaning social support for health concerns and rarely happens for the general population. It is not typical for people in East York to communicate online about their health issues; however unspecified online communication is the second most popular online activity.

Those who look for people with similar health care issues in online environments resemble the early adopter, if early adopters are defined to be the people with sufficient resources and motivation to try newly available technology.

Each of the East Yorkers who sought social support online was familiar with the spectrum of available resources online and had the motivation to seek it. They are web savvy and used to performing multiple tasks online. They also had significant health issues requiring continuous or immediate attention and they have a limited number of people in their social networks to go to for support for their health issues. While the sample of people using the Internet to access emotional support from strangers was small (n=3), their stories brought to life the experience of online support seeking and gave context to a beneficial and newly emerging behavior.

Few people in East York used the Internet to specifically look for emotional support from people they did not know, most people accessed emotional support for their health issues from people in their social networks. There are very few people without anyone in their network to help them with health information or help with a health concern. When these people lacking network supports are considered as a unique

grouping, two different responses emerge. They either go to their doctors, who they view as part of their social network, or they refer to Google as their source of health information and support for health concerns. Chapter Seven details the language used when referring to Internet search engines and the processes associated with going online.

Similarly, recall from Chapter Three that Mager (2009) also found that Google plays a central role for information users. She argues that Google is an influential actor in the social relation of information seeking and information source. Latour's (1995) Actor Network Theory provides the language and the context for looking at the relationship between the machine and the user. Latour highlights the value in considering the interactions and exchanges inherent in technology use. Through those interactions, the human actor can change and evolve as is evident when definitions and experiences of health change and new relationships emerge.

8.3 Implications of Using the Internet for Health Management

As web based technologies integrate into everyday life, the Utopian / Dystopian debate surrounding the effects of Internet use fades. Internet use is no longer viewed as an optimal solution to all social ills or a precursor of dire consequences. Instead, there are both positive and negative implications for the ease at which information is gathered and emotional connections for health issues are made. The Internet carries the burden of these implications as it is a medium through which information and emotional connections flow. Like a deviant acquaintance that challenges our habitual patterns, or a

stranger exposing new ways of doing things, the Internet can also overturn customary health practices.

Many of us have updated our health management practices to fit Internet use. The implications of this model of health management where the Internet is integral to the process are visible in the increased and empowered communication with medical professionals and the inclusion of online social support acquisition sought for its promise of improving health outcomes. While our collective knowledge of our bodies and our health is increasing, so too is the presumption that health maintenance is an individual responsibility. This is not necessarily a favorable outcome of Internet mediated health care because health outcomes are connected to social support and community standards. The World Health Organization assumes the position that health is a community issue and that individual health outcomes are as much a product of individual characteristics and behaviors as the physical, social and economic environments that predict them.

The residents of East York want to be informed and be up to date with current health care trends. They want to know about *Lifestyle* issues and they spend time online researching ways to manage their *Chronic* health care issues. Gone are the days of the passive patient, instead patients are engaged in knowledge exchange and are empowered as a result (Seçkin, 2009).

Canadian social work Professor Steven Hick identifies empowerment as a functional priority for social workers and offers the following comprehensive definition:

> Empowerment is the process of increasing personal, interpersonal or political power so that one can improve one's particular situation. Power can be a personal state of mind, in the sense that one feels that

> one can make a difference and have control and influence over one's own life. It can also be empowerment within an organization in the sense that one has tangible influence and legal rights. Empowerment, then, involves both a personal perception of being in control and tangible elements of power within the various social structures of society. Social workers seek to empower their clients as a way of helping them to focus on, among other things, access to resources and the structures of power (Hick, 2010).

Seemingly the empowered person, or patient that is disrupting a potentially oppressive relationship would be something to aspire to. Health information sought online is not simply empowering. Segal (2009) argues that patients exposed to health information are not empowered but remade. Online health information is neither stable nor reliable and creates a faulty view of knowledge expertise. Lay persons are not capable of the art of diagnosis and are not apprised of the context of medical knowledge when they are performing online research. As such, patients are not empowered. Instead, information provision can turn patients into health consumers, wanting to be involved in decision making while being opinionated and evaluative (Segal, 2009).

A typical East Yorker conducts online health research to be better prepared for a medical encounter with the expectation that their physician will respond favorably to their preparations. Better communication and increased awareness of symptoms, treatments and medications are the motivations for conducting health research online.

Whenever a resident of East York brought information they found online into a medical appointment, they were demonstrating their belief that they can participate in their own well-being and influence their own life. Are these individuals empowered to

take charge of their health care practices? Their doctor / patient relationships are no longer about passively receiving information; they are about cooperative health care where patients are bringing in their own questions and building on the knowledge they gain with information they search on their own.

In Switzerland, searching for health information online is not common. According to various national surveys only between 10 and 18 percent of Internet users report having performed online health research (Caiata-Zufferey, Abraham, Sommerhalder, & Schulz, 2010). This is explained because physicians are the most predominant and valuable sources of information among the Swiss population. By interviewing 27 people recruited from medical waiting rooms, Caiata-Zuffery et al (2010) sought to find out why patients search for information and how that relates to the medical encounter. They found that searching is done in relation to medical consultations to either prepare for, complement, validate or challenge. Further, their analysis suggested that online health information searching is performed to gain acknowledgement, reduce uncertainty, or broaden perspective. The majority of those they interviewed expressed that their online search behavior was driven by their individual sense of self-responsibility. The researchers interpret these results to reflect the growing social imperative to assume responsibility for one's own health.

Internet influenced models of health management are leading to an inevitability of people informing themselves of their health conditions and staying current with regards to wellness trends as they take charge of their health matters. Such empowerment is arguably a positive implication and can help to build favorable doctor patient

relationship. However, it runs the risk of masking healthism.

Recall from Chapter Three that healthism refers to a personal preoccupation with health and the belief that health and health care is an individual responsibility. It is characterized by "high health awareness and expectations, information seeking, self-reflection and high expectations…" (Greenhalgh & Wessely, 2004, p 210).

The participants in the Connected Lives Study expressed many of these same characteristics. Certainly they describe their health as though it is something they can control through diet, exercise and personal responsibility. Arguably, such interest in the pursuit of good health is favorable; however, the effects of the idea that health is an individual responsibility can be negative. Healthism distorts public health priorities, can increase health anxieties and reinforces individualism (Greenhalgh & Wessely, 2004).

In 1988 Barsky wrote that although collective health is improving, satisfaction with personal health is on the decline. He did not explicitly link his observations with healthism, but his argument parallels that of the negative consequences of healthism that as personal issues become medicalized everyday actions of eating and exercise become linked with health, no longer with pleasure, or free from moral obligation (Barsky, 1988).

As our lives become scrutinized by medical professionals, we define aspects of life along the continuum of health and illness within the context of a medical model. As such many of the pleasures of life become a means to an end, where the end is an obligation to achieve health. Consequently, a failure to achieve health through the modification of lifestyle becomes a moral issue. Illness becomes personal failure, and people are blamed for becoming sick. A recognition of the social and economic

influences on health and wellness is lost under the influence of healthist ideals. Given how many people in the research sample indicated they would be healthier if they only lost weight or exercised more, could it be that healthism is rampant in East York?

By assuming that health and health maintenance is an individual matter we identify only as our physical selves in relation to social expectations about health outcomes. In as much as healthism prescribes the belief that health outcomes are an individual's responsibility, if carried further, an individual becomes not only responsible for health management, but health is ultimately malleable. As such biology is no longer viewed as destiny, biology becomes changeable identity. When identity is based solely on biology and people join communities based on health issue rather than civic location, the notion of biological citizenship arises.

As individuals actively engage with biological explanations and form novel relations with figures of scientific or medical authority in the process of caring for, and about, health they are creating their biological identity and collecting around this identity that becomes increasingly biological. When connecting online and identifying oneself based on biology and somatic identity becomes easier, there is a chance to enact biological citizenship (Rose & Novas, 2004).

For social workers it is vital to be aware of the personal and the political implications of an individualistic agenda on health care. An over emphasis of individual responsibility for all health matters might be ultimately problematic, in the same way that an individualistic perspective of social issues ignores the social structures that oppress and marginalize general populations.

Now that the Internet is integrated into everyday life for the majority of Canadians, all aspects of Internet use are affecting health management. The consequences of this are that people's sense of health is evolving and their relationships with health care providers reflect a disruption to traditional values. This dissertation began as an attempt to describe and understand health management in the age of the Internet and evolved into a story of people's familiarity and habitual inclusion of the Internet as a tool and resource welcomed in their most personal and private matters.

8.4 Implications for Social Work Policy and Practice

Social work is concerned with ensuring optimal outcomes for individuals and communities. The Code of Ethics of the Canadian Association of Social Workers (2005), the Practice Statement of the Canadian Association of Social Workers (2005), as well as The Code of Ethics of the National Association of Social Workers (2008) include statements endorsing the obligation of societal systems to provide equitable structural resources for all their members.

Managing health issues falls within the rubric of providing resources for clients. A better understanding of the processes of general population health management has the potential to effect social work knowledge, research and practice. It is important to recognize the value of Internet information as social workers take a more active role in the promotion of online tools for assistance with health management issues. As Internet use is an integrated part of everyday lives social workers can begin to explore the value of online relationships, issue specific connections and changes to relationships when

devising overarching policy for health practices. As with all solutions deemed a panacea for the population's health ills, the Internet is complex, the repercussions of use are multifaceted, leaving social work to proceed with caution and confidence.

I investigated the integration of information and communication technology into our everyday lives in the context of health management. Schoech (2010) argues, social workers need to think about the value of connectivity technology and the ways social workers can learn to advance service delivery. Connectivity technology allows for community and human service agencies to work together. Social workers need to learn the tools and processes to advance service delivery while they are thinking globally about service delivery. This contemporary view echoes the work of LaMendola (1987) who called social workers and social work educators to fulfill their appreciable role in the information society. LaMendola's latest work invites social workers to "engage intimately with the practices of everyday life, with where life flows" (LaMendola, 2010, p 117). He calls social workers to increase their "presence", which by the nature of the work is a social presence and become engaged on and offline. By expanding definitions of locations of association, social workers can be with people where their relationships form and build.

Based on the findings of this dissertation, social workers can refer clients to online resources, and acknowledge how the Internet based research provides a supportive encounter as well as a connection to other people and to direct services. Offering information to clients empowers them to take charge of their own health and to be active in their own health management strategies.

Additionally, this dissertation illustrates that individuals with serious health conditions will benefit from the added support and information available to them through the Internet. As such it is appropriate to promote Internet use for health issues, teach research techniques and inform clients of strategies for finding and interacting with online information.

E-therapy is an emerging context for social work practice for which practitioners need to be specifically trained (Murphy, MacFadden, & Mitchell, 2008) and need to attend to ethical standards (Santhiveeran, 2009). As people integrate Internet into health management – so too will they integrate Internet in to therapy and therapeutic processes.

By increasing awareness of online resources, social work clients who are isolated may benefit from online connections and relationships. Social workers can encourage participation in online environments even for the marginalized, rural and remote communities and for those who are recent immigrants and far from their families abroad.

Social work practitioners are gaining resources to empower clients to improve their doctor patient relationships as the distribution and access of online health information increases. By encouraging the use of online information searches as a means to improve communication between patients and medical health care professionals, social workers indirectly affect the balance of power in potentially oppressive relationships.

Similarly, when social workers witness and support patients to be empowered and engaged in their medically oriented relationships they acknowledge the new phase in the doctor patient relationship (Hardey, 2010). As user created online content increases in popularity, patients are engaging in this evolution by creating online commentary about

medical service providers. The private critiques of a once confidential and privileged relationship are now exposed. How this advancement will affect the conceptualizations and experiences of health and health care is yet to be determined.

Ultimately the implications of changes to health and health care provisions will advance in concert with policy creation. The results of this dissertation will inform health policy through better recognition of how people are integrating the Internet into their everyday lives. The continued proliferation of an individualistic stance towards health care and personal responsibility in the achievement of health do have interesting political implications.

