THE ISSUE OF AVOIDANCE: INFORMATION AVOIDANCE IN THE CONTEXT OF PERSONAL HEALTH CONCERNS

by

Colleen Victoria Addison

B.A. (Hons.), University of Alberta, 1997

M.A., University of New Brunswick, 2001

M.L.I.S., University of Western Ontario, 2007

A THESIS SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF

DOCTOR OF PHILOSOPHY

in

The Faculty of Graduate and Postdoctoral Studies

(Library, Archival and Information Studies)

THE UNIVERSITY OF BRITISH COLUMBIA

(Vancouver)

August, 2017

Abstract

Information is increasingly available at the touch of a button, and yet limits are still present in the ability and willingness of individuals to access that information. These limits can result in information avoidance, a phenomenon in which individuals prefer not to seek or be exposed to information. Nowhere is this phenomenon more evident and more problematic than in health, where information has been linked to better health outcomes, and where the consumer health movement has shifted the responsibility of health information seeking from healthcare professionals to patients. This dissertation examines such health information avoidance, looking in particular at the mechanisms that constitute this phenomenon, and the affective, personality, and information source factors that influence it. Two studies were performed, the first an online survey using the crowdsourcing platform Mechanical Turk for recruitment, and the second a user study in which participants interacted with health information and were then interviewed. Both studies also employed scales such as the Need for Cognition scale, the Threatening Medical Situations Inventory (examining monitoring and blunting styles), and the Positive and Negative Affect short scale.

Results indicate that very few people are willing to report practising complete information avoidance. However, numerous participants reported avoiding some information, often through filtering mechanisms such as self-regulation and delegation. This evidence of partial avoidance suggests that information avoidance can be located on a continuum of information seeking behaviours, rather than existing as a simple negation of information seeking. Significant factors that influence the practice of information avoidance were found to include affect such as fear, disgust, and disinterest, all factors that can indicate a threat to the participant. While the personality and information source factors tested were also influential, this work found that for these participants, affective factors often functioned as a primary influence. This work indicates that health information avoidance is a situation-dependent information behaviour, rather than primarily a personality trait as previously claimed. As such, it should be included in models that depict people's general behavioural patterns with regard to information, such as Wilson's (1999) General Model of Information Seeking and Johnson's (1997) Comprehensive Model of Information Seeking.

Lay Summary

If you have health concerns, you probably turn, like most people, to Dr. Google. But how long do you search? And what sites do you look at? This dissertation examines the phenomenon of information avoidance, in which people avoid or filter out information about their own health concerns, rather than looking for it. I performed two studies, the first an online survey, the second a series of in-person interviews and website browsing sessions. Numerous participants reported regulating how they look for information, either by limiting their information searches or by letting others search for them. Although some of this behaviour was due to participants' personalities or issues with the information at which participants were looking, most participants cited emotional reasons: they were afraid, not interested, or disgusted. These emotions, fear, disgust and disinterest, show that participants look for information differently, based on the situation, rather than primarily following patterns of behaviour established by habit or personality.

Preface

The MedBrowser websites used in the Interview and Interaction study were created by Dr. Luanne Freund and myself, and included material found by a graduate research assistant. I was responsible for conducting all interaction sessions and interviews in this study, as well as for the administration of the scales. The Affect and Avoidance study design and questionnaire was developed with assistance from Dr. Luanne Freund and performed by myself.

Ethics was obtained for this research, under its former title "When Information Hurts." The University of British Columbia Human Ethics board granted approval using the number H14-00877.

Table of Contents

List of Tables

List of Figures

Acknowledgements

I would like to thank my participants. I am so thankful to all of you for helping me to understand your experiences, viewpoints, and struggles. I am also very grateful for your enthusiasm for my project. You guys are awesome!

Next I would also like to thank George and Anne Piternick, whose much-appreciated grant allowed me to pay my participants. Thank you as well to my local community centre, whose staff very kindly permitted me to use rooms at a discounted rental rate.

I am especially grateful to all of the people over the course of this degree, some of whom I knew and some who I didn't, who all showed interest and excitement in my topic. It was great to know that other people shared my fascination, and a good deal of your comments informed my reading and the final project.

This work would not have been possible without mentoring and support from my chief advisor, Dr. Luanne Freund. Thank you for all your help, advice, and (much) patience ☺ It was super fun working with you.

Thank you as well to members of my thesis committee, Drs. Heather O'Brien, Eric Meyers, and Leanne Currie, who provided me with valuable feedback and advice on my work. Thank you especially to Heather, whose timely and extensive comments were much appreciated.

And of course, thanks to my friends, family and my beautiful little kitty, for your love, support, hugs, great conversations (yes of course the cat talks ☺), cooking tips, tea-and-cookie afternoons, dating advice, movie nights, yoga classes, and some really cool new facts from Blair. Hey, are you guys reading this? Love to all, and special snuggles to my sweet Summer ☺

Dedication

To little kitty because she got better,
To my nieces—*STAY HEALTHY!!*
And to Dad. Thanks for the money!

1 Introduction

The scope and delivery of information in the Western world is undergoing a dramatic change. The advent of online resources has enabled more and better availability of information, resulting in new expectations for those newly informed and capable information consumers who access these resources. These expectations are especially evident in health, where the recent emphasis on consumer health lauds the power of newly available online information, which, it is said, will enable people facing health concerns to better research options, make suitable decisions, and more capably take charge of their lives (Harris, Wathen, & Wyatt, 2010; Barbarin, Klasnja & Veinot, 2016). Advocates of consumer health often refer to information searching as a means of empowerment, and point to what they see as the promise of information to grant information searchers a status akin to experts (Harris, Wathen & Wyatt, 2010; Barbarin, Klasnja & Veinot, 2016). But this promise has not been fully realized. Although many patients and caregivers are taking advantage of the wealth of health information now accessible via the Internet, the overall picture is more complex, with some people unable or unwilling to access health information: preferring to avoid rather than seek (Lambert, Loiselle & Macdonald, 2009; Howell & Shepperd, 2013, 2016, 2017; Sweeny & Miller, 2012). The stress on searching and searching benefits renders this avoidance problematic; avoiders can be disadvantaged and, in effect, disempowered by behaviour previously common in health care settings, the lack of searching out health information.

Access to quality information in health has long been associated with health benefits: better communication with doctors, the making of better health decisions and the taking of fewer health risks (see Johnson, 1997; Shneyderman, Rutten, Arheart, Byrne, Kornfeld & Schwartz, 2016; Weinstein, 1980, 1982; Lu, Dzwo, Hou & Andrews, 2011 for examples). These clear advantages of information in health are related to the concept of health literacy, defined as a level of communicative ability and skills necessary to make informed decisions (Ferguson, 2013; Hernandez & Pleasant, 2013), a desirable attribute under the banner of consumer health (Veinot, 2010). Here barriers to information seeking are attributed to difficulties with language and lack of education or searching ability, as well as to disparities in financial resources (see Oh & Cho, 2015 for one example). However, research shows that other forces may be at work, as studies indicate an association between stress, anxiety, and information (Miller, 1980; Lambert, Loiselle & Macdonald, 2009; Howell & Shepperd, 2013, 2016, 2017; Sweeny & Miller, 2012). In some cases, this research demonstrates, stressed people will avoid "threat-relevant" information (Miller, 1980, p. 156), preferring to remain ignorant rather than to learn (Miller, 1980; Howell & Shepperd, 2013, 2016, 2017; Sweeny & Miller, 2012). This phenomenon, referred to as "information avoidance" (Sweeny, Miller, Melnyk & Shepperd, 2010, p. 23) is little understood but is clearly linked to times of crisis such as when individuals face health concerns and to the negative emotions such as fear and anxiety generated by those concerns (Miller, 1980; Howell, Ratliff & Shepperd, 2016; Sweeny & Miller, 2012).

Many health initiatives designed to maintain good health and assist in disease management rely on information searching (Wyatt, Harris & Wathen, 2010; see Canada Health Infoway for one example). Some resources are designed specifically to assist those who have language or technology difficulties that prevent the access of information, although more initiatives are required in this area as well (Bjarnadottir, Millery, Fleck & Bakken, 2016). In contrast, those patients and caregivers who may not wish to search usually go unacknowledged (Dwyer, Shepperd & Stock, 2015; Howell & Shepperd, 2017).

Thus, while access to health information is linked to better choices and more effective health decisions, it is clear that at certain times, some people do avoid information, behaviour often ignored by health information providers (Case & Johnson, 2012). An important research goal is to learn more about this behaviour, to discover how, when and why information avoidance occurs.

Although the phrase "information avoidance" suggests the opposite of information searching, the phenomenon is more complex. The mechanisms by which people avoid information are little understood (Case, 2012; Howell & Shepperd, 2016; Case & Johnson, 2012; Case, Andrews, Johnson & Allard, 2005). Some studies of information avoidance have examined doctor-patient communications, looking at whether or not patients demanded information of health professionals (see Miller, 1980, 1987, 1995, 2014 for examples). These studies defined avoidance as simply not seeking, i.e., not asking information of the health provider (Miller, 1980, 1987, 1995, 2014). However, work in the past decade, which takes into account the ready availability of health information on the Internet, has suggested a more nuanced definition of information avoidance. Examples of more finely distinguished avoidance behaviours are found in some recent studies (Barbour, Rintamaki, Ramsey & Brashers, 2012; Lambert, Loiselle & Macdonald, 2009; Eheman, Berkowitz, Lee, Mohile, Purnell, Rodriguez, Roscoe, Johnson, Kirshner & Morrow, 2009; Howell & Shepperd, 2016). Barbour and colleagues (2012) report that strategies for avoiding information can include removing or ignoring stimuli (i.e., avoiding knowledgeable people) and controlling conversations (i.e., changing the subject), while Lambert, Loiselle and Macdonald (2009) suggests that avoidance behaviours can include a preference for one source over another (i.e., speaking to healthcare professionals only and not with friends or family; see also Sweeny et al., 2010). Lambert, Loiselle and Macdonald (2009) also describe information avoidance as following on previous seeking behaviours; after looking for information, patients may stop searching and just "go with the flow" (p. 32; see also Eheman et al., 2009; Savolainen, 2012).

Another, related, question is the issue of why people avoid information. Explanations have ranged from suggestions first that avoidance is a personality trait or a function of personality traits (Miller, 1980; Bandura, 1977) and second, that there are links between information avoidance and a person's affective state (Sweeny & Miller, 2012; Melnyk & Shepperd, 2012; Howell & Shepperd, 2016). A third, less explored factor is found in the characteristics of information sources, which can be said to influence people's information seeking, including decisions to use or ignore information (Nahl, 2005; Mentis, 2007; Mentis & Rosson, 2009; James & Nahl, 2014).