As social workers mindful of the micro and the macro aspects of each social issue, the view that health is the individual's responsibility is potentially dangerous. We need to challenge assumptions that *all* health care is the responsibility of the individual. This may include speaking on behalf of the marginalized that are being blamed for their disease while advocating for those who do not recognize that they are under the influence of healthist attitudes. This generation of social workers needs to promote positive health outcomes for the individual while acting on behalf of the collective. Health might be expressed individually, but it can reflect the status of a community. If individuals are not thriving, likely the health of the community needs the attention.

8.5 Strengths, Limitations and Future Directions

As this dissertation reaches its close, it is valuable to acknowledge what was successfully accomplished during the research process, what the limitations were and

what could be improved in future research.

The research design and methodology were significant strengths of the project, as were the variables created for analysis. The Connected Lives Project gathered information about many different types of Internet use across a diverse population in East York, Ontario. By employing mixed methods I was able to examine the complex issue of health management that does not lend itself to one clear answer. The sequential design of the project lead me to first perform a quantitative analysis to describe the Internet usage patterns of the population and follow up with subjective accounts of participants daily life experience and personal strategies.

The development of the Subjective Health Status variable and the inclusion of the categorical variable of Health Category were helpful and served to differentiate across patterns of Internet use. These variables were created to assist with the examination of the relationship between presenting health issue and health management strategy. During my analysis, the emergence of healthist ideals present in the population were illuminated.

The qualitative analysis of the interview narratives helped me to understand the meaning Internet use has for people in their daily lives and helped me make sense of what people are actually doing with the health management processes. Each interview helps to contextualize people's behaviors and communication styles by bringing to life the research questions I based my analysis on. My methods and analysis allowed me to gain clarity regarding how Internet use in the context of health management affords an observable interaction between human and non-human actors where transformations can occur (Latour, 2005). Similarly, I was able to see how technology is influencing

relationships with oneself and others. Gergen (1996) and Turkle (2005) prepared me for the eventuality of a change to the experience and enactment of self and my research analysis confirmed these effects.

While the qualitative analysis of my data did establish patterns across individuals who are using the Internet for information and emotional support for their health concerns, my statistical analysis did not reveal many significant relationships. A further limitation was the size of my sample of people going online for emotional support for their health issues. While the narratives brought to life the experiences of engaging with the Internet for emotional support, the answers to the research question would be stronger with more cases. Additionally, I did not begin my investigation looking for evidence of healthism, rather it emerged during my analysis. Future qualitative research could consider the evidence or reflection of healthism in everyday health management.

A redesign of the Connected Lives Project in 2011 would reflect an amended research focus and would include new research questions. Building on what I learned during the Connected Lives Project, I would like to explore in more detail the interaction effects of using the Internet for health management on expressions of self and experiences of health. I would like to investigate the differences between medical concerns and health concerns and gather data accordingly. Since most of the population I researched did not have specific medical issues, but were more interested in Lifestyle issues, I think it would be worth pursuing an investigation of the differences in health management process across these two issues.

Health management processes are changing and the diversity of information

available online is evolving to include user created content in addition to the information provided by medical professionals. Future research would be well advised to consider if peer created content offering emotional support will be sought to the same degree as information coming from professionally recognized sources.

Research is beginning to emerge that considers the doctor patient relationship in light of the availability of online health information (see Caiata-Zuffery, et al., 2010). There is a recognition of an evolution within the patient physician relationship and the associated consequences of this, and I would like to pursue that course.

8.6 Final Thoughts

Since the inception of this dissertation and heath management processes are transforming at rate difficult to keep pace with. In 2005 when the Connected Lives Project was conceived, it was the early adopters and the newly web savvy who looked beyond their social networks for information and social support on the Internet.

Today, even the President of the United State of America, Barack Obama is adapting his health management process to include Internet technologies (Leonhardt, 2009). President Obama conducts online health research in advance so he is able to talk to, not argue with, his medical professional about his health issues. His story typifies the experience of the East York resident that looks up information in follow up to a medical appointment and does not argue with the doctor. Instead people, the President included, are taking some charge of their own health and being informed is certainly an expectation of personal health management now. The discourse with medical professionals is

evolving as the expectation of a collaborative relationship solidifies.

As I write this final chapter, health information is spread through Facebook and Twitter and emotional support for health concerns for chronic, acute and rare health conditions are not only readily available, referrals through medical websites are common practice. Not only has Web 2.0 gathered momentum, Health 2.0 exists as a phrase to refer to the significant shifts to health care provision and consumption.

The concept of Web 2.0 was first coined in October 2004 in a conference brainstorming session between Tim O'Reilly and MediaLive International. Web 2.0 describes a change in the way people interact with information online, moving from passive consumption to active creation of content. Web 2.0 software (such as weblogs, social networking sites, wikis, user reviews) harnesses network effects and knowledge in an open, interactive manner (O'Reilly, 2005; Scanfeld, Scanfeld, & Larson, 2010).

Health 2.0 similarly coined from a conference title encapsulates 'user-generated healthcare'. Patients are now called users and are guiding their health care with the use of Internet based tools (blogs, Podcasts, tagging, wikis, and others). These tools in turn are integrating into health care system. Doctors, patients, and health care organizations use a new generation of online and mobile technologies that are fundamentally changing the way health care works.

The proliferation of information and the normalization of health care concerns are evident as strangers share information, personal accounts and linking to media outlets to identify if health information is viable and accurate. During the 2009 global outbreak of H1N1, Facebook became a source of information for many of the social networking

website users. Within a few days, thousands of posts and links about the virus spread within the website and the official Facebook weblog became a repository for information where incorrect and misleading information was challenged and removed (Corner, 2009).

Twitter is another popular social media tool created and popularized post Web 2.0. Twitter is a form of blogging that allows users to send brief text updates to be viewed by the public or a restricted group of people such as a social network. According to a Pew Internet & American Life survey, 12% of e-patients use Twitter or another service to share health-related updates about themselves or to see others' health-related updates (Fox & Jones, 2009). Scanfeld (2010) conducted a content analysis of publicly available Twitter status updates in 2009 mentioning "antibiotics" to determine if incorrect or misunderstood information about antibiotics is present in the dissemination of health information through this web based communication tool. The researchers found that health information is shared extensively on such network predominately in the form of information about general use and the distribution of advice and information. To a lesser degree Twitter users describe a misunderstanding about antibiotics or referring misusing them. Scanfeld (2010) argues that it is important for health care professionals to gain an understanding of and familiarity with social networking media services to enhance their own practice.

Technology can enhance the ability to acquire social support by bringing people together giving and the strength of the collective to individuals. I relish the ability to conduct my own research and be the champion of my body and my health outcomes. However, this emerging practice reinforces notions that health is an individualistic

pursuit. Use of the Internet indirectly promotes a duality of enhanced collectivism and self-reliant individualism laden with both positive and negative consequences. Ideally, everyone is empowered to take charge of their health and live longer, better lives. In the worst case, social and structural forces that cause collective harm will be ignored as the onus for all health matters is put on the individual.

As a social worker I adhere to a practice that reflects a belief in the value of the collective. As an Internet user I recognize the debate of the utopian / dystopia effects of the Internet is fading. Balancing an awareness of the objective (empirical) / subjective (personal) variation across the effects of the Internet is essential and requires a duality exercised by all proficient social workers.

Everyone has a health story and corporeal curiosities. As such, people are increasing their engagement with health information. The future generation is here and they are web savvy researchers in homes without the medical book on the bookshelf. As Internet use becomes the norm and not the exception it leaves the work of this dissertation time stamped and obsolete. That being said, this work captures a moment when the Internet and online research and social support seeking was new and users still had trepidations. It encapsulates the appropriation of the Internet into everyday life, and the ways in which its use starts to transform the relationships in health management and in the relationship between physician and patients. This work represents a critical phase of transition in the intermingling between people and machines. Ultimately, I am hopeful that my dissertation will serve as a benchmark to see just how far we have travelled.

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Appendix A

The Connected Lives Project Survey

Guide to the Connected Lives Survey

Dear Participant,

To make answering our survey a more pleasurable experience for you, we offer you a "road map" of our survey and some useful tips for filling it out.

First of all, there are no right or wrong answers to our questions. We are interested in your personal opinions.

When answering our questions, please select answers based on your own experiences. If you do not find an answer that completely meets your experiences or opinions, please check the answer closest to it.

If your first language is not English, you might want to use the help of somebody else in putting down your answers. If you use somebody else's help, please remember that we are interested in your personal opinions and experiences, and not those of the person helping you.

As you fill out the survey, you will see little symbols to help you. Each question will also have brief instructions.

CHECKBOX: If you see some circles ○1 ☛2 ○3 please check One: ○2
(The little number next to the box is for technical reasons.)

SQUARE CHECKBOX: ☛1 ☐2 ☛3 Same as above, except you can check all that apply.

FILL-IN (1): If you see a ✎_____ please fill in a value: ✎ 15

FILL-IN (2): If you see [ ] then please fill in a value: [Parent]

QUESTION: ? means the start of a new question

GO TO : ☞ means you might go to a new section, for example:

○1 Yes
○2 No ☞ *If you answered* NO, *please* SKIP *the rest of this page and go to* PAGE 5

NOT APPLICABLE: Some questions may not apply to you. If possible, select the "not applicable" box instead of skipping the question.

MISTAKES: If you make a mistake, simply cross out the wrong answer and write/check the right answer.
For example: ☒1 Unsure ○2 No ☛3 Yes

Take Your Time and Enjoy

Section 1 - About You

1.1 What is your gender?
[*Please check* ONE *answer*]
○1 Male
○2 Female

1.2 What year were you born? [*Please write the* YEAR] 19___

1.3 What is your highest completed level of school?
[*Please check* ONE *answer*]
○1 Less than high school diploma
○2 High school diploma or G.E.D.
○3 College or technical school diploma
○4 Some university
○5 Undergraduate university degree
○6 Advanced university degree (such as Ph.D., Masters, law degree, medical degree)

1.4 Are you currently a student?
[*Please check* ONE *answer*]
○1 No
○2 Yes - full time
○3 Yes - part time

1.5 In what year did you begin living at your current address?
○0 Always lived at this address, or...
[*Please write the* YEAR] 19___ or 20___

1.6 In what year did you begin living in the Greater Toronto Area (G.T.A.)?
○0 Always lived in the Greater Toronto Area (G.T.A.), or...
[*Please write the* YEAR] 19___ or 20___

1.7 Which of the following do you live in?
○1 House (detached, semi-detached or town house)
○2 Apartment building, less than 5 floors
○3 Apartment building, 5 or more floors
○4 Other _____

When you need to find <u>telephone numbers</u>, how often do you use the following?
[*Please check* ONE *per row*]

		Daily	Weekly	Monthly	Less than monthly	I don't use this
1.8	The phone book	○1	○2	○3	○4	○7
1.9	An address book on my computer	○1	○2	○3	○4	○7
1.10	A personal address book (paper) or a 'Rolodex'	○1	○2	○3	○4	○7
1.11	"Post-Its" / scraps of paper / my hand	○1	○2	○3	○4	○7
1.12	A portable device like a Blackberry or Palm PDA	○1	○2	○3	○4	○7
1.13	Numbers saved on my phone	○1	○2	○3	○4	○7
1.14	Asking someone else who might know	○1	○2	○3	○4	○7
1.15	Searching the Internet	○1	○2	○3	○4	○7
1.16	My memory	○1	○2	○3	○4	○7
1.17	Other _____(1.17a)	○1	○2	○3	○4	○7

To <u>remember occasions or plan your day</u>, how often do you use the following?
[*Please check* ONE *per row*]

		Daily	Weekly	Monthly	Less than monthly	I don't use this
1.18	Wall calendar in my home	○1	○2	○3	○4	○7
1.19	A "day timer" or agenda	○1	○2	○3	○4	○7
1.20	A portable device like a Blackberry or Palm PDA	○1	○2	○3	○4	○7
1.21	A pocket or wallet calendar	○1	○2	○3	○4	○7
1.22	My memory	○1	○2	○3	○4	○7
1.23	"Post-its" / scraps of paper / my hand	○1	○2	○3	○4	○7
1.24	A computer program	○1	○2	○3	○4	○7
1.25	My assistant	○1	○2	○3	○4	○7
1.26	Reminders from others	○1	○2	○3	○4	○7
1.27	Other _____(1.27a)	○1	○2	○3	○4	○7

SECTION 2 - YOUR COMPUTER USE

2.1 Do you currently have a computer in your home?

○1 Yes
○2 No ☞

If you answered NO, *please* SKIP *the rest of this page and go to* PAGE 7

2.* Who maintains your home computer day-to-day?
[*Please check* ALL *that apply*]

I do		☐2
My spouse / partner		☐3
	Male	Female
Child(ren)	☐4	☐5
Friends	☐6	☐7
Relatives	☐8	☐9
Neighbours	☐10	☐11
Technician	☐12	☐13
Other _____(2.15a)	☐14	☐15

Please tell us about your computer skills...
[*Please check only* ONE *per row*]

		Easily	With some difficulty	With help from someone I know	With help from a technician	I don't know what you mean by this
2.16	Using a word processor (such as Microsoft Word, WordPerfect, Wordpad)	○1	○2	○3	○4	○7
2.17	Using an Internet browser (such as Internet Explorer, Netscape)	○1	○2	○3	○4	○7
2.18	Downloading a file (music, picture, story) from the Internet	○1	○2	○3	○4	○7
2.19	Installing a program	○1	○2	○3	○4	○7
2.20	Protecting my computer against viruses	○1	○2	○3	○4	○7
2.21	Upgrading my operating system (for example, from Windows 98 to XP)	○1	○2	○3	○4	○7
2.22	Installing a home network	○1	○2	○3	○4	○7

Section 3: Your Internet Use

☞ *In this survey,* INTERNET *refers to all online activities, such as email, instant messaging, surfing the web / using Internet Explorer, chat rooms, etc...*

3.1 Have you ever used the Internet? [*Please check* ONE *answer*]

○1 Yes
○2 No ☞

If answered NO, please SKIP *the rest of this page and go to* PAGE 10

3.2 What was the first year you used the Internet?
[✎ *Please write the* YEAR] 19___ or 20___

3.3 Do you currently have Internet access at home? [*Please check* ONE *answer*]

○1 No
○2 Yes →

3.4 How do you connect to the Internet from home?
○1 Dial-up access (ties up the phone line)
○2 High speed (Such as Rogers Hi-Speed or Bell Sympatico High Speed)
○3 Other: ✎ _____(3.4a)

3.5 Do you have a home network (i.e. more than one computer can be online at the same time)?
○1 Yes ○2 No ○9 Not Applicable (One computer in my house OR no Internet at home)

How often do you go on the Internet from home and work/school ?
[*Please check only* ONE *per row*]

		Never	Less than monthly	About Monthly	About Weekly	About Daily	All Day
3.6	Home	○1	○2	○3	○4	○5	○6
3.7	Work / school	○1	○2	○3	○4	○5	○6

What <u>times of day</u> do you use the Internet from home and work/school?
[*Please check* **ALL** *that apply*]

		Early morning 5-8am	Morning 8am-Noon	Afternoon Noon-6pm	Evening 6-11pm	Late night 11pm-5am	Not applicable
3.8	Home	□1	□2	□3	□4	□5	□9
3.9	Work/school	□1	□2	□3	□4	□5	□9

3.10a,b For each of home and work/school, please underline the square for when you <u>use the Internet the most</u>.

During a typical week, about how many hours do you actively use the Internet from home, and from work/school?

[*Please write the* NUMBER *of hours per week on EVERY line that applies*]
[*If you are not working and not in school, please check* "Not applicable", *and fill out for home only.*]

		# of hours ➔	Home	Work / school ○99 Not applicable
3.11-2	Overall Internet use		#_____	#_____
3.13-4	For work/ school		#_____	#_____
3.15-6	For general information		#_____	#_____
3.17-8	Finding product information or shopping		#_____	#_____
3.19-20	For health information		#_____	#____
3.21-2	Communicating with others		#_____	#_____

In general, how much has the Internet affected the following?

[*Please check only* ONE *per row*]

		Made it much more difficult	Made it somewhat more difficult	Has not affected it	Made it somewhat easier	Made it much easier	Don't use the Internet for this
3.23	Getting health care information	○1	○2	○3	○4	○5	○7
3.24	Shopping	○1	○2	○3	○4	○5	○7
3.25	Managing money	○1	○2	○3	○4	○5	○7
3.26	Connecting with household members	○1	○2	○3	○4	○5	○7
3.27	Connecting with relatives	○1	○2	○3	○4	○5	○7
3.28	Connecting with friends	○1	○2	○3	○4	○5	○7
3.29	Meeting new people	○1	○2	○3	○4	○5	○7
3.30	Learning about new things	○1	○2	○3	○4	○5	○7
3.31	The way you work	○0	○1	○2	○3	○4	○7

3.32 How much would you miss going on the Internet, if you could no longer do so?

○1 Very much
○2 Somewhat
○3 Very little
○4 Not at all

3.33 How many email accounts do you have that you use regularly? [*Please check* ONE]

○0 ○1 ○2 ○3 ○4 ○5 or more

During a typical week, <u>how many emails</u> do you send from home, and from work/school?

[*Please write the* NUMBER *of emails on EVERY line*]

[*Not working and not in school, please check* "Not applicable"*, and fill out for home only.*]

	# of emails: ➔	Home	Work / School ○99 Not applicable
3.34,35	To household members	#_____	#_____
3.36,37	To relatives	#_____	#_____
3.38,39	To friends	#_____	#_____
3.40,41	Work / school related	#_____	#_____

When you need to find <u>email addresses,</u> how often do you use the following?

[*Please check* ONE *per row*]

		Daily	Weekly	Monthly	Less than monthly	I don't use this
3.42	Email program automatically completes addresses	○1	○2	○3	○4	○7
3.43	A personal address book (paper) or a 'Rolodex'	○1	○2	○3	○4	○7
3.44	Search address book on my computer	○1	○2	○3	○4	○7
3.45	Address book on my Blackberry or PDA	○1	○2	○3	○4	○7
3.46	My memory	○1	○2	○3	○4	○7
3.47	Use address from an existing message	○1	○2	○3	○4	○7
3.48	Ask someone else who might know	○1	○2	○3	○4	○7
3.49	"Post-its" / scraps of paper / my hand	○1	○2	○3	○4	○7
3.50	Search for address on the Internet	○1	○2	○3	○4	○7

3.51-53 Have you ever used the Internet to communicate about <u>physical health or mental health</u>?

[*Please check* ALL *that apply*]

With a doctor or other health care professional No □1 Yes □2

With friends or family members No □1 Yes □2

With other people with similar health care issues No □1 Yes □2

SECTION 4 - YOUR JOB

4.1 What is your current employment status?
[*Please check* ONE *and fill out the question* NEXT *to your answer*]

○1 Not employed →

4.2 Which of the following best describes your situation?
- ○1 Between jobs / unemployed
- ○2 Full-time homemaker
- ○3 Student
- ○4 Retired
- ○5 Disability / long-term leave
- ○6 Other: (Please specify) ✎_____(4.2a)

☞ *If you are not currently employed, please* SKIP *the rest of this page and go to* PAGE 13

○2 Self-employed →

4.3 Do you employ other people?
- ○1 No
- ○2 Yes **How many?** ✎#_____ (4.3a)

4.3b How many clients / customers do you have in a year?
✎#_____ or ○9999 Not applicable

○3 Employee →

4.4 About how many people does your company employ?
[*Please check* ONE *answer*]
- ○1 1-24 employees
- ○2 25-99 employees
- ○3 100-499 employees
- ○4 500 or more employees

4.5 Do you have a second paid job?
[*Please check* ONE *answer*]
- ○1 No
- ○2 Yes - second job is self-employed
- ○3 Yes - second job is an employee

4.6,7 What is your paid occupation?

[If you have MORE THAN TWO JOBS*, please refer to the two jobs you consider* MOST IMPORTANT. *]*

Main job _____

Second job _____

4.8,9 On average, how many hours per week do you work?

Main job #_____ hours per week

Second job #_____ hours per week

During a typical week, what percentage of your work time is spent at the following places?

4.10 %_____ Working at home

4.11 %_____ At a regular workplace outside the home (such as office, factory, shop)

4.12 %_____ Travelling (for example, to job sites, clients, business trips)

4.13 %_____ At someone else's regular workplace (such as client's office, trade show, supplier's office)

4.14 Do you have an email account for work?

[*Please check* ONE *answer*]

○1 No

○2 Yes - exclusively for work

○3 Yes - for work and other reasons

4.15 Do you do any paid work at home?

[*Please check* ONE *answer*]

○1 Yes

○2 No ☞ *If* NO *then please* SKIP the rest of *this page and go to* PAGE 13

4.16,7 On average, how many <u>hours per week</u> do you work AT HOME?

Main job #_____ hours at home per week

Second job #_____ hours at home per week

4.* Is your work at home...

[*Please check* ALL *that apply*]

☐18 Related to your main job
☐19 Related to your second job

4.* Is your work at home...

[*Please check* ALL *that apply*]

☐1 Overtime
☐1 Regular work instead of going to another workplace

4.* What are your main reasons for working at home?

[*Please check* ALL *that apply*]

☐22 It is a requirement of the job
☐23 To catch up with work
☐24 Better working conditions at home
☐25 To avoid commuting
☐26 It saves time
☐27 It saves money
☐28 Childcare
☐29 Other family responsibilities
☐30 For my health
☐31 Other: ✎_____(4.31a)

[PLEASE LOOK AGAIN AT YOUR ANSWERS ABOVE
AND CIRCLE THE MOST IMPORTANT REASON FOR WORKING AT HOME]

4.*. Thinking about a typical day when you work at home:
How many times per DAY while you are home...

DO YOU CONTACT
people related to work:

ARE YOU CONTACTED BY
people related to work:

[*Write a* NUMBER *below for each activity* **even if** *you do it* **zero** *times during a typical day*]

32 I set up conference calls ✎#_____ times
33 I invite work contacts home ✎#_____ times
34 I send a fax ✎#_____ times
35 I start an instant messaging session ✎#_____ times
36 I phone ✎#_____ times
37 I leave voice mail ✎#_____ times

38 They set up conference calls ✎#_____ times
39 They invite me to their home for work ✎#_____ times
40 They send me a fax ✎#_____ times
41 They start an instant messaging session ✎#_____ times
42 They send work-related email ✎#_____ times
43 They phone ✎#_____ times
44 They leave voice mail ✎#_____ times

SECTION 5 - YOUR SPOUSE / PARTNER

5.1 What is your current relationship status?
[*Please check* ONE *answer*]

- ○ 1 Married
- ○ 2 Common-law
- ○ 3 Long-term relationship
- ○ 4 Single ☞
- ○ 5 Divorced ☞
- ○ 6 Widowed ☞
- ○ 7 Separated ☞

If you are currently single, divorced, widowed or spearated, please SKIP *the rest of this page and go to* PAGE 15.

5.2 Do you live with your spouse/partner? [*Please check* ONE *answer*]

- ○ 1 No
- ○ 2 Yes → **5.3 What year did you begin living together?**
  [✎ *Please write the* YEAR] 19___ or 20___

5.4 What is your spouse/partner's gender? [*Please check* ONE *answer*]

- ○ 1 Male
- ○ 2 Female

5.6 What is your spouse/partner's highest completed level of school?
[*Please check* ONE *answer*]

- ○ 1 Less than high school diploma
- ○ 2 High school diploma or G.E.D.
- ○ 3 College or technical school diploma
- ○ 4 Some university
- ○ 5 Undergraduate university degree
- ○ 6 Advanced university degree (such as Ph.D, Masters, law degree, medical degree)

5.7 Which of the follow best describes your spouse / partner's employment status?
[*Please check only* ONE *answer*]

- ○ 01 Self-employed
- ○ 02 Employed full-time
- ○ 03 Employed part-time
- ○ 04 Between jobs / unemployed
- ○ 05 Full-time homemaker
- ○ 06 Student
- ○ 07 Retired
- ○ 08 Disability / long-term leave
- ○ 09 Other: (Please specify) ✎ _____ (5.7a)

5.8 What is your spouse / partner's main occupation? ✎ _____

During a typical <u>week</u>, how many <u>hours do you spend</u> with your spouse/partner...