The notion of information avoidance as a personality trait is well established. Miller (1980), in her seminal explanation of information avoidance, divided people into two groups: monitors, who search for information in times of stress; and blunters, who do not (see also Baker, 1996, 1997). Although research has linked this behaviour most thoroughly to health problems (Howell & Shepperd, 2016; Williams-Piehota et al, 2009), Miller's (1980, 1995) research, and the scale she later developed (Miller, 1987), points to a tendency of some people to avoid information that persists across a range of situations, from a dangerous plane ride to a potential job loss. Similarly, researchers have also examined other personality traits that might stimulate the avoidance of information in a range of situations. Folkman and Lazarus's (1984) stress and coping theory posits two personality-linked categories, problem-focused copers and emotion-focused copers, depending on which aspect of the situation people pay attention to while under stress: problems (i.e., people may cope by searching for solutions) or emotions (i.e., people may cope by attempting to relax and not think about the stress-inducing problem). This theory has been linked to information seeking and avoidance (Lambert & Loiselle, 2007; Howell & Shepperd, 2016), with problem-focused copers tending to seek information while emotion-focused copers tending to avoid it.

A more situational approach to information avoidance considers it to be a function of the negative affect people in situations of crisis experience (Dawson, Savitsky & Dunning, 2006; Howell & Shepperd, 2013; Sweeny & Miller, 2012). Negative affect in general is associated with hindrances in information seeking (Wilson, 1999; Nahl, 2005). Fear and anxiety, emotions that have been shown to result from health problems have also been closely linked with people's refusal to search for information (Howell & Shepperd, 2013; Sweeny & Miller, 2012; Savolainen, 2014). Health research shows that problems that are extremely serious and more likely to produce negative affect, as in the diagnosis of a fatal disease, and those in which the outcome will remain unaffected by people's behaviour, as in an untreatable disease, are the most likely to produce information avoidance (Melnyk & Shepperd, 2012; Lambert, Loiselle & Macdonald, 2009; Case & Johnson, 2012; Johnson, 2014; Dawson, Savitsky & Dunning, 2006). Similarly, Uncertainty Management Theory (Babrow, 1992; Brashers, Neidig, Haas, Dobbs, Cardillo & Russell, 2001; Neuberger & Silk, 2016), a theory that has been linked to health suggests that people might control (i.e., either increase or decrease) their information seeking in order to manage their uncertainty about possible outcomes.

Another factor is found in the characteristics of the information sources. Research exists that details people's preferences for certain information sources over others; for example, a common information science principle that people prefer interpersonal information sources over other types is detailed by, among others, Wathen and Harris (2007). This preference may be reordered in times of stress or crisis, particularly in health, where people may seek information from traditionally authoritative sources such as healthcare professionals (Case & Johnson, 2012; Lambert, Loiselle & Macdonald, 2009; Wathen & Harris, 2007; Toms, O'Brien, Kopak & Freund, 2005). Other research suggests links between health information seeking and common characteristics of information sources such as ease of use (Weng, Weng, Kuo, Yang & Lo, 2013; Lialiou & Mantas, 2015; Lazar & Briggs, 2015); presence or absence of medical jargon (Baker, 1996; York, Brannon & Miller, 2012; Williams-Piehota, Latimer, Katulak, Cox, Silvera, Mowad & Salovey, 2009), and presence or absence of personal narratives (Crutzen, Cyr, Larios, Ruiter & de Vries, 2013). However, the range and relative importance of such features are still open questions.

1. 1 Research Focus

This dissertation explores the phenomenon of information avoidance, its process, and the effect of three factors, personality traits, affective state, and information source characteristics. The project focuses on the subject of health, as this is an arena in which information plays a critical role, and as avoidance has been documented as a response to information by people who are experiencing health concerns (Howell & Shepperd, 2013, 2016, 2017). As this project is in the information behaviour domain, information behaviour is defined very broadly and includes a wide range of information related activities such as gaining information from interpersonal sources, including family, friends and professionals; active seeking of information through the use of the Internet or other electronic and print resources; and passive or incidental acquisition of information through exposure to the news or other media. In some health domains, stronger distinctions are sometimes made between information-related activities such as shared decision-making, diagnosis and screening leading to divisions between healthcare avoidance (Lund-Nielsen, Midtgaard, Rørth, Gottrup & Adamsen, 2011, p. 277) and information avoidance (see also Persoskie, Ferrer & Klein, 2014). However, this project takes a broader approach consistent with the information behaviour domain.

The following research questions guide this work:

1. What factors contribute to information avoidance? More specifically, to what extent do personality traits, situational affect, and the nature of available information sources influence information avoidance?

Previous research has suggested that these three factors influence information avoidance, but little research has compared the three or looked more closely at how the influence of these factors may function. Personality is here defined in accordance with Phares (1991) as “a pattern of characteristic thoughts, feelings, and attitudes that distinguishes one person from another and that persists over time and situations (p. 4). Affect is here defined as the broad range of people’s emotional and mood based experience (Nash, 2010). An information source is defined as an object that is commonly supposed to contain information, such as a book or an Internet website (Johnson, 1997).

2. What are the mechanisms of information avoidance?

Information avoidance includes various patterns of behaviour (i.e., controlling conversations, ignoring certain sources) and multiple levels (i.e., from total avoidance to the preferences for some sources over others or under certain conditions). I examine these more closely to ascertain the ways in which people may avoid information.

1.2 Contributions

This research contributes to the disciplines of information science and health communication by extending our understanding of the nature and processes of information avoidance, and by potentially informing practices within professional realms such as nursing and librarianship. Information avoidance is infrequently studied, and caregivers and information providers can benefit from understanding when and how people are likely to avoid information. This project also adds to the growing body of research in information science on affect, which Nahl (2007) cites as an important field of study, one that rectifies previous views of the user as a simple sender-receiver of messages and more fully examines people’s motivations and disincentives for searching. I explore the hindering effects of negative affect, which, although touched upon by several researchers (Nahl, 2005; Mentis, 2007; James & Nahl, 2014 for examples) have not as yet been examined in depth.

This work also benefits the health community, in areas such as health communication. While some researchers in this field have looked at this topic, questions do remain. A concentration on information source characteristics, perhaps understandably, has not entered into the realm of health research on information avoidance (see Melnyk & Shepperd, 2012; Dawson, Savitsky & Dunning, 2006 for examples). While researchers have examined the effect of information source characteristics on selection, few have looked at the effects of such characteristics on avoidance under stressful conditions, an important consideration in the health domain. In practical terms, the results provide guidance on the presentation and dissemination of consumer health information, especially information regarding life-threatening illnesses.

This dissertation will detail the studies that constitute the research as well as discussing implications of the results. I will begin with a review examining the literature that guided the research (Chapter 2). Next, I will continue with a methods chapter (Chapter 3) outlining the two studies that make up the research, following with two chapters (Chapters 4 and 5) that explain the results of each study. In the next chapter (Chapter 6), I will discuss the results, looking at the theoretical and practical implications of the research before concluding the dissertation in a final chapter (Chapter 7).

2 Literature Review

2.1 Introduction

"We can seek knowledge in order to reduce anxiety...we can also avoid knowing in order to reduce anxiety." So said Maslow (1963, p. 114), and yet fifty years later, information avoidance, conceptualized by Sweeny, Melnyk, Miller & Shepperd (2010) as "any behaviour intended to prevent or delay the acquisition of available but potentially unwanted information'' (p. 341) remains largely unclear. The situation is particularly problematic in health, as the avoidance of information by patients and caregivers can lead to delayed treatments, a lack of knowledge of the effects of health conditions, and poor decision-making. Explorations of this topic have been relatively rare, in part because information avoidance has been viewed as a negative and abnormal behaviour that counters the dominant narratives of healthcare and information studies in which information seeking is viewed as a positive and normative behaviour. This subject is currently of concern, but many questions still remain: among these are uncertainties regarding the personality traits and affect of avoiders and seekers, and the sources they choose or do not choose. This review of the literature explores the research on information avoidance, information behaviour and health information seeking in order to identify some of the open questions that remain.

2.2 Theories and concepts of information avoidance

Research on information avoidance tends to focus, with some exceptions, on two theoretical frameworks, Miller's (1980, 1987, 1995, 2014) Monitoring and Blunting theory and the concept of Selective Exposure (Hyman & Sheatsley, 1947; Festinger, 1957, 1961). Research also exists that discusses information avoidance particularly in the area of health, sometimes referencing Uncertainty Management Theory.

2.2.1 Monitoring and Blunting

Miller's (1980) seminal study looked at information avoidance among stressed patients preparing for a medical procedure. Based on previous research, Miller (1980) proposed a division of these patients into two categories, concluding that monitors are people who under stress are comforted by information and will welcome and seek it out, while blunters are people who under stress are made more anxious by information and will thus avoid it. Miller's (1980, 1987) categories differentiate behaviour in situations of stress, hence their presence in medical patients experiencing extreme stress. However, Miller's (1980) research posits that these categories are present in other stressful situations as well. Miller (1980, 1987) also developed and tested a scale, the Miller Behavioural Style Scale (MBSS), which gives people four hypothetical stress-inducing scenarios, one that pertained to health. The specific health scenario asks participants to "vividly imagine that you are afraid of the dentist and have to get some dental work done" (Miller, 1980, p. 155). The rest of the scenarios present other stressful situations: being held hostage, a plane crash, and job loss. Monitoring or Blunting statements follow: "I would ask the dentist for an explanation" or "I would do mental puzzles in my head" (p. 155). Respondents check those statements that apply. This method of assessing personality tendencies is limited because to "vividly imagine" (p. 155) is not to experience, and thus people's reactions to such scenarios might not match their actual behaviour (Lambert & Loiselle, 2007; Evans, Roberts, Keeley, Blossom, Amaro, Garcia, Stough, Canter, Robles & Reeb, 2014). However, this scale, as well as later scales based on the MBSS such as the Threatening Medical Situations Inventory (van Zuuren, de Groot, Mulder & Muris, 1996) and Miller's (1980, 1987, 1995) Monitoring and Blunting categories are often used as a way of characterizing and assessing information avoidance (see Baker, 1996; Williams-Piehota et al., 2009; McCloud, Jung, Gray & Viswanath, 2013; Howell & Shepperd, 2016; Miller, 2014).