[*Please check* ONE *per row*]

	# of hours:	0	1-4	5-8 (average 1 hour /day)	9-12	13-16 (average 2 hours /day)	17-20	21+
5.9	Overall (not including sleep)	○1	○2	○3	○4	○5	○6	○7
5.10	Watching TV	○1	○2	○3	○4	○5	○6	○7
5.11	Using the Internet	○1	○2	○3	○4	○5	○6	○7
5.12	Doing other recreational things	○1	○2	○3	○4	○5	○6	○7

How often do you...

[*Please check* ONE *per row]*

		Not Applicable	Never	Less than monthly	About Monthly	About Weekly	About Daily
5.13	Call your spouse/partner from a cell phone	○9	○1	○2	○3	○4	○5
5.14	Call your spouse/partner from a regular phone	○9	○1	○2	○3	○4	○5
5.15	Email your spouse/partner when you are both in the same house	○9	○1	○2	○3	○4	○5
5.16	Email your spouse/partner when you are NOT in the same house	○9	○1	○2	○3	○4	○5
5.17	Instant message your spouse/partner when you are both in the same house	○9	○1	○2	○3	○4	○5
5.18	Instant message your spouse/partner when you are NOT in the same house	○9	○1	○2	○3	○4	○5

SECTION 6 - YOUR CHILDREN

6.1 Do you have any children? [*Please check* ONE *answer*]

○ 1 Yes
○ 2 No ☞

If you answered NO, *please* SKIP *the rest of this page and go to* PAGE 17

Please fill out following chart: Start with the oldest child. If you have more than 4, please fill out for the 4 oldest. For each child,

(1) **What are their ages? [For example: "6"]**
(2) **What is their gender?**
(3) **Are they living with you?**
(4) **What is the highest schooling they've completed?** [**For example: "primary" / "high school"**]
(5) **Do they have cell phones?**
(6) Are they experienced computer users?

		Age	Gender	Lives at home	Highest schooling completed	Has a cell phone	Experienced computer user
6.2-7	First Child	[ ]	○ 1 Male ○ 2 Female	○ 1 Yes ○ 2 No	[ ]	○ 1 Yes ○ 2 No	○ 1 Yes ○ 2 No
6.8-13	Second Child	[ ]	○ 1 Male ○ 2 Female	○ 1 Yes ○ 2 No	[ ]	○ 1 Yes ○ 2 No	○ 1 Yes ○ 2 No
6.14-19	Third Child	[ ]	○ 1 Male ○ 2 Female	○ 1 Yes ○ 2 No	[ ]	○ 1 Yes ○ 2 No	○ 1 Yes ○ 2 No
6.20-25	Fourth Child	[ ]	○ 1 Male ○ 2 Female	○ 1 Yes ○ 2 No	[ ]	○ 1 Yes ○ 2 No	○ 1 Yes ○ 2 No

During a typical week, in total how many hours do you spend with your child(ren)...
[*Please check only* ONE *per row*]

	# of hours: ➔	0	1-4	5-8 (average 1 hour /day)	9-12	13-16 (average 2 hours /day)	17-20	21+
6.38	Overall (not including sleep)	○1	○2	○3	○4	○5	○6	○7
6.39	Watching TV	○1	○2	○3	○4	○5	○6	○7
6.40	Using the Internet	○1	○2	○3	○4	○5	○6	○7
6.41	Doing other recreational things	○1	○2	○3	○4	○5	○6	○7

How often do you....
[*Please check only* ONE *per row*]

		Not Applicable	Never	Less than monthly	About Monthly	About Weekly	About Daily
6.26	Call your child(ren) from a cell phone	○9	○1	○2	○3	○4	○5
6.27	Call your child(ren) from a regular telephone	○9	○1	○2	○3	○4	○5
6.28	Email your child(ren) when you are both in the same house	○9	○1	○2	○3	○4	○5
6.29	Email your child(ren) when you are NOT in the same house	○9	○1	○2	○3	○4	○5
6.30	Instant message your child(ren) when you are both in the same house	○9	○1	○2	○3	○4	○5
6.31	Instant message your child(ren) when you are NOT in the same house	○9	○1	○2	○3	○4	○5

6.* At home, who is mainly responsible for monitoring your child(ren)'s Internet use?
[*Please check* ALL *that apply*]

☐9 Not applicable - we do not have the Internet at home
☐32 My child(ren) monitor themselves
☐33 I monitor my children
☐34 My spouse/partner monitors the children
☐35 We are equally responsible for monitoring
☐36 We use computer software to monitor the children
☐37 Other:_____(6.37a)

SECTION 7 - OTHER HOUSEHOLD MEMBERS

If your household consists only of you, a spouse/partner and/or children, please SKIP *this page and go to* PAGE 18.

In this section, we would like to know a little bit about any other people who live in your home and share the SAME KITCHEN with you.

Please fill out this chart for the 4 oldest household members that have not been mentioned yet, starting with the oldest. For each member,

(1) **How old are they? [For example: "39"]**
(2) **What is their gender?**
(3) **What is their relations to you? [For example: "grandmother", "roommate"]**
(4) **Do they have cell phones?**
(5) Are they experienced computer users?

		Age	Gender	Relation to you	Has a cell phone	Experienced computer user
7.1-5	Member 1	[ ]	○1 Male ○2 Female	[ ]	○1 Yes ○2 No	○1 Yes ○2 No
7.6-10	Member 2	[ ]	○1 Male ○2 Female	[ ]	○1 Yes ○2 No	○1 Yes ○2 No
7.11-15	Member 3	[ ]	○1 Male ○2 Female	[ ]	○1 Yes ○2 No	○1 Yes ○2 No
7.16-20	Member 4	[ ]	○1 Male ○2 Female	[ ]	○1 Yes ○2 No	○1 Yes ○2 No

Household Jobs

During a typical week, how many hours do you spend at home doing the following...

[*Please check only* ONE *per row*]

	# of hours: ➔	0	1-4	5-8 (average 1 hour /day)	9-12	13-16 (average 2 hours /day)	17-20	21+
7.21	Household chores and cleaning	○1	○2	○3	○4	○5	○6	○7
7.22	Cooking and baking	○1	○2	○3	○4	○5	○6	○7
7.23	Yard work and gardening	○1	○2	○3	○4	○5	○6	○7
7.24	Home repair and maintenance	○1	○2	○3	○4	○5	○6	○7
7.25	Childcare	○1	○2	○3	○4	○5	○6	○7

During a typical week, how many hours does your spouse/partner spend at home doing the following...

[*Please check only* ONE *per row*]

○9 Not Applicable *(skip the table and go to the question below)*

	# of hours: ➔	0	1-4	5-8 (average 1 hour /day)	9-12	13-16 (average 2 hours /day)	17-20	21+
7.26	Household chores and cleaning	○1	○2	○3	○4	○5	○6	○7
7.27	Cooking and baking	○1	○2	○3	○4	○5	○6	○7
7.28	Yard work and gardening	○1	○2	○3	○4	○5	○6	○7
7.29	Home repair and maintenance	○1	○2	○3	○4	○5	○6	○7
7.30	Childcare	○1	○2	○3	○4	○5	○6	○7

7.31 Does someone else in the household do these tasks?

[*Please check* ONE *answer*]

○1 No

○2 Yes ➔ **7.32 If YES: What is this person's relation to you?**

_____

During a typical week how do you do the the following, and how long does it take you?

[*Please check* ALL *that apply &* TOTAL HOURS *per week*]

	Yourself	Online	Phone	In person	Total hours per week
7.*	Keeping in touch with friends	☐33	☐34	☐35	→ 36 #_____
7.*	Keeping in touch with family	☐37	☐38	☐39	→ 40 #_____
7.*	Arranging social events with family or friends	☐41	☐42	☐43	→ 44 #_____
7.*	Shopping	☐45	☐46	☐47	→ 48 #_____
7.*	Taking care of finances	☐49	☐50	☐51	→ 52 #_____

During a typical week, how does your spouse/partner do the following, and how long does it take?

[*Please check* ALL *that apply &* TOTAL HOURS *per week*]

○9 Not Applicable - *I don't have a spouse/partner (skip the table and go to the question below)*

	Your spouse/partner	Online	Phone	In person	Total hours per week
7.*	Keeping in touch with friends	☐53	☐54	☐55	→ 56 #_____
7.*	Keeping in touch with family	☐57	☐58	☐59	→ 60 #_____
7.*	Arranging social events with family or friends	☐61	☐62	☐63	→ 64 #_____
7.*	Shopping	☐65	☐66	☐67	→ 68 #_____
7.*	Taking care of finances	☐69	☐70	☐71	→ 72 #_____

7.* Does someone else in the household do these tasks?

[*Please check* ALL *that apply*]

☐0 No

☐73 Yes, online →

☐74 Yes, by phone →

☐75 Yes, in person →

7.76 What is this person's relation to you?

_____

Section 8 - Communicating with Household Members

Please write the number of devices in each of the following rooms...
[*Please write the NUMBER in each space*]

		Telephones	TVs	Personal computers
8.1-3	Kitchen	#_____	#_____	#_____
8.4-6	Rec room / family room	#_____	#_____	#_____
8.7-9	Office / study	#_____	#_____	#_____
8.10-12	Living room	#_____	#_____	#_____
8.13-15	Master bedroom	#_____	#_____	#_____
8.16-18	Child(ren)'s bedroom (If there is more than 1 room, write the total for all bedrooms)	#_____	#_____	#_____
8.19-22	Other 1: (such as spare bedroom) _____(8.19)	#_____	#_____	#_____
8.23-26	Other 2: _____(8.23)	#_____	#_____	#_____

If you DO NOT *have Internet access at home, then please* SKIP the rest of this page and go *to* PAGE 21

Please indicate how much you agree with the following...
[*Please check only* ONE *box per row*]

		Strongly agree	Agree	Neutral	Disagree	Strongly disagree	Not applicable
8.27	Emailing has improved how I communicate with household members	○1	○2	○3	○4	○5	○9
8.28	Instant messaging has improved how I communicate with household members	○1	○2	○3	○4	○5	○9
8.29	The Internet has replaced time together as a household	○1	○2	○3	○4	○5	○9

		Never	Some of the time	About half of the time	Most of the time	All of the time
8.30	Are there disagreements among household members about who gets to use the Internet?	○1	○2	○3	○4	○5
8.31	Are there disagreements among household members about someone using the Internet too much?	○1	○2	○3	○4	○5
8.32	Do household members interrupt you when you are on the Internet at home?	○1	○2	○3	○4	○5

Section 9 - Your Personal Community

In this section, we are interested in learning about how you spend time with people **outside your household.**

How often do you...? [*Please check only* ONE *per row*]

		Daily	A few times a week	Once a week	A few times a month	Monthly or less	Never
9.1	Attend a regularly scheduled meeting such as a sports league, volunteer organization, or church group	○1	○2	○3	○4	○5	○6
9.2	Go to a regular hangout where you will know people (for example: a community centre, bar, mall, or coffee shop)	○1	○2	○3	○4	○5	○6
9.3	Drop into someone's house unannounced (or call just a few minutes ahead of time)	○1	○2	○3	○4	○5	○6
9.4	Have a conversation with your neighbours	○1	○2	○3	○4	○5	○6
9.5	Talk to people in an online chat room	○1	○2	○3	○4	○5	○6

9.6 Which best describes how you spend your leisure time with people outside your household?

[*Please check* ONE *answer*]

○1 Spend most of my leisure time by myself
○2 Spend most of it with just one or two people, who are usually the same people
○3 Spend most of it with just one or two people, who change from day to day
○4 Spend most of it with a single group of people
○5 Divide my time among different groups of people

Please think about the people currently in your life who do not live with you. We would like you to consider those who you are VERY close to, and those who you are SOMEWHAT close to.