Other limitations of Miller's (1980, 1987, 1995, 2014) work is that her categories do not explain much about how people avoid information, and that they do not include online sources such as websites and social media. Some researchers have extended Miller's (1980, 1987) study. Two groups of researchers, Lambert, Loiselle and Macdonald (2009) and Barbour, Rintamaki, Ramsey and Brashers (2012), identify some patterns of avoidance behaviour. Lambert, Loiselle and Macdonald (2009) state that Miller's (1980) term Blunting is inexact, proposing instead two further categories: information disinterest (minimal information seeking) and avoidance (guarded information seeking), giving examples of each (Hertwig & Engel, 2016). However, their description of avoidance is incomplete and does not explain why some guarders seek more information than others. Barbour et al. (2012), in their attempt to clarify what they considered the typical oversimplification of research on information avoidance, conducted a qualitative study in which they distributed questionnaires to 507 students and 418 community participants regarding their health information behaviour. They identified two avoidance strategies, removing or ignoring stimuli and controlling conversations. Both sets of researchers suggest that people avoid information in other ways; however, neither looks at these multiple ways of avoidance.

2.2.2 Selective Exposure

Selective Exposure, originally conceptualized by Hyman & Sheatsley (1947) as the purposeful selection of some stimuli over others, is often associated with information avoidance (Sweeny et al., 2010). Based on work by Festinger (1957, 1961), Selective Exposure is a cognitive process wherein people who have pre-existing ideas about a topic or issue are thus motivated to seek out information that agrees with their existing state of knowledge (see also Mills, 1965; Muramatsu & Pratt, 2001; Westerwick, Johnson & Knobloch-Westerwick, 2013, 2016; Nielsen & Shapiro, 2009). Sears and Freedman (1967), building on Festinger's (1957, 1961) work, added a caveat in their finding that people may temper their ideas with incongruent facts, rather in the manner of exceptions proving rules. However, the majority of dissonant information is avoided.

Some work on Selective Exposure has been done, resulting in the documentation of certain source preferences exhibited by non-healthcare professionals (Wathen & Harris, 2006; Lustria, 2007; Case & Johnson, 2012; Johnson, 2014; Westerwick, Johnson & Knobloch-Westerwick, 2013, 2016). Johnson (2014) cites the common information science principle that interpersonal sources are more likely to be consulted (see also Gretzel, 2007; Chang & Caneday, 2011) but suggests that in some health situations, these preferences may be altered in favour of other, traditionally authoritative, health sources such as doctors, nurses, or emergency room professionals (see also Johnson, 1997; Case & Johnson, 2012; Savolainen, 2007; Catellier & Yang, 2012; Veinot, Kim & Meadowbrooke, 2011). These source preferences may not be complete; Westerwick, Johnson and Knobloch-Westerwick (2013, 2016) found that many people engage in self-regulatory behaviours involving partial consultation of information sources, particularly when these sources might encourage or discourage health beliefs or actions.

Johnson's (1997; Case & Johnson, 2012; Johnson, 2014) Comprehensive Model of Information Seeking (CMIS) theorizes that some factors present in health information seekers result in different source choices. The CMIS, which was independently developed and then empirically tested in various areas such as health and business organizations (Case & Johnson, 2012), defines these factors as demographics, experience, beliefs, and "salience" (Johnson, 1997, p. 71), a form of personal relevance in which individuals perceive the applicability of information to a faced problem. Johnson (1997) details stages in which the varying salience alters the choice of sources consulted by health information seekers: *casual*, in which a generalized interest in health and little salience is present; *purposive-placid*, which involves slightly more salience and awareness of health, but no specific concerns; *purposive-clustered*, in which people seek information about a particular issue or disease and thus more salience is present; and *directed*, usually occurring after a disease diagnosis and where much salience is present. Johnson's (1997) contention is that sources consulted in the purposive-clustered and directed stages, where people are seeking information that personally concerns them, are generally those sources which are considered more authoritative by the seeker. Case and Johnson (2012), though, suggest that in some cases people disagree on which other sources possess authority (see also Ward, Coffey & Meyer, 2015). Catellier and Yang (2012), for example, point out that trust of certain institutions, government for example, increases the likelihood that people will seek information on material they perceive as associated with those institutions.

Monitoring and Blunting and Selective Exposure both propose some mechanisms of people's information avoidance such as not asking questions of a health professional and selecting one source over another. However, this list of patterns of behaviour seems incomplete, particularly with regards to broader range of sources and ways people interact with information. Monitoring and Blunting and Selective Exposure also suggest only partial explanations for this behaviour. Monitoring and Blunting suggests that avoidance is linked to people's innate reactions to stress, leaving out situational factors such as affect. Selective

Exposure does include affect but attributes information avoidance only to fear, omitting other forms of affect or indeed other personality traits that may function as influences on information behaviour. Thus how and why people avoid information remain open questions.

2.2.3 Health Information Avoidance

Information avoidance has been documented in the field of health, where people can avoid health information pertaining to their illnesses or conditions (Sweeny et al., 2010; Miller, 1980, 1987, 1995; Sweeny & Miller, 2012; Case & Johnson, 2012; Lu, Dzwo, Hou & Andrews, 2011; Lambert, Loiselle & Macdonald, 2009; Howell & Shepperd, 2013; 2016). Some research links health information in certain cases to increased anxiety and fear (Howell, Shepperd & Logan, 2013; Shepperd, Emanuel, Howell & Logan, 2015; Lu, Andrews & Hou, 2009; Melnyk & Shepperd, 2012; Sweeny & Miller, 2012; Miller, 1980, 1987, 1995). In a focus group study, Howell, Shepperd and Logan (2013) studied participants, 80 black adults, as to the barriers that prevented these people from undergoing screening for mouth and throat cancer (MTC), a condition for which they were particularly at risk. The researchers found that, in cases where the adults were more fearful about MTC, they were less likely to be screened, calculating that the fear of not knowing was preferable to the terror and anxiety that a positive screening would bring.

One consideration here is the notion of health information itself, for which definitions differ. The key theories described in sections 2.2.1 and 2.2.2, Monitoring and Blunting and Selective Exposure, include diverse aspects of healthcare in the category of “information,” e.g., questions posed to healthcare professionals and to adjacent staff such as receptionists and facts on informational brochures (Miller, 1980; Hyman & Sheatsley, 1947; Sweeny et al., 2010; Case & Johnson, 2012). This broad definition of information is consistent with research in the information behaviour field of study, and conforms to approaches taken by many studying the acquisition and avoidance of health information (Howell & Shepperd, 2013, 2016; Wathen & Harris, 2007; Warner & Procaccino, 2004). Howell and Shepperd (2013, 2016) comment on the avoidance of screening results, informational websites, and visits to healthcare professionals as “health information avoidance” (Howell & Shepperd, 2013, p. 258), while Wathen and Harris (2007) refer to websites, comments from healthcare professionals, and phone calls from relatives as "health information" (p. 639). Other researchers distinguish between some forms of information, e.g., Internet and social media information, information from healthcare professionals (Lund-Nielsen et al., 2011; Persoskie, Ferrer & Klein, 2014). Other researchers consider that some of the above constitute "information," i.e., written information from the Internet, social media platforms, and print resources, and other, often verbal information from healthcare professionals is part of healthcare (Lund-Nielsen et al., 2011; Kryworuchko, Hill, Murray, Stacey & Fergusson, 2012; Feenstra, Boland, Lawson, Harrison, Kryworuchko, Leblanc & Stacey, 2014). Lund-Nielsen and colleagues note that "healthcare avoidance" (p. 277), i.e., information and potential treatment from healthcare professionals, is poorly defined and may or may not include information sources recommended by healthcare professionals such as websites. However, a more inclusive approach to information can also be limited, as it may ignore differences stemming from situation, e.g., a verbal diagnosis from a healthcare professional employed in a decision-making scenario differs significantly from information provided by an online website. Patterns of avoidance may vary in these different situations.

2.2.3.1 Uncertainty Management

Some health research links avoidance and seeking of information to the management of uncertainty (Case & Johnson, 2012; Neuberger & Silk, 2016; Sairanen & Savolainen, 2010; Barbour et al., 2012; Brashers et al., 2001). Uncertainty Management Theory suggest that people experience uncertainty, defined in this dissertation as a "cognitive state causing affective symptoms of anxiety and lack of confidence" (Kuhlthau, 1993, p. 347), in various manners, depending on cognitive appraisals of the situation (Babrow, 1992; Brashers et al., 2001). Negative uncertainty, for example, a gap in knowledge, is often perceived as a stimulus to information seeking (Kuhlthau, 2004; Wilson, 1999); yet people can maintain uncertainty in situations where it is viewed as positive, for example, where remaining uncertain can engender hope when faced with a disease with a possible negative prognosis (Folkman, 2010; Shepperd, Pogge & Howell, 2016). Following this logic, people may use information to manipulate uncertainty, seeking information when negative uncertainty occurs and avoiding information in order to preserve positive uncertainty (Neuberger & Silk, 2016). In a study by Sairanen and Savolainen (2010), for example, nine students discussed their reactions to health information, citing instances where they chose to preserve uncertainty and avoid information. Avoidance was common in situations in which the students felt that information would cause them to face such negative affect as fear, anxiety and depression, and at times when the students felt particularly unable to cope with such affect due to other stressors.

One instance of the above stated preservation of positive uncertainty has been found in people's efforts to maintain their optimistic bias (Lu, Andrews & Hou, 2009; Sairanen & Savolainen, 2010; Shepperd, Pogge, Howell, 2016). The optimistic bias theory suggests that people have great confidence in their own abilities to withstand risks, as compared with their peers (Weinstein 1980, 1982). In Weinstein's (1982) study, 100 college students rated their susceptibility to 45 health- and life-threatening problems; Weinstein (1982) discovered that most saw their chances of experiencing these problems as below average. Optimistic bias has been associated with avoiding information, in particular with the avoidance of screening tests for various diseases (Lu, Andrews & Hou, 2009; Shepperd, Klein, Waters & Weinstein, 2013; Howell, Shepperd & Logan, 2013; Shepperd, Emanuel, Howell & Logan, 2015). In Lu, Dzwo, Hou & Andrews's (2011) study, for example, optimistic bias was cited as one reason that many of the 566 Taiwanese respondents surveyed indicated that they would not seek information about potential restrictions regarding arsenic-contaminated frying oil, despite the serious health risks inherent in such food and the predominant use of the oil in Taiwanese cuisine; i.e., these respondents were optimistic that their food would not be contaminated. Shepperd and colleagues (Shepperd, Klein, Waters & Weinstein, 2013; Shepperd, Pogge, Howell, 2016), though, point out that while such optimistic biases are prevalent, they can vary in intensity and thus may not always directly predict information seeking actions.

Thus much information avoidance takes place in the health domain, where the receipt of information can be associated with negative affect and where the lack of information may allow positive emotions to persist. Two common information avoidance theories are Miller's (1980, 1987, 1995, 2014) Monitoring and Blunting theory and the concept of Selective Exposure (Hyman & Sheatsley, 1947; Festinger, 1957, 1961). Monitoring and Blunting explains that people fall generally into two categories regarding their responses to stressful situations: monitors concentrate on the stress-causing problem, while blunters concentrate on the emotions resulting from that problem. These categories have been criticised as they do not explain how information avoidance takes place, and as they omit ways that people access or encounter information online. Selective Exposure, originally defined by Hyman & Sheatsley (1947) as the purposeful selection of some stimuli over others, Selective Exposure details a cognitive process wherein people having pre-existing ideas about a topic or issue seek out information that agrees with these ideas. Selective Exposure has been influential in the health domain, where the source preferences of patients and caregivers have been documented, in particular by Johnson (1997; Case & Johnson, 2012; Johnson, 2014) as explain in his Comprehensive Model of Information Seeking (CMIS). Research also exists that discusses information avoidance particularly in the area of health, although this research, as discussed, can define "health information" in dissimilar ways. Uncertainty Management Theory explains that uncertainty, here defined as both affective and cognitive, functions as a stimulus and hindrance to information seeking, with negative uncertainty being associated with information seeking and positive uncertainty linked to information avoidance. The next section (2.3) discusses reasons for information avoidance, thus detailing the literature regarding one of the research questions. This section will refer back to some of these theories in order to explain why people avoid.

2.3 Reasons for Information Avoidance

A second element of information avoidance that is not well explained is why people avoid information. Health information behaviour has to do with complex factors including, among other factors, finances, time, information searching habits, perceived efficacy of searching behaviour, and perceived efficacy of healthcare professionals recommending the behaviour (Johnson, 2014; Prochaska & DiClimente, 1983; Kryworuchko et al., 2012; Nouvet et al., 2016). This research focuses on a subset of all possible factors: personality, affect, and information source. Other factors may of course influence people's health information behaviour, but they are beyond the scope of this dissertation. Miller (1980, 1987, 1995) offers a personality-linked explanation; she found that innate reactions to stress among her participants led to distinct patterns of information behaviour, resulting in two categories, monitors and blunters. Selective Exposure suggests an affective state-based explanation: some information results in negative affect among people, which leads them to ignore this information as opposed to other, less frightening information. A third explanation related to Selective Exposure is found in the characteristics of information sources, in which some elements of some information sources cause them to be avoided. In this section, I will review these three factors, personality, affect, and information sources, as to how they relate to information avoidance.

2.3.1 Personality

Some researchers see information avoidance as a behaviour strongly influenced by personality (see Moorman & Matulich, 1993; Dutta-Bergman, 2004, 2006; Bandura, 1977; Folkman & Lazarus, 1984; Miller, 1980). Personality is here defined in accordance with Phares (1991) as "a pattern of characteristic thoughts, feelings, and attitudes that distinguishes one person from another and that persists over time and situation" (p. 4). Values and preferences are also incorporated in this definition of personality, an inclusion that points to one of the key difficulties in defining personality (Heinstrom, 2003, 2010). In her work, Heinstrom (2003) notes that studies of personality are often criticised, as it is problematic to determine whether traits belonging to people persist over time or are due to a particular, and more fleeting, situation. She additionally comments that in some situations such as extreme illness, the influence of personality can be modified or even reversed as people struggle to encompass difficult circumstances. This difficulty is made manifest in the work of some health researchers, who comment that preferences and values can be changeable in situations such as acute or end-of-life care, and thus resultant decisions regarding aspects of these situations must be achieved by continuous consultation with patients (Kryworuchko et al., 2012; Feenstra et al., 2014; Nouvet, Strachan, Kryworuchko, Downar & You, 2015). Despite these criticisms, though, personality has been identified as an influence on health information seeking and avoidance. Moorman and Matulich (1993), for example, suggest that people have different and consistent attitudes about health; this health motivation, defined as a "goal-directed arousal to engage in preventative health behaviours" (p. 210) is considered personality-based and can result in varying levels of health information seeking (Dutta-Bergman, 2004, 2006; Oduyemi, Ayegboyin, & Salami, 2016).

Similarly, Bandura's (1977) concept of self-efficacy has been related to health information seeking and avoidance (Nabi & Thomas, 2013; Lee & Hawkins, 2016). In a description of this concept, Bandura (1977) comments that people have different beliefs in their ability to follow a model of new behaviour, and thus those people with low self-efficacy may search for information less than others (see also Chatman, 1991, 1996, 1999). Johnson (1997; Case & Johnson, 2012) notes, too, that people's beliefs in the efficacy of good "health behaviours" and the efficacy of treatment, can govern their information seeking decisions and behaviours. Some of these beliefs may reflect a desire to be optimistic; Folkman (2010) posits that medical hope can be maintained by a lack of information seeking and a blind faith in personal strength, a higher power or God, or the expertise of healthcare professionals. Although Bandura's (1977) original concept is situation-specific, other later researchers conceptualize a similar "perceived competence" (Wallston, Osborn, Wagner & Hilker, 2010, p. 110) that remains constant over time (Smith, Wallston & Smith, 1995; Wallston, 1989). Bandura's (1977) concept can also be related to another personality-based trait, health perception. This trait is a complex concept determining people's personal views of their own health (Powers & Oltmanns, 2013; Lu, Andrews & Hou, 2009; Lu, Dzwo, Hou & Andrews, 2011). Health perception can be difficult to ascertain as laypeople can define health differently than do healthcare professionals (Huber, Knottnerus, Green, van der Horst, Jadad, Kromhout, Smit et al., 2011).

Self-efficacy can also be related to other personality traits. Folkman and Lazarus (1984) identify different personality-based reactions to stress, which can also affect information seeking. Stress and coping theory defines stress as a particular relationship between a person and his/her environment appraised by the person as threatening or otherwise beyond his/her ability to handle. People cope with stress either by focusing on the problem from which the stress originates or by concentrating on the emotion generated by the stress-inducing problem. Problem-focused coping has been linked to information seeking, while emotion-focused coping is connected with avoidance (Lambert & Loiselle, 2007; Howell & Shepperd, 2016; Williams-Piehota et al., 2009).

Though these links between personality and information seeking have been questioned (see Lambert & Loiselle, 2007 for one example), the link between personality traits and information seeking has been further developed in the work of Heinstrom (2003, 2010), who relates such personality traits or "dimensions" (Heinstrom, 2003, p. 165) to information styles such as invitational, exploring, purposeful, passive, and avoiding, with that last being linked to such traits as introversion and lack of conscientiousness (see also

Bawden & Robinson, 2011). One limitation of this work is that, as stated earlier, personality is difficult to determine, with multiple meanings; additionally, tests to determine personality are also controversial (see Heinstrom, 2003; Bawden & Robinson, 2011 for criticisms). Another problem is that the influence of personality on information behaviour is equally difficult to determine, due to the effect of other contributing factors such as situation and affective state (Ek & Heinstrom, 2011; Heinstrom, 2010; Heinstrom, Sormunen, & Kaunisto-Laine, 2014). Nevertheless, personality traits are often suggested as a reason for information avoidance (Miller, 1980, 1987, 1995).

2.3.2 Affective State

Affect itself is also difficult to define. It is usually explained in accordance with Nash (2010) as broadly denoting the ranges of people's emotional and mood based experience, containing lists of elements such as Nahl's (2007) "emotion, feeling, mood, sentiment, affection, disposition, preference, interest, value, motivation, intention, and goals" (p. xviii; see also Kuhlthau, 2004). However, some researchers consider affect to be equivalent to emotion (Fulton, 2009); they argue that, otherwise, affect functions as a catch-all, with all human attributes that do not correspond to cognition or behaviour being placed in the category of affect.

Despite these difficulties defining affect, negative affect in particular has been strongly linked to information avoidance. Research shows that in many cases where extreme negative affect is generated, when people fear, for example, the diagnosis of a severe and untreatable health condition or the approach of an unalterable and difficult life situation, information avoidance is more likely to take place (Melnyk & Shepperd, 2012; Sweeny & Miller, 2012; Howell & Shepperd, 2013, 2016, 2017; Dwyer, Shepperd & Stock, 2015). In their studies on avoidance of breast cancer information among undergraduate women and women over the age of 35, Melnyk and Shepperd (2012) found that greater negative affect, specifically fear, exacerbated the likelihood of these women avoiding information detailing their lifetime risk for breast cancer. Melnyk and Shepperd (2012) distributed brochures that alternately depicted controllable and uncontrollable aspects of breast cancer and then gave participants the opportunity to be tested for genes strongly linked to breast cancer, the BRCA1 and BRCA2 genes. The study found that more women who read about uncontrollable factors of breast cancer were fearful of the disease and less likely to opt to learn their risk than those who read about controllable factors. Similar experiments have taken place manipulating disease severity with similar results (Dawson, Savitsky & Dunning, 2006; Sweeny & Miller, 2012).

2.3.3 Source Characteristics

Although few conclusions have been reached about which sources are chosen when people selectively expose themselves to information, some relevant research does exist on source choice.[1] Some research has identified characteristics that affect people's choice of sources; these include perspective (Nielsen & Shapiro, 2009; Neuberger & Silk, 2016; Barbour et al., 2012) and presence or absence of personal narratives (Yli-Uotila, Rantanen & Suominen, 2013; Beck, Aubuchon, McKenna, Ruhl & Simmons, 2014; Crutzen, Cyr, Larios, Ruiter & de Vries, 2013). Nielsen and Shapiro (2009), citing research on Selective Exposure (see above), suggest that the perspective of the source, whether convergent or divergent with people's previously held beliefs, may influence its selection (see also Neuberger & Silk, 2016); however, they do not address other factors such as format. Barbour and colleagues (2012) in their survey of students and community members, found several strategies for information avoidance in interpersonal communications, usually taking place with friends, including purposefully not paying attention and changing the topic of conversation. However, these strategies were not found to be present in communications with physicians, with many people choosing to simply avoid going to the doctor. Barbour and colleagues (2012) propose that friends might be sought out over physicians, as there is a greater possibility that friends' perspectives may be convergent with the patient's own. Physicians, whose perspective is more likely to be divergent, were more often avoided (see also Lambert, Loiselle & Macdonald, 2009; Veinot, Kim & Meadowbrooke, 2011). Shepperd and colleagues (Shepperd, Emanuel, Howell & Logan, 2015) add that personal circumstances may also influence this behaviour; these researchers found that people who possessed coping resources were less likely to avoid physicians, even in situations where a divergent perspective might be expected.