VERY CLOSE:
- Those that you discuss important matters with,
- Those that you regularly keep in touch with, or
- Those who are there for you if you need help.

SOMEWHAT CLOSE:
- More than just casual acquaintances, but not 'very close'.

In this section you'll find it helpful to use the attached tear-off worksheet. There is no need to return the worksheet with the survey.

About how many people are you VERY close to?
About how many people are you SOMEWHAT close to?

[*Count each person only* ONCE, *use the* WORKSHEET *to remember names*]
[Please count *only people* OUTSIDE *your HOME*]

		VERY close	SOMEWHAT close
9.7,8	Members of your **immediate family** who don't live with you (such as parents, siblings, children)	#_____	#_____
9.9,10	Other **relatives**	#_____	#_____
9.11-2	Neighbours	#_____	#_____
9.13-4	People you currently **work** with, or go to school with	#_____	#_____
9.15-6	People you know only **online**	#_____	#_____
9.17-8	People from **organizations** (such as church, sports leagues, business associations)	#_____	#_____
9.19-20	**Friends** not included above	#_____	#_____
9.21-2	**Other people** not included above Relationship to you: [ ](9.22a)	#_____	#_____

The next few pages will be about these two types of people - those you feel VERY close to and those you feel SOMEWHAT close to. Please refer to the worksheet if you need to refresh your memory.

[*Please write the NUMBER in each space*]

	About how many of these two types of people are...	VERY close	SOMEWHAT close
9.23-4	Women	#_____	#_____
9.25-6	Men	#_____	#_____

	About how many of these two types of people...	VERY close	SOMEWHAT close
9.27-8	Live in Canada and more than an hour's travel away	#_____	#_____
9.29-30	Live outside of Canada	#_____	#_____

	About how many of these two types of people...	VERY close	SOMEWHAT close
9.31-2	Do you call by **cell phone**, typically at least once a week	#_____	#_____
9.33-4	Do you call by **cell phone**, typically between once a week and once a month	#_____	#_____
9.35-6	Do you call by **telephone**, typically at least once a week	#_____	#_____
9.37-8	Do you call by **telephone**, typically between once a week and once a month	#_____	#_____
9.39-40	Do you send an **email** to, typically at least once a week	#_____	#_____
9.41-2	Do you send an **email** to, typically between once a week and once a month	#_____	#_____
9.43-4	Do you send an **instant message** to, typically at least once a week	#_____	#_____
9.45-6	Do you send an **instant message** to, between once a week and once a month	#_____	#_____
9.47-8	Do you talk with **face to face**, typically at least once a week	#_____	#_____
9.49-50	Do you talk with **face to face**, typically between once a week and once a month.	#_____	#_____
9.51-2	Meet you at a **bar or restaurant**, typically at least once a week	#_____	#_____
9.53-4	Meet you at a **bar or restaurant**, typically between once a week and once a month	#_____	#_____
9.55-6	**Visit you at home** (or will have you as a visitor), typically at least once a week.	#_____	#_____
9.57-8	**Visit you at home** (or will have you as a visitor), typically between once a week and once a month	#_____	#_____

Think about planning with all of the people who are VERY close. In total, how often do you do the following...

[*Please check only* ONE *per row*]

	VERY Close	About Daily	A few times a week	Once a week	A few times a month	Monthly or less	Never
9.59	Make plans in person	○1	○2	○3	○4	○5	○6
9.60	Make plans by cell phone (voice)	○1	○2	○3	○4	○5	○6
9.61	Make plans by cell phone (text)	○1	○2	○3	○4	○5	○6
9.62	Make plans by regular phone	○1	○2	○3	○4	○5	○6
9.63	Make plans by email	○1	○2	○3	○4	○5	○6
9.64	Make plans by instant messaging	○1	○2	○3	○4	○5	○6
9.65	Reschedule your plans	○1	○2	○3	○4	○5	○6
9.66	Break your plans	○1	○2	○3	○4	○5	○6
9.67	Forget to meet someone	○1	○2	○3	○4	○5	○6
9.68	Arrive late	○1	○2	○3	○4	○5	○6

Think about planning with all of the people who are SOMEWHAT close. In total, how often do you do the following...

[*Please check only* ONE *per row*]

	SOMEWHAT Close	About Daily	A few times a week	Once a week	A few times a month	Monthly or less	Never
9.69	Make plans in person	○1	○2	○3	○4	○5	○6
9.70	Make plans by cell phone (voice)	○1	○2	○3	○4	○5	○6
9.71	Make plans by cell phone (text)	○1	○2	○3	○4	○5	○6
9.72	Make plans by regular phone	○1	○2	○3	○4	○5	○6
9.73	Make plans by email	○1	○2	○3	○4	○5	○6
9.74	Make plans by instant messaging	○1	○2	○3	○4	○5	○6
9.75	Reschedule your plans	○1	○2	○3	○4	○5	○6
9.76	Break your plans	○1	○2	○3	○4	○5	○6
9.77	Forget to meet someone	○1	○2	○3	○4	○5	○6
9.78	Arrive late	○1	○2	○3	○4	○5	○6

When talking with people you are VERY close to, how often do you get new information about...
[*Please check only* ONE *box per row*]

	VERY Close	About Daily	About Weekly	About Monthly	Less than monthly	I do not discuss this
9.79	Political issues	○1	○2	○3	○4	○5
9.80	Musicians or musical groups	○1	○2	○3	○4	○5
9.81	Restaurants	○1	○2	○3	○4	○5
9.82	Movies	○1	○2	○3	○4	○5
9.83	Books	○1	○2	○3	○4	○5
9.84	Issues related to your job	○1	○2	○3	○4	○5

When talking with people SOMEWHAT close, how often do you get new information about...
[*Please check only* ONE *box per row*]

	SOMEWHAT Close	About Daily	About Weekly	About Monthly	Less than monthly	I do not discuss this
9.85	Political issues	○1	○2	○3	○4	○5
9.86	Musicians or musical groups	○1	○2	○3	○4	○5
9.87	Restaurants	○1	○2	○3	○4	○5
9.88	Movies	○1	○2	○3	○4	○5
9.89	Books	○1	○2	○3	○4	○5
9.90	Issues related to your job	○1	○2	○3	○4	○5

Do you know someone VERY close or SOMEWHAT close who does any of the following jobs?

[*Please check* ALL *that apply*]

		VERY close	SOMEWHAT close
9.*	Lawyer	☐91	☐92
9.*	Truck driver	☐93	☐94
9.*	Pharmacist	☐95	☐96
9.*	Janitor or caretaker	☐97	☐98
9.*	Engineer	☐99	☐100
9.*	Cashier	☐101	☐102
9.*	Waiter or waitress	☐103	☐104
9.*	Carpenter	☐105	☐106
9.*	Computer programmer	☐107	☐108
9.*	High school teacher	☐109	☐110
9.*	Human resources manager	☐111	☐112

How many of the following people know each other?

[*Please check only* ONE *per row*]

		None know each other	Only some know each other	About half know each other	Most know each other	They all know each other
9.113	Only the people you feel SOMEWHAT close to	○1	○2	○3	○4	○5
9.114	Only the people you feel VERY close to	○1	○2	○3	○4	○5
9.115	ALL of these people TOGETHER	○1	○2	○3	○4	○5

SECTION 10: YOUR CULTURAL HERITAGE

While many people in Canada view themselves as Canadians, to what ethnic or cultural group did your ancestors belong? (For example, English, Chinese, East Indian, or French)

[*If they belonged to more than one group, please list the 1 or 2 ethnic groups that you most closely identify with*]

10.1 _____

10.2 _____

Thinking again of the people you are **Very** close to or **Somewhat** close to...

About how many of these people are your own ethnicity?	VERY close	SOMEWHAT close
10.3-4	#_____	#_____

[*Please write the NUMBER in each space* **even if** *the number is* **zero**]

Not including those of your own ethnicity, about how many of these people are...		VERY close	SOMEWHAT close
10.5-6	Hispanic or Latino	#_____	#_____
10.7-8	South Asian (such as Indian, Pakistani, Sri Lankan)	#_____	#_____
10.9-10	East Asian (such as Chinese, Filipino, Korean, Thai)	#_____	#_____
10.11-12	Middle Eastern (such as Lebanese, Iranian)	#_____	#_____
10.13-14	First Nations, Inuit, Métis	#_____	#_____
10.15-16	Black or African-Canadian	#_____	#_____
10.17-18	White	#_____	#_____
10.19-20	Other _____(10.20a)	#_____	#_____

10.20b What language do you speak most often at home?

○0 English, or...

[Please write the language] _____

10.21 In what country were you born?

○0 Canada, or...

[Please write the country]

_____ and... →

10.22 What year did you arrive in Canada?

[*Please write the* YEAR]

19___ or 20___

Section 11 - Social Support

This section is about the help you receive from and give to others.

Please look at the following situations.
Circle the groups of people who you would receive help from, and who you would give help to.

[*For this page, please* CIRCLE *ALL That Apply*]
[*Use the WORKSHEET to refresh your memory*]

	HouseHold members	Immediate Family	Other Relatives	Neighbours	or go to School with	currently Work with	know only oNLine	from oRGanizations	Other FRiends	OTher
Advice on important matters										
Receive advice from	HH_0	IF_1	OR_2	N_3	WS_4	NL_5	RG_6	FR_7	OT_8	
Give advice to	HH_{10}	IF_{11}	OR_{12}	N_{13}	WS_{14}	NL_{15}	RG_{16}	FR_{17}	OT_{18}	
Advice about new job opportunities										
Receive advice from	HH_{20}	IF_{21}	OR_{22}	N_{23}	W_{24}	NL_{25}	RG_{26}	FR_{27}	OT_{28}	
Give advice to	HH_{30}	IF_{31}	OR_{32}	N_{33}	WS_{34}	NL_{35}	RG_{36}	FR_{37}	OT_{38}	
Care for a serious health condition										
Receive care from	HH_{40}	IF_{41}	OR_{42}	N_{43}	WS_{44}	NL_{45}	RG_{46}	FR_{47}	OT_{48}	
Provide care to	HH_{50}	IF_{51}	OR_{52}	N_{53}	WS_{54}	NL_{55}	RG_{56}	FR_{57}	OT_{58}	
Help with home renovations										
Receieve help from	HH_{60}	IF_{61}	OR_{62}	N_{63}	WS_{64}	NL_{65}	RG_{66}	FR_{67}	OT_{68}	
Give help to	HH_{70}	IF_{71}	OR_{72}	N_{73}	WS_{74}	NL_{75}	RG_{76}	FR_{77}	OT_{78}	
Help looking for information about a health issue										
Receive help from	HH_{80}	IF_{81}	OR_{82}	N_{83}	WS_{84}	NL_{85}	RG_{86}	FR_{87}	OT_{88}	
Give help to	HH_{90}	IF_{91}	OR_{92}	N_{93}	WS_{94}	NL_{95}	RG_{96}	FR_{97}	OT_{98}	
Advice on using a personal computer										
Receive advice from	HH_{100}	IF_{101}	OR_{102}	N_{103}	WS_{104}	NL_{105}	RG_{106}	FR_{107}	OT_{108}	
Give advice to	HH_{110}	IF_{111}	OR_{112}	N_{113}	WS_{114}	NL_{115}	RG_{116}	FR_{117}	OT_{118}	
To be there just to talk about the day										
They will be there to listen to you	HH_{120}	IF_{121}	OR_{122}	N_{123}	WS_{124}	NL_{125}	RG_{126}	FR_{127}	OT_{128}	
You will be there to listen to them	HH_{130}	IF_{131}	OR_{132}	N_{133}	WS_{134}	NL_{135}	RG_{136}	FR_{137}	OT_{138}	

Are you a member of any voluntary organizations? ○Yes ○No
Are you an active member, that is, you regularly attend meetings, contribute time or money, or hold a leadership position.

[*Please check* ONE *per row &* NUMBER *of years*]

		Not a member	Member, but not active	Active member		Number of years as an active member
11.139	Business association	○1	○2	○3 →	(11.139a)	#_____
11.140	Professional association	○1	○2	○3 →	(11.140a)	#_____
11.141	A sport's league	○1	○2	○3 →	(11.141a)	#_____
11.142	Your child's sports league	○1	○2	○3 →	(11.142a)	#_____
11.143	Religious organization	○1	○2	○3 →	(11.143a)	#_____
11.144	Hobby group or club	○1	○2	○3 →	(11.144a)	#_____
11.145	Community service group	○1	○2	○3 →	(11.145a)	#_____
11.146	Ethnic association	○1	○2	○3 →	(11.146a)	#_____
11.147	Environmental group	○1	○2	○3 →	(11.147a)	#_____
11.148	Labour union	○1	○2	○3 →	(11.148a)	#_____
11.149	Women's group	○1	○2	○3 →	(11.149a)	#_____
11.150	Other _____ (11.150b)	○1	○2	○3 →	(11.150a)	#_____

SECTION 12 - YOUR OPINIONS

How much do you agree or disagree with the following statements? [*Please check* ONE *per row*]

		Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
12.1	I am responsible for my own successes	○1	○2	○3	○4	○5
12.2	I can do just about anything I really set my mind to	○1	○2	○3	○4	○5
12.3	My misfortunes are the result of mistakes I have made	○1	○2	○3	○4	○5
12.4	The really good things that happen to me are mostly luck	○1	○2	○3	○4	○5
12.5	Most of my problems are due to bad breaks	○1	○2	○3	○4	○5
12.6	I have little control over the bad things that happen to me	○1	○2	○3	○4	○5
12.7	I am responsible for my failures	○1	○2	○3	○4	○5
12.8	There is no sense planning a lot - if something is going to happen it will	○1	○2	○3	○4	○5

SECTION 12 - YOUR OPINIONS (CONTINUED)

How much do you agree or disagree with the following statements? [*Please check* ONE *per row*]

		Strongly agree	Agree	Neutral	Disagree	Strongly disagree
12.9	I am outgoing and sociable	○1	○2	○3	○4	○5
12.10	I am original, coming up with new ideas	○1	○2	○3	○4	○5
12.11	I am reserved	○1	○2	○3	○4	○5
12.12	I am sometimes shy and inhibited	○1	○2	○3	○4	○5
12.13	I have an active imagination	○1	○2	○3	○4	○5
12.14	I have an assertive personality	○1	○2	○3	○4	○5
12.15	I am curious about many different things	○1	○2	○3	○4	○5
12.16	I am talkative	○1	○2	○3	○4	○5
12.17	I prefer work that is routine	○1	○2	○3	○4	○5
12.18	I like to explore new art, music or literature	○1	○2	○3	○4	○5
12.19	I tend to be quiet	○1	○2	○3	○4	○5

How much do you agree or disagree with the following statements? [*Please check* ONE *per row*]

		Strongly agree	Agree	Neutral	Disagree	Strongly disagree
12.20	We should be more tolerant of people who choose to live according to their own standards, even if they are very different from our own	○1	○2	○3	○4	○5
12.21	We have gone too far in pushing equal rights in this country	○1	○2	○3	○4	○5
12.22	This country would have fewer problems if there were more emphasis on traditional family values	○1	○2	○3	○4	○5
12.23	It is more difficult for non-whites to be successful in Canadian society than it is for whites	○1	○2	○3	○4	○5

12.24 Do you generally think of yourself as being a little closer to one of the federal parties than to the others? Please check which party you think you are closest to...

○1 Conservative ○2 Liberal ○3 NDP ○4 Other _____(12.24a)

Section 13 - Conclusion

13.1 Do you have a particular religion or faith? [*Please check* ONE *answer*]

- ○ 1 None
- ○ 2 Protestant - Which denomination? (13.2) _____
- ○ 3 Roman Catholic
- ○ 4 Muslim / Islamic
- ○ 5 Hindu
- ○ 6 Sikh
- ○ 7 Confucian
- ○ 8 Other (13.3) _____

13.4 What was your <u>PERSONAL income</u> last year before taxes?

[*Please check* ONE *answer*]

Under $20,000	○ 1
$20,000 to under $30,000	○ 2
$30,000 to under $40,000	○ 3
$40,000 to under $50,000	○ 4
$50,000 to under $75,000	○ 5
$75,000 to under $100,000	○ 6
$100,000 to under $150,000	○ 7
$150,000 or more	○ 8

13.4 What was your <u>HOUSEHOLD income</u> last year before taxes?

[*Please check* ONE *answer*]

Under $20,000	○ 1
$20,000 to under $30,000	○ 2
$30,000 to under $40,000	○ 3
$40,000 to under $50,000	○ 4
$50,000 to under $75,000	○ 5
$75,000 to under $100,000	○ 6
$100,000 to under $150,000	○ 7
$150,000 or more	○ 8

On behalf of the NetLab team at the University of Toronto, thank you very much for completing this survey.

Someone should be dropping by your house soon to pick up your survey.
If you would like to arrange a specific time for pick-up please call 416-978-0250.

Remeber to include the consent form when returning the survey

☺☺☺ Thank You ☺☺☺

Appendix B

The Connected Lives Project Interview Schedule

Connected Lives: Communication, Technology and Society Project
Interview Guide

Before Interview starts:

- **Record Participant Number on Consent Form before interview**
- **Go over consent form and get signature**
- **Give Participant Cash**
- **Test the recording device**
- **Record/Announce Participant Number**
- **Record/Announce Date and your name**

Interview Information:

Participant #: _____

Date: _____

Interviewer: _____

***Note: Are there other household members present during the interview?**

- ❑ **Yes – Who? _____**
- ❑ **No**

***Note: Is the Interview being held at the Participant's home?**

- ❑ **Yes**
- ❑ **No – Where? _____**

Introduction to Interview

First, I would like to thank you for letting me come into your home to talk to you. I would like to go beyond the survey to discuss more about how you use technology and also talk about your social interactions.

Section One: Household

Introduction to Household Members

- Tell me a little about the **people in your home**. Who lives here and what is there relationship is to you? (*check for husband/ wife/ partner*)
- What is a **typical day** like for you in your household? What is the routine, what do you do? *(who does chores like housecleaning, cooking, shopping etc)*
- Is it different on the **weekend**? How so?

[Discussion about household tasks here – probing about daily activities and who does what, how this came to be]

- Do you have a set **routine** or schedule? How is it working for you? (*too much to do, comfortable, frustrated, content*) How did it come about? Are there any **changes** you'd make? (*Spend less time washing dishes etc)*
- What do you like to do in **your spare time**? (by yourself, with partner/spouse/ household members) *(watch tv, read, play cards, go to movies etc)*.
- How **often** do you do this? Would you do it more if you could? (Why/not?)
- What about going out **socially** to visit family, friends, neighbours or people you work with? **Who** do you go out with? How **often** do you do that? Would you do it more if you could? (Why /not?)
- Are you working right now? Where? (*Probe: hours, location, size of company*)
- Do you do **work at home**? Can you tell me more about that? (*probe for general time of work; how did you come to the decision to work at home?)*

    - **IF SO:**
    - Tell me about the **kind of work** do you do at home. What does it involve? (*probe: specific tasks such as reading or writing reports, repairs, communication*

with clients, etc.) Where do you do this work at home? (*what room*)

- Of what you just told me, what's the most **important task**? Why?
- What **hours** do you work at home? How did you **choose** these hours? (*probe: work related reasons such as clients available at certain time, family schedule, etc.)*
- Can you tell me more about what **happens in the house** during this time? Where are other family/household members while you are working? If they are at home, what are they doing while you are working?
- Do you schedule breaks for yourself? What happens when you want to take a **break**? What do you do (*probe – leave the house, spend time with children*)?
- Do any **problems** ever come up? How do you deal with them? (*probe: interruptions from family, interruptions from colleagues, colleagues not available*, etc.)
- When you work at home, do you try to keep your work and home life separate? **How do you go about it**? (*probe: try to keep schedule different, close door, discuss and agree with family members on when they can interrupt and when not, etc.)*
- Tell me about how working at **home affects your job** (*probe – does it make it more difficult or easier, more or less efficient, do you find it isolating, flexibly scheduled etc.*).
- What about how working at **home affects your personal life**? (*probe – do you find you are available for children, do you have more time for your family, OR do you find work related phone calls disruptive, rooms not available for family activities*).
- If we ask them, what do you think your **household members would say** about your working at home? (*probe: likes and dislikes)*
- Overall, do you think working at home **works for yo**u? Why (*probe for advantages and disadvantages)*

Computer Skills

- What kinds of home electronics do you have? (*probe for telephones, computing communications and media)*
- [**If they work at home**] Which of these do you use for working at home? *(probe:* What's most **useful**?)
- What **kind** of computer do you have? (*probe: sensitive to technical vs. brand details).*
- How **old** is it? / When did you get it? What kind of software do you use?
- Who **set it up**? How did that come about?
- If something went wrong with your computer right now, how would you **deal with** that? (*who would you call on to help you?)*
- What do you **do with** your computer? (*recipes, finances, resumes*)
- How do you **use** the computer other than using the Internet? (*money managing, work/ school, writing resumes etc*)
- How did you **learn to use** one (*taught myself, book)?* Who first **showed** you how to use a computer (*friend, course, spouse*)? How **long ago** was that?
- How **comfortable** you are with the computer?
- Has anyone **show you stuff** recently? *(tricks, programs, websites, etc.*)
- How do you think your computer skills **compare to others** in your home? How do you feel about that? (*Wish they knew more etc)*
- How about compared to your **friends**?
- Has anyone in your household **personalized** your computer at all – like with pictures, screen savers and so forth? Why does this person do that?
- Who **manages the files** on the computer?
- (*if one computer in home)* How does **sharing** the computer work for everyone in your home? Are there any problems at all?

[Ok, let's talk about the Internet.]

Internet in home:

- Tell me a little about they **layout** of your household - number and types of rooms you have
- Does anyone have a **specialized work** space? Or where do people do their work?
- What made you decide to **get the Internet** in your home? (*for work, children, leisure*). Who's idea was it?
- How has having the Internet affected your **financial** situation – in terms of buying a computer and then getting access? *(good to earn money, cost of access a burden etc)*
- How do you **like** having Internet access in your home?

Location of Internet Access Point:

[Let's talk about where you have the Internet set up. It's in the _____.

- (*If they have more than one computer*) You mentioned in the survey that you have _____ computers, which ones have **Internet access**? *(If they have more than one with access)* Are they **networked** at all? Who set that up?
- How did you decide to put the computer with Internet **access here**?
- Has it always been in this spot, or have you **moved** at all? (If so, how come?).
- How does having the Internet in this **spot work for you**? What about other household members? (*it's private, it's communal etc).* Would you rather have it in a **different** spot? How come?
- (*If they have more than one computer*) Which one is **used most**? How come?

Personal Internet Use:

- How many **hours** per day do you usually use the Internet during the week? What about on the weekend? (*If different, why*) (or how much time did you spend on the Internet yesterday? Is this typical?)

- When do you use the Internet **most** at home? Why at this time? *(Quiet, no one else using it)*. Is there another time when you'd rather be using it? Why aren't you using it at this time?
- Do you use the Internet anywhere else? Is your home Internet use different from (work, school, café)? **Why** do you use the Internet at home? (*More time? More quiet?).*
- Are you ever **interrupted** when you use the Internet at home? (Who interrupts and why? *Or* why not –is the time of day or good scheduling*?*
- Tell me about **how you use** the Internet. What do you do online? (email, searches, finances) (Probe for culture/leisure activities: e.g., reading newspapers, zines, or online comics; looking up information about cultural activities such as books, movies, fine arts, sports; buying tickets for events; maintaining their own website)

[Let's talk more about how you use the Internet from home specifically.]