---

[1] Please note that here, despite some discussion of a distinction between information 'sources' and information 'channels' (see Johnson, 1997; Case & Johnson, 2012), the term 'source' will be used here to denote both in accordance with other research that does not distinguish between the two (see for

The presence or absence of personal narratives may also affect health information seeking; however, the extent of influence may vary (Yli-Uotila, Rantanen & Suominen, 2013; Beck et al., 2014; Crutzen et al., 2013). Yli-Uotila and colleagues (2013) used an online questionnaire with open-ended questions to examine the information seeking of 74 Finnish cancer patients, finding that these patients looked to the Internet for the social support unavailable from friends and family and sought out people with narratives similar to the patients' own. Similarly, other studies claim that personal narratives are the key element in source selection, although the attention paid each source is limited. In a content analysis of celebrity health narratives, Beck and colleagues (2014) conclude that such narratives shape health policy by encouraging conversations about various health conditions. However, the effect of these narratives is often short-lived, waxing and waning as it does with fame and media attention. Crutzen and colleagues (2013), in a multi-methods health communication study, examined the effects of the social presence, i.e., human images and personal testimonials, on Internet interventions about Hepatitis A, B, and C, measuring both frequency of access and reading time. They found that while reading time between those Internet sites with social presence and those without did not differ, participants accessed the sites with social presence more frequently.

Researchers have also found that genre is a key element in information seeking in general, with specific genre-related aspects of health information material being more or less consulted in differing circumstances. Freund (2008, 2013) found that users consider genre, defined as "typified communicative actions characterized by similar substance and form and taken in response to recurrent situations" (Yates & Orlikowski, 1992, p. 299), when selecting information in response to an information need or task. Freund (2013) further demonstrated that some genres, such as web or homepages and news articles, are considered more "useful" (p. 1116) than others. This preference may also be felt in health information seeking; as other researchers point out that compact and easy-to-digest formats such as those present on health websites and news articles are preferred by health information seekers (Weng, Weng, Kuo, Yang & Lo, 2013; Lialiou & Mantas, 2015; Lazar & Briggs, 2015). Similarly, researchers posit that people have inclinations regarding the use or non-use material they view as containing medical jargon, usually defined in accordance with plain language guidelines as "specialized terms used by a group or profession" (Wright, n.d.) (Baker, 1996; York, Brannon & Miller, 2012; Williams-Piehota, Latimer, Katulak, Cox, Silvera, Mowad & Salovey, 2009). Health-related disabilities such as vision impairment may also influence choice of genre; for example, some people with vision impairments may prefer larger fonts (Lazar & Briggs, 2015; Blechner, 2015).

This review has considered three possible explanations for information avoidance. Personality traits may cause some people to avoid information, as, for example, Miller's (1980, 1987, 1995) reactions to stress. People's affective state may also result in information avoidance, with negative affect often documented as a hindering influence on people's information seeking. Information source characteristics, for example divergence from people's previously held beliefs and likings for certain genres, can also lead to information avoidance.

2.4 Related Research in Information Behaviour

Information avoidance has been relatively infrequently studied in the information behaviour field, which tends to focus on information seeking. Commonly referenced models, for example, do not mention information avoidance. One reason for this focus may be the emphasis placed by information studies on the positive aspects of information. Information behaviour, a term introduced in 1994 by Wilson but based on early communication research (see Wilson, 2010), is defined as the identification of "aspects of information-related behaviour that…appear to be identifiable, observable, and, hence, researchable" (Wilson, 1994, p. 16). A later, more complete definition sees information behaviour as the study of the "totality of human behaviour in relation to sources and channels of information, including both active and passive information seeking and information use" (Wilson, 1999, p. 249; Fisher, Erdelez & McKechnie, 2005). Information seeking, a subset of information behaviour, is defined as the "purposive seeking for information as a consequence of a need to satisfy some goal" (Wilson, 2000, p. 49) and often functions as the subject of information behaviour research (Bawden & Robinson, 2009, 2011, 2015; Case & Johnson, 2012).[2] Bawden and Robinson (2009, 2011, 2015) point to a need for a deeper understanding of information behaviour; similarly, Case and Johnson (2012) specifically identify information avoidance as an area often ignored by researchers who concentrate on information seeking behaviour. This stress on information seeking may be the reason for little discussion of the mechanisms of information avoidance; in Monitoring and Blunting, for example, information avoidance is seen as a simple negation of information searching, in this case asking questions of healthcare professionals.

2.4.1 Information Literacy

Information access tends to be seen as positive, with the information garnered viewed as beneficial (Bawden & Robinson, 2009; Case, Andrews, Johnson & Allard, 2005; Hertwig & Engel, 2016); thus information skills such as search strategies and database training are assumed to be advantageous (Eisenberg, Low & Spitzer, 2008). Studies in the field of information literacy are based on the assumption that people who do not find and

---

[2] One exception here is the work of McKenzie (2001, 2003, 2004, 2010), who refers to information practices rather than information behaviour. Information practices encompasses both Wilson's (2000) definition as well as instances in which information comes or is given through the initiatives of other agents.

use relevant and available information are somehow lacking or deficient (Gross & Latham, 2011, 2013, 2007, 2009; see Bawden & Robinson, 2009 for an opposing view). This assumption runs counter to the notion that some people purposefully avoid information.

Information literacy, a term introduced by Zurkowski (1974), is defined as a "set of integrated abilities encompassing the reflective discovery of information, the understanding of how information is produced and valued, and the use of information in creating new knowledge and participating ethically in communities of learning" (Association of Research & College Libraries, 2016, 2000). These information literacy skills are highly valued, linked as they are to the new information economy, and subsequently to economic success (Eisenberg, Lowe & Spitzer, 2008; Nazari & Webber, 2012). This definition of information literacy has been questioned in other work (Lloyd, 2005, 2006, 2011, 2012, 2014; Lloyd & Somerville, 2006; Bawden & Robinson, 2009; Julien & Williamson, 2010), and recent changes to the Framework for Information Literacy for Higher Education (Association of Research Libraries, 2016) refers to foundational ideas or "threshold concepts" (Townsend, Hofer, Hanick & Brunetti, 2015, p. 23) such as a comprehension of the value of information, rather than skills such as how to operate an informational database. This new framework serves as a way to shift the discipline's attention away from a checklist and towards underlying concepts that people need to understand in order to be information literate. However, one criticism raised is the difficulty this new framework presents to teachers of information literacy, who may be unable to translate these ideas into workable lessons (Hosier, 2015).

2.4.2 Information Overload

One exception to the general perception of information as positive within information behaviour is the attention paid by some researchers to negative aspects of information. Researchers have noted the existence of a broader range of information behaviours outside of information seeking. One example is information encountering, in which people "bump into" (Erdelez, 1999, p. 25) information rather than actively seeking it (see also Erdelez, 2004). However, these behaviours still indicate that reception or seeking of information has positive results. Bawden and Robinson (2009), on the other hand, identify difficulties with information that have to do with the amount of information searching necessary in the information age, what they call "information pathologies" (p.

180): information overload, information anxiety, infobesity. The first of these, information overload, is a term popularized by Toffler (1970) who speculated that vast amounts of information have the potential for instilling negative affect, what he termed shock, in information seekers (see also Johnson, 2014). In Toffler's (1970) view, limits on the human ability to deal with multiple messages can cause people to be overwhelmed by too much information (see also Miller, 1956; Bawden & Robinson, 2009; Johnson, 2014). These feelings of overload can be exaggerated in times of crisis; research on stress states that cognitive activity in stressful times taxes cognitive resources, leaving little for information processing (Johnson, 2014).

The association of information with the production of negative affect is present in some studies of information behaviour, particularly with regards to health information (Lu, Dzwo, Hou & Andrews, 2011; Melnyk & Shepperd, 2012). Many studies focus on the importance of access to health information (Howell & Shepperd, 2013; see Dwyer, Shepperd & Stock, 2015 for one example). However, other researchers have found that both information searching and information acquisition can lead to the production of anxiety and fear (Sweeny & Miller, 2012; Toffler, 1970; Johnson, 2014).

The majority of work in information behaviour has thus focused on information seeking, with a strong positive value assigned both to skills that enable people to seek information and to the information itself. Such an emphasis may give rise a more simplistic view of information avoidance, as simply the opposite of information seeking; however, other behaviours have been noted with regards to people's interactions with information. A minority of researchers, though, have noted that some information access is associated with negative affect, particularly in the area of health.

2.5 Research in Health Fields

Some research conducted in fields relating to health has to do with information avoidance. Researcher in the field of health communication perform studies that examine how people respond to heath messages, while consumer health studies consider the changing role of patients and caregivers in a system which increasingly regards these people as consumers. This last field has received some criticism regarding the attitudes held by health consumer advocates concerning information seeking, also detailed here.

2.5.1 Health Communication

The field of health communication, which measures the effects of health interventions and communications from health providers and organisations to patients and caregivers, places a strong emphasis on the positive nature of information (Nabi & Thomas, 2013; York, Brannon & Miller, 2012; Williams-Piehota et al, 2009). Much health communication research has to do with passive attention, which is contrasted with information seeking, the "purposive seeking for information as a consequence of a need to satisfy some goal" (Wilson, 1999, p. 49; Howell & Shepperd, 2013). Passive attention can include such behaviours as watching a television commercial, viewing website pop-up advertisements, or listening to someone speak (Wilson, 1999; Lambert & Loiselle, 2007). Thus health communication deals not with people's active information seeking, but with their reception and use of information provided by the health care system. Here such reception and use is generally associated with positive benefits; however, health communication does emphasize that information must be presented in certain ways in order to increase these benefits. In Nabi and Thomas (2013), for example, a health communication experimental study tested the effects of television advertisements about healthy eating on snack choices; however, only advertisements that were aired during reality television programs about weight loss led to better snack choices among participants. Similarly, York, Brannon and Miller (2012) examined how website pop-ups can alter attitudes about binge drinking among undergraduates, finding that some pop-ups on websites for advertising commodities other than alcohol led to less alcohol consumption, although other pop-ups located on sites advertising alcohol did not. One aspect of health communication is the self-management of chronic diseases, in which patients may be expected to adhere to complex management regimens requiring much attention to information (Barbarin, Klasnja & Veinot, 2016). In a study of 38 families, Barbarin, Klasnja and Veinot (2016) concluded that those families who kept informal records of their personal health were able to meet their information needs, including the temporal need to reflect on the illness experience.