<u>Communication:</u>

- Who do you communicate with the **most** on the Internet from home? How do you do it – email or IM? Why (*instead of F2F or preference of one over another?)*
- What kinds of things are you talking about? How much time do spend online communicating?
- Do you ever email or IM the people in your home?
    - (If yes) How much **time** do you spend emailing/IMing them? Why might you email/IM them instead of talking to them face-to-face or by telephone? Or (if not) why do you think you don't email/IM them?
- Has the Internet made communicating with people easier or more difficult?

- [<u>If they work at home</u>]When you are working at home, whom do you usually contact for work? (*probe: clients, coworkers, partners, etc. Write down numbers for each*

category.) Why? Can you give me an example?

- Who usually contact you for work, when you are working at home? Why? Can you give me an example?

Information Seeking:

- Tell me about the **kind of** information you look for online when you are at home *(Probe for seeking information about interests & hobbies—do they look up background info about bands/books/TV shows/sports teams/movie reviews? Do they look for information on live performances and events—gallery openings, concerts, etc.?)*
- How do you **go about searching** for information online? *(process – search engine)*
- How do **you like** the Internet as an information source? *(reliable or not, useful, trustworthy etc)*
- How did you look for this information **before** you had the Internet in your home?
- If something **came up** during the day, and you needed some information, what would you do? Would you go online? How would that work? *(maybe phone number, or info about illness, cultural event information, etc)*
- Have you ever accessed the Internet for **health** information (if not already discussed)? Where did you start – can you remember the story? Was it a general concern or a chronic condition? Did you forward this to anyone?
- Do you ever use the Internet to search for information about your ethnic heritage or to search for information about events relating to your country of origin? Can you tell me more about that? *(Where do they go? What kind of information do they look for? Are they reading news sites, or talking to people?)*
- Do you ever use the Internet to search for information about local organizations or services related to your religion or ethnic heritage? *(E.g., religious services, ethnic business associations, stores selling specialized goods such as halal meat) (Once again: Where do they go? What kind of information do they look for? Are they reading news sites, or talking to people?)*

Scheduling Internet Use among Household Members:

(If person has other people in the household ie: roommates, family and computer is shared)

- Is there one person in your home who uses the Internet **more than others** when you are home? Why is that? (Who uses it the most? Why?)
- Do you feel that anyone's Internet use in your home is **more important** than the others? Why is that? (*school, work)*
- (if they have one internet access point) What would happen if two people needed to go online at the same time? How would that be **worked out**? Does this happen often?
- Who makes the **decisions** about the Internet (how it's used or maintained etc) in your home? How come?
- What about **bookmarks** in the browser or Internet downloads? Does anyone take care of these?
- Do you personally have a **routine** set up for your Internet use? How is Internet use organized in your home? (*For example, a schedule*)
- **Who made** this schedule? Why did he/she do it and not someone else?
- Tell me about the ways (if any) having the Internet in your home **changed** your typical daily *routine*? (*made easier, added work, able to do more etc)*

Internet and Family:

(*If person is living with other family members*)

- Do you find you spend most of your **time on the Internet** by yourself or with other people in your home? How come?
- Are you online at the same time as members of your family who live outside of the home?
- How much time do **you spend with people** in your home using the Internet together/ at the same time? Would you like to spend more? How come?
- What kinds of things are you **doing online together**? (*school, recreation/leisure or*

communicating with friends and family?). How is that working for everyone?

- Do you think that having the Internet in your home has **affected the relationships** you have with people in your home in any way? (*brought closer, or drove farther apart*)
- How has the Internet affected the time you spend with your spouse/partner **doing other things** at home like watching TV or playing games? (*less time, more time, same)*. What about going out socially?
- Do you do this **less now** than before you had the Internet?
- What about your children? How has having the Internet in your home affected the time you **spend with your children** doing other things at home? (*less time, more time, same)*.
- How has having the Internet in your home **affected any of your relationships** outside the household with family, friends, neighbours, and co-workers? (*communicate with them more, see them less*)
- Can you think of a time when using the Internet (you personally) may have **interfered** with your family life?
- What are some of the **positive** ways that the Internet has affected your home? (*time saving, info source*)
- What are some of the **negative** ways that the Internet has affected your home? *(takes up time, difficult to use*)
- Can you tell me about a time when there may have been some **disagreements** or arguments between people in your home because of the Internet? What happened? How was it resolved? OR why do you think there haven't been any issues or problems?

<u>Household Roles:</u>

- If you could spend **more time** on the Internet when you are at home, would you? (*If so)* What kinds of things keep you from spending more time on the Internet?
- How has the Internet affected the time you spend on **other jobs around the house**?

(*such as, housework, childcare, and meal preparation*)?

- Has the Internet affected your household responsibilities? (*probe: has it added to your workload or changed the role, if so in what way?)*
- Aside from your personal use of the Internet, in what ways do you **use the Internet for** your **home** or household maintenance? (*groceries, finances etc*)?

Children:

(If participant has a child/ren)

[*Let's talk about your children and the Internet.]*

- How often do your **children use** the Internet when they are at home? (If a lot) Does this cause any problems for you or other people in your home?
- What kinds of things are they **doing online**?
- Tell me about **what's going on** with others in the home when your child is online. Are you in the same room; are you watching or helping or doing something else? Why do you do this?
- What **concerns** do you have about your children's Internet use? What is your major concern and why? (*porn, stalkers etc)*. How do you deal with this?
- How often do your children come home with **schoolwork** that involves Internet use?
- Who **is responsible** for helping your children with their Internet schoolwork?
- How **much time** does this usually involve? Is this more or less time spent for you before to the Internet homework?

[INTERVIEWER MARK TIME ON THE RECORDING _____:_____]

Section Two: Name Generator

Mark Colors: (you should use the same colors for the stickies and for the lines)

*Very Close:*_____

Somewhat Close: _____

1. Familiarization

Let's talk about your friends and family who **live outside** the household. In the survey, we asked you about people who are Very Close and Somewhat Close to you (*present card 1- RED*). Just to remind you:

VERY CLOSE:

- discuss important matters with, or
- regularly keep in touch with, or
- there for you if you need help.

SOMEWHAT CLOSE:

- More than just casual acquaintances, but not 'very close'.

This is our **Name Template** [*Present the template*]. On each of the little strips, you will be able to **write down the names** of people you know.

2. <u>Name Generating</u>

Okay, now think of people who fit that "Very Close" description. Please **write down** all the **names** of the people you feel **very close**. Please do not include people who you live with.

Now think of people who fit the "Somewhat Close" description. Please write down all the **names** of the people you feel **somewhat** close.

INSTRUCTIONS: Once they are done, refresh their memory using the YELLOW card. They should look over each category.

Now, just to make sure that we got all of the people that you are somewhat close to and very close to, on the YELLOW card is a **list of the different ways** you might know people. Have a look at this card and see if it refreshes your memory.

NOTE: this might or might not generate additional names.
NOTE: A couple would have two strips – one for each person. Handle separately.
NOTE: check for duplicate names (get last initial to differentiate).

3. <u>Roles – Multiplexity</u>

INSTRUCTIONS: Respondents should write one or more numbers next to each name. The number corresponds to the numbers on the YELLOW card.

Now that we have some names, we would like to know the **different ways** in which you **know these people**. Next to the names on the strips, please write down the **number**

corresponding to the ways you know this person.

If you know the person in more than one way, please **write down all** the corresponding numbers. For example, if you work with your immediate family, write 1 for family and 4 for currently work with.

NOTE: Spouses outside house are "other"; Grandparents are extended family.

4. <u>Plotting Networks</u>

INSTRUCTIONS: They will build a social network in two stages:

1. *Laying out the stickies*
2. *Drawing the lines. Read out the following instructions to help them lay out the stickies.*

Here is the sheet where we will **draw your social network**. It will look something like this when it is done. [*show them the example sheet*]

1. Start with the very close names
2. Put the people who know **each other closer** together, and
3. Put the people who you feel **closest to nearest** to you

NOTE: None of the little stickies should overlap.
NOTE: Sticky part on the line.

4. Now let's add the somewhat close names
5. Try to **use all the circles**, you can rearrange the names until you are happy with it

5. <u>Network connectivity</u>

INSTRUCTIONS: This is the second stage, and it's tricky so take your time. They will draw lines between people who know each other, and do this IN SEQUENCE.

*NOTE: Very and somewhat close pen colors should match very and somewhat close sticky colors. ***

- <u>Step 1</u>: **Circle groups** of people who are **very close**. (*NOTE: This will probably be a group of immediate family)*
- <u>Step 2</u>: **Draw lines** between pairs of people who are ve**ry close**
- <u>Step 3</u>: **Circle groups** of people who are at least **somewhat close**. This circle can include people who are either very close (since the line is already drawn) or somewhat close. (*NOTE: This will probably be a group of friends or workmates*)
- <u>Step 4</u>: **Draw lines** between pairs of people who are **somewhat close**

NOTE: People may want to draw a line from a group (or circle) to a name outside the circle this is okay but it should be clearly drawn.

6. <u>Reasons for closeness</u>

So now we know what your social network looks like. We can move on to **find out a little** about these people.

First I'd like to know a little about what very and somewhat close **means to you**.

INSTRUCTIONS: Use card 1 (RED) again. We will be looking for the person with the <u>lowest "rank number</u>" in each of the four rings (total four people). Do the following for each person:

1. You said that this person was [Very/Somewhat] Close. Looking again at the three reasons for closeness **which of them does this person fill**? It is okay if they fit all

of the reasons, just one, or none.

2. Are there **any other reasons** that you had for deciding that this person is [Very/ Somewhat] close which we didn't include?

NOTE: If they only have people in three rings, get the second-lowest person from the centre ring.

7. <u>Network members in detail and frequency of media usage</u>

For this section, we are going to do a little **mini survey** on some of the people in your social network. We will be talking about how you communicate with them. [*hand them the sheet*] – if some of these don't apply, just skip that part. I'll be doing this with you in case you have any questions. (*NOTE: Instant Messaging won't apply to most people)*

INSTRUCTIONS: For this section, you will <u>sample</u> people from the network based on <u>their rank number</u> (regardless of whether they are the lowest "somewhat" or "very" close people)

Step 1: Take the three lowest numbers from the centre circle.

- *Mark a * on those names.*

Step 2: "working your way out of the rings"

- *Start with the inside ring. Do the following until you have 12 people (so that's 15 in total) or until you run out of people.*
    - *i. Find the person with the lowest number that doesn't have a **
    - *ii. We shouldn't get two people from a couple. So if a person's partner is already got a * then get the next lowest person. Ask the respondent.*
    - *iii. Mark a * on that person.*
    - *iv. Move out to the next ring (if you are at the outermost ring, go back to the inner ring)*

v. Go back to 'i'

*When you are done, complete the mini survey with the people who have *'s next to their names.*

NOTE: probes for the out-loud questions in the mini-survey:

- Job: [*includes homemaker*]
- Ethnicity: [*if they say Canadian, prompt where the family is originally from*]
- Where does he/she live? If in the Greater Toronto Area, what's the intersection; otherwise, what's the city [*If GTA, try to get as much as detailed information here; e.g. West / East*]
- Where do you usually see him/her? If in the Greater Toronto Area, what's the intersection; otherwise, what's the city [*If GTA, try to get as much as detailed information here; e.g. West / East*]

8. <u>Specific Social Event Questions</u>.

This next section is about socializing with other people. I will first select - with your help - some members of your social network, and then I will ask some questions about the last time you socialized with them

INSTRUCTIONS: Once again, we have an iterative sampling procedure. This time, instead of 15 people, we are looking for 6 social events

"Working your way out of the rings" - You want six people in total.

Start in the inner ring:

- *Get the * person from that ring that they socialize with most often in the Greater Toronto area. Circle that name.*

- *Go out to the next ring (if you are on the outermost ring, go back to the inner ring). Repeat until you get 6.*

*NOTE: If they don't socialize in Toronto with any * people in that ring, move out to the next ring and continue. If you have run out of * people but you still have less then 6 events, start in the inner ring and use the non-* people that they socialize with most often in Toronto and move outwards until you have 6 events.*

INSTRUCTIONS After the sampling procedure, ask the following social event questions with each person whose name is circled.

NOTE: social meeting defined as activities that involve mainly social interaction (e.g. visiting, hosting, going to a restaurant or pub) rather than attending an event (e.g. sport event, cinema).

Can you tell me a little about the <u>last time</u> you socialized with [him/her] in TORONTO*?*

[prompt card 4 – BLUE]

8.1. About the specific activity

- **What**: What did you do when you got together? [*places where people socialize together - hosting / visiting / restaurant or pub RATHER THAN attending same event such as movies, concerts]*
- **When**: What time of day was it? [*morning, noon, afternoon, evening, night or approx. time*]
    - Was it a weekday or a weekend? [*day of the week: important to differentiate between Fridays and other weekdays]*
    - About how much time did you spend together? [*length of the meeting*]
- **Where:** Where did you go? / Where in Toronto was this, just the main intersection is fine [*preferably the main intersection, including west/east if applicable; if not remember, the best possible detail*]
- **Who**: Was anyone else there, not just the people you talked about a minute ago? [*distinguish between people who were mentioned in their personal network and others*]
- **Mode**: How did you meet with [person 1]: did you take the TTC, car, walk

- **Planning the activity:**
    - Did you plan it or were you invited?
    - How was it planned? [*probe: f2f, email, tel/on going/routine*]
    - How far in advance was it planned? [*spontaneous; same day, week, month, year; pre-set activity/regular commitment*]

8.2. About the activity in general

- **Frequency**: Have you done this activity in a previous occasion? [*If previous answer YES*] How often do you do [this] with [person 1]?
- **Place**: Do you normally meet at the same place, or different places? Why do go to this place(s)? [*close to work / home / other places, I / We like this place, cheap, it has been seen by someone else*]
- **Day / Time:** Is it usually at the same time? Is it at the same day of the week? Why do you meet at this time(s) / day(s)? [*pre-set time / day, commitment, depends on availability of participants*]

9. Social Support Questions
[prompt card 5 – PURPLE]

Now, I would like to ask you some questions about **information and advice**. (*No sample on this one, just whoever they say in their network*)

Who has given you help with the following:

- Advice on important matters
- Advice about new job opportunities
- Care for a serious health condition
- Help looking for information about a health issue
- Help with home renovations
- Advice on using a personal computer
- Who do you just talk about the day with?

10. General Health

When we talked about social support, some health matters were mentioned. I'd like to follow up on those now. When I say health, I am talking about both physical and mental health issues

- Do you think of yourself as a **healthy person**?
- On a scale from **1-10**, where ten is "excellent health", how would you rate your own health?(*Looking for number and perhaps more information*)
- (*In the event the answer is 10*) **How** do you manage to do that?
- (*In the event the answer is less than 10*)
    - What would **need to change** to give yourself a 10 rating? (*get a list of reasons*)
    - Are you doing anything to **make those changes**? (*probe for information, clinics, social support*)
    - (*If the list is long*) What do you consider to be **your health priority**?
- Would you describe any of your health issues **chronic or long-term**?
  If yes:
    - **Who** do you go to for information, help or support for this condition?
    - Are they in your **social network**?

- When you have an **acute or unexpected health** issue who do you go to for information, help, or support?
- Are they in your **social network**?

- Can you tell me about the **last time** you **looked** for health **information or support** for any of the things you might have mentioned?
    - Where did you **start** / How did you begin that **process**?

(Interested in source of information, people that you talk to, a variety of places that you went, what is the sequence of the events, you want all of the details and the information, rich data.

Use all of your coaxing skills and your "and then's" and active listening.)

- Have you ever **wanted to talk** to someone who has a similar health matter?
- Did you connect with them **online**?

If yes:

- Have you put them in your social **network**?
- How would you **describe your relationship** or connection with that person?
- Where did you first meet them?
- Please tell me about the **experience of finding** them? [probes: process, steps, emotional impact]
- What **kinds of support** did you receive? (probes: information, or emotional support)
- How **successful** was your experience? (Probe for advantages and disadvantages of each source of support that has been mentioned.)

- Are there people **who come to you** for help and advice for health matters?

If no, you can go to next section.

If Yes:

- Are they in your social **network**?

If No:

- **Who** are they? Describe the relationship *(family, friends, online only)*

If Yes (and for the no's)

- What **kinds of support** did you provide (*information, advice, support*)
- How was your **experience**? *(Probe for advantages and disadvantages if mention different sources)*

11. <u>Leisure Time</u>

Next I'd like to talk to more about the **things you do** in your free time, and **who you talk to** about those activities. *Get out cue cards arranged by thematic areas: television/film, music, fine art, performing arts, sport & games, ethnic & national heritage, reading & writing.*

I have **eight cards** here. On the front of each card is a topic that some people are interested in. (*Lay out the cards one by one, topic area face up. As you lay down each card, read the topic out loud.)*

- Do any of these topics **interest** you? Which topic is **most interesting to you**? Then which one? (*And so on to least interesting) (Make an ordered/ranked pile of the cards reflecting the participant's interest.)*

- Let's go through these now, starting with the one you're the most interested in:

What **kinds of things** or activities do you do? **How often**? *(Try to narrow scope of interest. Use probing skills about decision making and starting point.*)

Let's take a closer look at the first two areas you said you were interested in:

- **How you decide** what to do/listen to/make/read/watch/buy?
- Where you get **information** and **recommendations** for *(topic1)*?
- How about *(topic2)*? How do you **decide** what to do?
- Where do you get **information and recommendations** about *(topic 2)*?

1. Do you ever **get suggestions** or **recommendations** about *(topic)* from other people? (*if no, go onto #2*)

- Are they on the list we created earlier? **Who**?
    - [**<u>If not</u>**] Can you tell me a bit about them? – relationship descriptors

- **Do you** typically **ask** them for recommendations, or **do they** usually **volunteer** recommendations?
- How often do you make suggestions? (**often,** occasionally?)
- How often do you **take their suggestions**?
- Do you ever get suggestions from them about other things you're interested in?
- **How** do you usually talk about *(topic)*? (F2F, phone, email, IM, etc.)
    - Is it the same people all the time, or to different people?
    - Are they on the list we made earlier?
    - Have you ever arranged to meet any of these people?
    - Do you ever post questions online anywhere?
    - Do you ever show people things that you've made or announce your website/photo albums/weblog, etc.?

2. Do you ever **make suggestions** or recommendations about *(topic)* to others? (*if no, go onto #3)*

- Are they on the list we created earlier? **Who**?
    - [**<u>If not</u>**] Can you tell me a bit about them? – relationship descriptors
- How often do you make suggestions? (never, occasionally?)
- **How** do you usually talk about these things? (F2F, phone, email, IM, etc.)
    - Is it the same people all the time, or to different people?
    - Are they on the list we made earlier?
    - Have you ever arranged to meet any of these people?
    - Do you ever post questions online anywhere?
    - Do you ever show people things that you've made or announce your website/photo albums/weblog, etc.?

12. Observation Guidelines

(if participant has internet access – if not, go to health observations)

12.1. General Observations

Now, let's change the pace a little. Let's take these cards and you can **show me how** you use your computer and what you do on the Internet. (*if more than one computer*) Which computer do you usually access the Internet from? Can I take a picture of it? (*Take a photograph of the computer/internet set-up – Remember to bring recorder with you!)*

12.2. Leisure Observations

Ok, we still have our cards (*lay them down again*). Do you use the internet for the two most interesting topics you chose before? (*if not chose another they do use internet for.*)

1. Do you ever use the Internet to get information or recommendations about (*topic*)? (*if no go to Observation*)

[**If yes**] **What do you do**? (Web sites – which ones? E-mail? IRC?)

- What **kinds of information** do you typically look for? (*Background/bio? Concert dates? Ticket info? Reviews? Samples? Recommendations*?)
- Do you **trust** recommendations and reviews that you **read online** more or less than recommendations and reviews that you **receive from people** you know? Why?
- Do you ever **talk about** recommendations and reviews you read online with other people? How does that influence what you decide to do/listen to/make/read/ watch/buy?

I'd like you to show me how you use the Internet in relation to these two cards. Can you show me what you do when you go online for/about *(topic)*? *(Enter name of activity/ category and appropriate verb. Be sure to ask the interviewee to talk out loud.)*

(Questions or things to cover in the observations – can use this as probes if necessary)

1. Getting There:
    - **How** are you getting to where you need to go? *(Process of finding sites: search engines, memory triggers, bookmarks, links in email, links on web pages, etc. NOT user interface material and issues*.)
    - How did you first discover this site (*Search engine/recommended by someone they know—who?/linked to it from another site/saw the it in a newspaper/ magazine/on TV, etc*.)

2. The Site: Is this somewhere you **go regularly**?
    - How often do you visit here?
    - What do you like about this place/activity? Is there anything you don't like about this place/activity?

3. Once at the Site: **What are you doing** once you get there?
    - For example: Seeking information about the topic? What kinds of information? (*E.g. television spoilers, recommendations about camera filters, music samples, performance times and locations*.)
    - How do you **use** this information? (*Make purchases based on online recommendations? go to ethnic stores they read about online?)*
    - Are you doing anything other than reading/information seeking? (*Posting to forums, asking or answering questions, downloading music, putting up blog entries, playing games, shopping, posting photos, buying tickets, etc*.)

Ok, let's talk about **the second** area/activity/topic (r*epeat above for second card/activity/ topic)*

12.3 Health Observations

Thank you for showing me how you use the Internet for your leisure activities. Now we are going to look at something a little different. I am curious about how you get health information and how you share that information with others.

Here are some more **cards** for you to look at about Health. (*Lay out and read five Health Cue Cards: Lifestyle, Public Health, Chronic/long term health conditions, acute / emergency health conditions, Mental Health issues)*

Think about health issues, either ones we have already talked about, or ones that you have recently looked for information about using the Internet.

(*If they do not use the Internet, ask them why not and where else they would go for information about Health issues.)*

- Which **category** does the issue fit into? (*They can pick two different categories/ issues.)*

- Can you show me **how you look** for information about (this health issue)?

Things to make note of and ask about:

- Where do they start on the Internet?
- Do they go to that site regularly?
- How do they decide which site to go to?
- What do they like about the site?
- Do they ever go to chat sites, or group sites?

- When looking for information do they search, read complete sites or go to the FAQ sections (if applicable)
- Once you have found what you are looking for, do you go for a second opinion?
- If so, where *(another site, a medical professional)*

- Do you **ever share** the information that you find? With who? How?

Things to make note of and ask about:

- Are you using e-mail only to ask people questions?
- Do you post questions to web chats?
- Is this information for them or for a "tie"?

Conclusion

That concludes our interview with you today. Do you have any other comments or questions?

Thanks so much for taking the time to talk to us.

Appendix C

Connected Lives Interview Health Cards

LIFESTYLE

- Nutrition
- Exercise
- Sleep

1

PUBLIC HEALTH

- SARS
- The Flu
- Immunization

2

ACUTE / EMERGENCY HEALTH CONDITIONS

- Fever
- Injury
- Cancer

3

CHRONIC /LONG TERM HEALTH CONDITIONS

- Arthritis
- Diabetes
- High blood pressure

4

MENTAL HEALTH ISSUES

- Depression
- Attention Deficit Disorder
- Anxiety

5

Appendix D

Qualitative Coding Tree

Qualitative Code		Level One		Level Two
Health story	Context of Internet use	• Before medical appointment • After medical appointment • Instead of a medical appointment • No Internet use	Interview language describing Internet use	• always • go • opinion • involved • plan / prepare • know more • background • start conversation
	Effect of Internet use	• Becoming Informed • Becoming Healthy • Habitual Use	Interview language describing Internet use	• trust • rapport • healthier • always • never • familiar • research • look up

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