Some health communication research is problematic in that it tends to conflate information reception with information use, with such "use" variously defined (see Williams-Piehota, Latimer, Katulak, Cox, Silvera, Mowad, & Salovey, 2009; York, Brannon & Miller, 2012 for examples). Savolainen (2009) proposes two explanations for information use: knowledge creation and decision-making (Savolainen, 2009). Health communication tends to lean towards the second form of use, decision-making, when people may simply be using the information garnered to fill knowledge gaps. For example, Williams-Piehota et al. (2009) describe information tailoring, in which messages are tailored according to characteristics of respondents such as their gender or their willingness to receive information (see also Johnson, 2014). In the view of Williams-Piehota and colleagues (2009), this tailored information will result in changed behaviour, as the information will be more likely to be greeted with increased scrutiny. However, this perception is not grounded in research on how people change their health behaviours, as seen in the Transtheoretical Model of Health Behaviour Change (Prochaska & DiClemente, 1983; Prochaska, DiClimente & Norcross, 1992). This model lists five stages through which people progress when changing health behaviour, precontemplation, contemplation, preparation, action, and maintenance. The model posits that people proceed linearly through these stages, but they can stop frequently along the way, either temporarily or permanently. These stages demonstrate that behavioural change is much more complex than merely receiving and acting upon information.

Thus health communication research tends to emphasize a positive view of information, with the receipt of relevant information assumed to lead to better health behaviours. One problematic aspect of health communication is that a common definition of "use" of information is not currently received. However, the field does stress that information must be presented in such a way that people accept it.

2.5.2 Consumer Health

Despite evidence of information avoidance in health, many researchers have unaccountably either ignored people's avoidance of information or portrayed people who avoid information as in some way lacking. Information access is often seen as beneficial, with information seeking the dominant—and correct—approach. This view predominates in the consumer health movement in which information access is often described as "empowering" (Wyatt, Harris & Wathen, 2010, p. 2). This consumer health movement views health information as a purchasable consumer good much like cars or clothing, to which access is highly desirable (Wyatt, Harris & Wathen, 2010; see also Johnson, 2013). Access to information can allow patients to cross previously established boundaries between doctors and patients, permitting patients to access medical knowledge (Wilson, 2010; Aronson, 2013; Campbell, Scott, Skovdal, Madanhire, Nyamukapa & Gregson, 2015). Wilcox (2010) describes the concept of what she calls an "expert patient" (p. 41). Although she does indicate that this expertise can mean the personal experience of being a patient as well as healthcare professional expertise, Wilcox (2010) points to the use of the term expert patient as a signifier that the doctor-patient hierarchy is, in consumer health, equalized.

In this movement, new opportunities to search are viewed as advantageous (Wyatt, Harris & Wathen, 2010; Johnson, 2014). For some advocates of the consumer health movement, information access can mean an ability to engage with the health care system, becoming an active participant in this system and in one's own health (Wilcox, 2010). Being active is generally viewed as positive; Henwood, Harris and Spoel (2011) point to the use of the word "choice," stating that this word is often used in discourses of consumer health. These researchers comment that "choice" is often not representative of how health care is practiced, as budget considerations can restrict the number of available treatment alternatives in both public and private systems. Nevertheless, these researchers posit that the "logic of choice" (Henwood, Harris & Spoel, 2011, p. 2027), with its implication of personal freedom on the part of the patient, dominates discourses of consumer health (see also Adams, 2010; MacGregor & Wathen, 2014).

This positive view may be one reason why patients with chronic conditions are being encouraged to practice *self-management*, a series of skills, attitudes and behaviours that allow patients to become more knowledgeable about their health and thus able to "live well" (Adams, Greiner & Corrigan, 2004, p. 57) with any conditions they might have (see also British Columbia Ministry of Health, 2011). Researchers, however, have pointed out that the consumer health notion of health information access as empowering may not be completely valid (Wyatt, Harris & Wathen, 2010; MacGregor & Wathen, 2014; Bakardjieva, 2010; Veinot, 2010). Indeed, "there is little evidence to demonstrate that improved access to health information...actually ‘empowers’ patients” (Wyatt, Harris & Wathen, 2010, p. 2). Many studies, in fact, suggest the reverse, that information seeking disempowers patients, becoming a form of “healthwork” (Mykhalovskiy & McCoy, 2002, p. 17) a term denoting the active and purposeful work that people do to manage their health. Researchers have posited that some people can find healthwork onerous and time-consuming (MacGregor & Wathen, 2014), which can lead to a preference for a more traditional model of healthcare whereby healthcare professionals do the healthwork and patients remain passive (Lawn, McMillan & Pulverenti, 2011).

Another difficulty with consumer health is the contrast presented by this new role of the patient as an informed questioning person to the role previously established by traditional health care (Aronson, 2013; Buist, 2011; Campbell, Scott, Skovdal, Madanhire, Nyamukapa & Gregson, 2015). Healthcare professionals and researchers have noted the desire in patients to be “good patients” (Aronson, 2013, p. 796); however, “good patient” is a contested term, with studies showing that healthcare professionals and patients can view “good” in differing and often contrasting ways. Aronson (2013) concluded that patients and caregivers may feel a strong impulse to be passive and unquestioning of medical authority, while Buist (2011) noted that patients should be exhorted to be active participants in their health. Campbell and colleagues (Campbell, Scott, Skovdal, Madanhire, Nyamukapa & Gregson, 2015), in their study of patient-and-nurse interactions in a Zimbabwean free clinic discuss various views of how to be a “good patient” (p. 404) and concluded that patients could use different behaviours from presenting healthcare professionals with easy-to-solve problems to adhering completely to good health behaviours in order to establish themselves as good patients.

Much health research assumes that people wish to know about their health. In particular, the viewpoint of consumer health portrayed health patients who are empowered by such information and more in control of their own health. However, complicated attitudes surround patients and their willingness to assume healthwork; while consumer health assumes that all patients want to know about their health, the truth is far more complex. These assumptions on the part of consumer health, though, are one reason why there is little research on information avoidance scratching below the surface of this phenomenon.

2.6 Conclusion

Researchers have long acknowledged that people avoid information, particularly in cases where they are experiencing negative affect (Sweeny, Melnyk, Miller & Shepperd, 2010; Miller, 1980, 1987, 1995; Howell & Shepperd, 2013, 2016, 2017). However, information avoidance behaviour has been infrequently studied, with limited research detailing how and why people avoid information. Two concepts related to information avoidance are Miller's (1980, 1987, 1995) Monitoring and Blunting theory and Selective Exposure (Hyman & Sheatsley, 1947; Festinger, 1957, 1961), both of which suggest some patterns of avoidance behaviour as well as some explanations for information avoidance. Patterns of behaviour suggested are not asking questions of health professionals and choosing to consult one information source over another, while three possible explanations for this behaviour are personality, affect, and information source characteristics. Part of the reason for this lack of detail may be the value placed on information seeking and on information in general. Although some information behaviour researchers look at the negative aspects of information, most do not, with the skills needed to obtain information being viewed as highly valued. Even in health, in which much information avoidance has been documented, many researchers stress the positive aspects of the information, in particular in consumer health. Thus issues still remain, particularly around the patterns of behaviour that form information avoidance and the explanations for this behaviour. These issues provide the basis for the research undertaken and described in the following chapters, which answer the following research questions: 1. What factors contribute to information avoidance? More specifically, to what extent do personality traits, situational affect, and the nature of available information sources influence information avoidance? 2. What are the mechanisms of information avoidance?

3 Methods

3.1 Introduction

Rather like Pontius Pilate, the Roman general who announced to Jesus that there were multiple forms of truth, neopragmatists such as myself also believe that there are *truths*: that much in the world possesses a higher, unknowable truth beyond the level of linguistic explanation, an Everest-type goal to which one should aspire (Patton, 2002; Feilzer, 2010; Johnson & Onwuegbuzie, 2004; Rorty, 1999). As these researchers-cum-philosophers suggest, attempting to embody this Everest-style truth in research is extremely difficult; they advocate instead more "commonsense" (Johnson & Onwuegbuzie, 2004, p. 20) approaches to find solutions to practical problems. Thus in lieu of finding this ultimate, all-encompassing truth about information avoidance, my aim in conducting this research is to reach a "real world" (Creswell & Plano Clark, 2007, p. 28) understanding of how and why people avoid information.

Therefore, I took a mixed methods approach in examining people's reasons for and process of avoiding health information when faced with health difficulties. In choosing mixed methods, I bore in mind Fidel's (2008) and Greene's (2005) arguments that care must be taken to ensure that the methods are integrated together rather than appearing as a precise delineation of research question equalling research method. Thus the methods were an online survey containing qualitative and quantitative elements and using an online labour market for recruitment and an experimental user study which included quantitative scales, a timed session of information seeking and qualitative interviews. Both studies were used to answer both research questions.

Data collection began with the Affect and Avoidance study consisting of an online survey, conducted in January of 2015. 198 participants were surveyed using a questionnaire exploring their general information seeking preferences as well as their emotional responses to health scenarios. The survey was conducted via an online labour market, Amazon's Mechanical Turk (2017) (MTurk). A user study, the Interview and Interaction study, was then conducted in the summer of 2015 in a large Canadian West Coast city, with 35 members of the general public. This second study collected demographic and health-related information, and included both a timed health information interaction session and a qualitative interview.

The following section will detail the specifics of the methods used to conduct this research, beginning with the research design and followed by recruitment and participation, measures, procedures and data analysis for each study.

3.2 Research design

Hailed as an "intellectual and practical synthesis" (Creswell & Plano Clark, 2007, p. 129) of qualitative and quantitative methods, mixed methods are selected when a problem benefits from being viewed comprehensively from multiple angles. By "methods" I mean "methodologies," which includes issues and strategies involving data collection, research, and philosophical stances (see Greene, 2006), which Johnson, Onwuegbuzie and Turner (2007) state is the usual interpretation of the word "methods" in mixed methods research.

Of the research that exists on information avoidance, much examines separate aspects of avoidance, rather than the topic as a whole (Sweeny, Melnyk, Miller & Shepperd, 2010; Hertwig & Engel, 2016). Researchers most often examine only one situation or condition; thus Miller (1980) studied gynaecological patients waiting for surgery, while Sweeny and Miller (2012) presented university students with potential romantic entanglements. By contrast, these studies asked people about their health information as it pertained to numerous conditions, thus examining information avoidance as a broader phenomenon and at a higher level of granularity.

This research project is comprised of two studies, an online survey and a mixed methods user study and interview. A complementary mixed methods approach, in which different and overlapping facets of a topic are studied (Greene, Caracelli & Graham, 1989), was chosen to look at the influencing factors of why and how people avoid information in the area of health. A sequential explanatory strategy was used, with a primarily quantitative study (QUAN-qual, in the words of Creswell and Plano-Clark, 2007) being first, followed by a primarily qualitative (QUAL-quan) study. Concurrent methods were viewed as impractical as the implementation and results of the first study were employed to aid in the design of the second study. For example, responses given to an optional comment in the first study were employed to aid in the creation of an interview guide in the second study. This design was selected with the intent of using the primarily quantitative study as an informative base from which to explore some aspects of this issue in finer detail. The design also proved especially beneficial in this case as unexpected results arose from the first study; i.e., a very small amount of participants admitted to avoiding information, leading me to consider aspects such as the societal value of health information seeking that might have contributed to this finding (Creswell & Plano-Clark, 2007).

In research such as this that involves discussion and exposure to information regarding health concerns that may have a strong emotional and personal impact on participants, ethics are of foremost importance. Both studies used scenarios that described health concerns in some detail, and in the second study, participants were also exposed to potentially distressing health information material and were asked questions regarding their own personal health concerns. Ethics approval for these studies was sought and granted through the University of British Columbia Behavioural Human Ethics Board. Care was also taken that participants should be comfortable; i.e., all questions, both written in the online survey and verbal, were optional (see Appendices A and B for questionnaires), and a private room was used for in-person sessions. Additionally, procedures such as interviews about general health information seeking and instruments such as descriptions of health concerns were based on those from previous studies in which no ill effects were reported in participants (Miller, 1980; Melnyk & Shepperd, 2012; McKenzie, 2001; Lambert, Loiselle & Macdonald, 2009). (See Appendices C and D for recruitment and consent forms.)

3.3 Research Questions

The studies were designed to answer the following research questions:

1. What factors contribute to information avoidance? More specifically, to what extent do personality traits, situational affect, and the nature of available information sources influence information avoidance?
2. What are the mechanisms of information avoidance?

The individual studies are detailed in the following sections. Ethics approval was applied for and granted for both studies through the University of British Columbia Behavioural Human Ethics Board.

3.4 Study 1: Affect and Avoidance Study

The Affect and Avoidance Study, a scenario-based assessment of the role of affect and other factors on health information avoidance, was conducted in January and February of 2015. It consisted of an online survey designed to measure respondents' personality traits and emotional responses in relation to self-reported information seeking and avoidance questions. The study also functioned to test the effect of ten hypothetical medical scenarios varied by disease (comprising five diseases) and level of severity (comprising two levels of severity) on user behaviour and affect. (Please see Appendix A for the questionnaire used in this study.)

3.4.1 Procedure and Instruments

Data were collected using online questionnaires hosted by LimeSurvey (Schmitz, 2015) software. Recruiting was carried out via crowdsourcing software, Amazon's Mechanical Turk (2017) (MTurk), chosen due to its ability to reach a large number of participants quickly and the fact that the survey was short and well-suited to this micro-task crowdsourcing platform (see Paolacci & Chandler, 2014; Paolacci, Chandler, & Ipeirotis, 2010; Rand, 2011). Participants began the Affect and Avoidance Study by logging on to MTurk (2017). After indicating their consent to participate, they followed a link to LimeSurvey (Schmitz, 2015), a survey instrument with content stored in Canada[3], which led to the questionnaire. Separate questionnaires were created for each of the ten scenarios, and these surveys were released sequentially. The first 20 participants responded to the first scenario, then next 20 to the next scenario, and so on until all 10 scenarios were complete. Overall, each participant responded to a single scenario of the ten scenarios used. Upon completion, participants were given a code, which, when entered into MTurk (2017), signified completion of the study and made them eligible for compensation. Participants' MTurk (2017) IDs were checked to ensure that participants completed the survey only once each; no duplications were found.

The online questionnaire (see Appendix A) was presented as a series of web pages. All questions included a non-response option.

The first section contained demographic questions asking participants to indicate their gender, age, and education level.

Next, participants were asked how they perceived their current level of health on a five-point Likert scale, a question taken from the RAND-36 Health Status (Hays & Morales, 2001), as health perception has been linked to information avoidance (Lu, Andrews & Hou, 2009; Shepperd, Klein, Waters & Weinstein, 2013). Participants were also asked how they perceived their health as compared with one year ago, measured on a second five-point Likert scale. This second question was included as researchers point out the difficulty of measuring self-perception using a single item (Oh & Cho, 2015). In addition, it was felt that a question involving a comparison with another time period (here "one year ago") would allow people to give a more accurate description of their health.

Internet usage was measured using a six-point Likert scale, using a scale tested in a previous study (Freund & Berzowska, 2010). Participants were then given the test question asking them to define disease, which was used to assess the quality of responses by measuring English language and attention levels.

Next, participants' Need for Cognition was measured using the Need for Cognition scale (NCS). Originally developed in 1982 by Cacioppo and Petty, the NCS scale was chosen as it represents one personality-based trait that might influence health information avoidance: the Need for Cognition, long held to be a trait that influences people's overall desire to look for information (Wilson, 1997; Cacioppo, Petty, Feinstein & Jarvis, 1996). The scale consists of eighteen statements, of which sample statements include "I would prefer complex to simple problems." "The notion of thinking abstractly is appealing to me." "I usually end up deliberating about issues even when they do not affect me personally." Participants rate the statements on a five point Likert scale, ranging from extremely uncharacteristic to extremely uncharacteristic. Although some forms of this scale contain a nine-point scale, the five-point scale was chosen as research shows participants have difficulty responding to scales with more than seven options (see Peterson, 2000). The scale is reliable, with Cronbach's alpha measurements reported as being between 0.82 and 0.88 (Salvador, Arquero & Romero-Frias, 2015).

Emotional state was tested using the twenty point Positive and Negative Affect Schedule short form (see Appendix B; PANAS), developed in 1988 by Watson, Clark and Tellegren. PANAS is well established as a measure of emotional response and has been much used in research on information seeking (McCay-Peet, Laimas & Navalpakkum, 2012; Lopatovska, 2014). Using this scale, participants stated the extent to which they felt a certain emotion as measured on a five point Likert scale ranging from 1 (very slightly or not at all) to 5 (extremely). Ten emotions are ranked as positive affect (PA); 10 are ranked as negative affect (NA). In this scale, high PA is signalled by such terms as "excited," "delighted," "active," and "determined," while a score of low PA represents the opposite: lethargy and depression. High NA is represented by another broad range of moods, "nervous," for example, or "afraid," "guilty," or "hostile," while low NA again points to the opposite of these moods, calm and relaxed (see Watson, Clark, & Tellegren, 1988). Although PANAS can be used to determine current and past emotional states, including last week, last month, and last year, the wording regarding the current emotional state was used, i.e. "This question will ask you about your current emotional state." This scale is reliable, with Chronbach's alpha measurements reported as ranging from .82 to .86 for the positive factors and .84 to .87 for the negative factors (Serafini, Malin-Mayor, Nich, Hunkele & Carroll, 2016; Thompson, 2007).

At this point, participants were shown a scenario, one of ten. As noted above, scenario assignment was based on the order of registration of participants with only one scenario per participant. In these scenarios, participants were informed that they had just been diagnosed with a specific medical condition. Participants were also asked about their level of knowledge and perceptions of this condition. This between-subjects design, with each participant experiencing only one scenario, was chosen to maintain a level of naturalism (Polit, 2010); i.e., diagnoses usually come singly.

Participants then completed the PANAS scale again to measure their emotional response after exposure to the scenario.

Next, participants were asked how likely they would be to look for information about the condition described in the scenario, as measured on a six-point Likert scale, and finally, were asked to give an optional comment providing more details about their choice.

3.4.2 Scenarios

With significant input from my supervisory committee, I created ten hypothetical disease scenarios describing various health conditions and asking participants to imagine that they had just been informed that they were diagnosed with this condition (Table 3.2). Hypothetical scenarios have been much used in other research on information seeking and avoidance (see Miller, 1980; Weinstein, 1982; Dawson, Savitsky & Dunning, 2006; Melnyk & Shepperd, 2012; Sweeny & Miller, 2012) and are usually cited as stimuli for either information seeking or avoidance. Scenarios created for this study were based on those used in previous studies (Dawson, Savitsky & Dunning, 2006; Melnyk & Shepperd, 2012; Sweeny & Miller, 2012; see also Miller, 1980; van Zuuren & Hanewald, 1993; van Zuuren & Muris, 1993). I emulated the style, wording, and format of scenarios found in these studies, substituting new conditions. All scenarios started with a sentence stating, "Your doctor tells you that you have…" and concluding with a medical condition. This sentence was followed by a short definition and some side effects of the condition. Finally, two or three possible treatments were included. Although scenarios used in previous work began with a sentence such as "Imagine you are in your doctor's office," this sentence was omitted as other researchers pointed out that these studies unduly emphasized the hypothetical nature of the scenario and resulted in participants feeling overly removed from the study (Evans et al., 2014; Dawson, Savitsky & Dunning, 2006; see also Miller, 1980; van Zuuren & Hanewald, 1993; van Zuuren & Muris, 1993).

The employment of scenarios has been questioned, as researchers point out that these are artificial stimuli and thus responses are not necessarily reflective of people's real behavior (Lambert & Loiselle, 2007). Researchers have, though, pointed out the many benefits of the use of these scenarios. Hypothetical scenarios may allow for participants to feel some psychological distance and thus remove observer effects such as "yea-saying." Such scenarios have also been seen as ways to ethically examine people in problematic situations (Sweeny & Miller, 2012; Evans et al., 2014) and also as a useful way to demonstrate how people react to similar but slightly modified situations (Evans et al., 2014; van Zuuren, Groot, Muris & Mulder, 1996; Dawson, Savitsky & Dunning, 2006; Melnyk & Shepperd, 2012). The situations in this study, for example, all began with the same phrase but included different conditions and different side effects, a tactic similar to other studies that used versions of the same scenario to measure different factors that might influence people's information seeking (Dawson, Savitsky & Dunning, 2006).

The Affect and Avoidance Study employed a range of conditions from potentially fatal to non-life-threatening and from permanent to temporary (see Table 3.1 for a list of conditions). Although it is difficult to determine people's impressions concerning health conditions and thus problematic to label any condition more severe than another, van Zuuren and colleagues (van Zuuren, Groot, Muris & Mulder, 1996) point out that medical stressors center around two factors: the potential controllability of the disease and the potential predictability of the disease. Thus acoustic neuromas, lupus, and meningiomas were selected as the courses of these conditions are less likely to be predictable. For example, these conditions are fatal in some cases but not in others. Crohn's disease and Bell's palsy, while also unpleasant, are much less likely to be fatal, given that any condition can be fatal in extreme circumstances such as advanced age or unusual complications. Similarly, Crohn's disease can more easily be controlled with medication and Bell's palsy with time (it is usually a temporary condition), while meningiomas, lupus, and acoustic neuromas are less easily controllable.

These conditions were chosen in reference to other studies, which have used similar distinctions between "severe" and "less severe" descriptions of diseases (Dawson, Savitsky & Dunning, 2006; Melnyk & Shepperd, 2012; Williams-Piehota, Latimer, Katulak, Cox, Silvera, Mowad & Salovey, 2009; Flight, Wilson, Zajac, Hart & McGillivray, 2012). Conditions chosen were relatively rare, and it was hoped that their rarity would encourage a response uninfluenced by experiences participants had with their own or others' health. The conditions were gender- and age-neutral and thus able to strike anyone at any time. Table 3-1 lists the conditions used with definitions.

Table 3-1

Conditions used in Study 1 with definitions

Condition	Definition
Acoustic neuroma	A benign tumour located in the ear canal
Bell's palsy	Idiopathic facial paralysis (usually temporary)
Crohn's disease	A digestive disorder
Lupus	An autoimmune disorder
Meningioma	A malignant or benign tumour located in the meninges of the brain

Table 3-1 Conditions with descriptions

Scenarios were also varied with respect to the tone of the description. For each disease, two levels of description were created: strong negative and weak negative (see Table 3-2 for the full set of scenarios). These changes in wording were modelled on other studies in which participants were exposed to conditions described alternately as treatable and untreatable, and severe and mild (Dawson, Savitsky & Dunning, 2006; Melnyk & Shepperd, 2012; Williams-Piehota et al., 2009; Flight et al., 2012). In the strong negative scenario, side effect severity was emphasized and more specific details were provided (e.g. the growth of the tumour is described as 1.5mm/year in the strong negative scenario and as 'the tumour grows slowly' in the weak negative scenario). The number of scenario treatment options given varied depending on the options cited in the medical literature I used to construct the scenarios. For example, the treatment for lupus was cited as medication, while the treatment for meningiomas was noted as observation, surgery, or radiation. This use of varying treatment options reduced some of the control and consistency between scenarios; for example, decision-making regarding surgery can be more complex than decision-making regarding medication (Evans et al., 2014). However, this disparity in treatment options was intended to reflect the nature of the underlying condition.

Table 3-2

Scenarios used in study 1 by condition and scenario tone

Condition and Scenario tone	Scenario
Acoustic neuroma: strong negative	Your doctor tells you that you have an acoustic neuroma, a noncancerous tumour located in your ear and close to your brain. It has a number of side effects, the most common being hearing loss in the tumour ear; others include facial paralysis, loss of brain function, and even death. The tumour grows at a rate of 1.5mm/yr. Treatment options are observation, surgical removal or radiation.
Acoustic neuroma: weak negative	Your doctor tells you that you have an acoustic neuroma, a rare noncancerous tumour located on the hearing nerve connecting your ear to your brain. It has a number of side effects, but these are mild in most cases, the most common being loss of hearing in the affected ear. The tumour grows slowly and if small, can be managed by watchful observation. If you do need treatment, radiation and surgery are options.
Bell's palsy: strong negative	Your doctor tells you that you have Bell's palsy, in which a problem with the nerves in your skull results in complete or partial facial paralysis. This condition has a number of side effects, including not being able to move at least 50% of your face, to blink, smile, or frown properly for weeks. Bell's palsy can result in permanent facial problems. Treatments include steroids, surgery, and physiotherapy.
Bell's palsy: weak negative	Your doctor tells you that you have Bell's palsy, in which a problem with the facial nerve results in difficulties in moving parts of the face. Bell's palsy has a number of side effects, including problems making facial expressions, winking, lifting one eyebrow, or smiling broadly. In most cases, Bell's palsy disappears in a few weeks. If treatment is needed, steroids, physiotherapy, and in very rare cases, surgery can all help.
Crohn's disease: strong negative	Your doctor tells you that you have Crohn's disease, a severe form of inflammatory bowel disease, which requires immediate treatment. This disease, if untreated, will lead to a number of side effects, including the breaking of your intestine. Surgery is required, and a number of different surgical options must be considered.
Crohn's disease: weak negative effect	Your doctor tells you that you have Crohn's disease, a form of inflammatory bowel disease in which your digestive system does not function properly. Crohn's has a number of side effects, which can include weight loss, low iron, and damage to your intestine. By and large, people who have this disease can live full and productive lives.

Scenarios used in study 1 by condition and scenario tone

Condition and Scenario tone	Scenario
Meningioma: strong negative	Your doctor tells you that you have a meningioma, a type of brain tumour that in your case requires immediate treatment. If untreated, meningiomas can lead to serious side effects, including problems with brain function. Treatment options are surgery and radiation.
Meningioma: weak negative	Your doctor tells you that you have a meningioma, a type of tumour located in the membranes surrounding the brain or spinal cord. Meningiomas have a number of side effects; however, most people only experience these side effects when the tumours are large. Meningiomas may only need to be observed.
Lupus: strong negative	Your doctor tells you that you have lupus, a chronic inflammatory disease that occurs when your body attacks your own tissues and organs. This disease has a number of side effects, including brain and kidney damage. This disease will require you to significantly adjust your lifestyle.
Lupus: weak negative	Your doctor tells you that you have lupus, a chronic inflammatory disease that occurs when your immune system does not function properly. Lupus has a number of side effects, including problems with your kidneys and forgetfulness. If you have lupus, it can be managed with medication.

Table 3-2 Strong and weak scenarios

3.4.3 Participation and Recruitment

201 participants, 111 men and 90 women, received 50 cents for completing a questionnaire, which took approximately 5 minutes. Another 8 participants failed to complete the study; these people did not receive compensation, and these data were discarded. These participants were recruited primarily from among MTurk (2017) workers with experience (minimum completion of 500 previous tasks) and high rates of completion of tasks started (over 90%) (https://www.mturk.com/mturk/welcome)[3]. The rate of payment was set in accordance with recommendations from MTurk (2017) documentation and prior research (Paolacci & Chandler, 2014). In accordance with the same documentation and research, only participants who completed the study received payment. Additionally, quality control in the form of a basic skill-testing question was used in order to

---

[3] I relaxed the requirements on workers for the final survey due to lower levels of recruiting. This was not a concern as a quality control mechanism, a skill-testing question regarding the nature of disease, was built into the survey.

ascertain that participants were paying attention and providing relevant responses. 198 participants answered this question correctly; 3 participants did not and their data were discarded. Thus, the final total of participants was 198.

The study sample of 198 participants included 110 (56%) men and 88 (44%) women. 119 (60%) had a college diploma or higher level of education. The majority, 166 (84%), saw their health as good or better, and few (16 or 8%) indicated a negative change in their health from last year. Most participants were familiar with Internet searching, with over 80% searching regularly, i.e., daily or a few times per day, for personal interests, entertainment and news information. Almost two thirds (117 or 59%) also sought health information monthly or a few times per year. 133 participants, or 67% of the survey sample, were under 40, with only 10 or 5% being 60 or over.

All participants were English-speaking and North American, although only language was a criterion of participation. English-speaking participants were selected as the survey instrument was in English. The skill-testing question asking the definition of the word "disease" also served to verify people's knowledge of English as well as their attention to the survey (Paolacci, Chandler & Ipeirotis, 2010). Country of origin was not a criterion. Although there are differences in local and national health care systems, these differences and their effect on people's information seeking were deemed outside of the scope of this research.

3.4.4 Data Analysis

Data analyses were conducted using SPSS Statistics for Windows (Version 20.0) (2011), and MS Excel for Mac (Version 14.5.8) (2011). The significance threshold for all tests was set at .05. Bonferroni corrections were used when necessary.

Need for Cognition (NfC) scores were determined as per the guidelines (Cacioppo & Petty, 1982); i.e., scores were assigned to each point on the Likert scale, and these scores were added, with some reversed scores included as necessary. Frequency counts were calculated for the question asking for reported information seeking in response to the scenarios question. All characteristics were tested for associations with this question; i.e.

Spearman's correlations were calculated for Information Seeking and the factors Age, Level of Education, General Health Perception, and NfC.

PANAS scores were also examined as per guidelines, total scores for positive and negative affect being calculated separately. Scores are assigned to points on the Likert scale, and scores are added accordingly. To assess the impact of the scenarios, the pre- and post-scenario PANAS scores were compared using Related Samples Wilcoxon Signed Rank tests. The strong and weak negative pre- and post-scenario PANAS scores were also compared using ANOVA if normally distributed and Kruskal-Wallis tests if not.

Reported information seeking in response to separate scenarios was also examined to determine whether there was a differential impact by scenario or some other factor. Spearman's correlations were employed to test for associations between overall pre- and post- positive and negative PANAS scores as well as for the individual emotions included in the PANAS scale. Results from the two open questions were analyzed using qualitative content analysis (Sandelowski, 2000, 2010). These results comprised of 198 short written responses to the question 'what do you think of when you hear the word(s) ___________?' and 157 optional comments given in response to the reported information seeking question. Qualitative content analysis was selected as it has been identified as the least theoretical form of qualitative analysis and thus most suited to my theoretical stance of neopragmatism. Related to grounded theory, qualitative content analysis is a "dynamic form of analysis of verbal and visual data that is oriented toward summarizing the informational contents of that data" (Sandelowski, 2000, p. 238). Both inductive and deductive codes are employed; thus codes included the pre-existing codes "information seeking" and "information avoidance" but also comprised data-driven codes such as "healthcare professionals as sources."

3.5 Study 2: Interview and Interaction Study

The Interview and Interaction with health information materials study, here known as the Interview and Interaction Study, took the form of a user study in which participants were given a scenario and interacted with a collection of health information material and were then interviewed regarding their health information behaviour. The interviews covered both their behaviour in response to the scenario and their general health-related information behaviour. This study was an extension of the first study and used many of the same instruments, including the demographic and health demographic questions, as well as selected scenarios. However, in this study, participants had the opportunity to actually select and interact with online information and to discuss their experiences with health information in detail. This study began with a preliminary test of the procedures and instruments with one participant. I had originally planned to perform the PANAS survey both before and after the scenario, as I did in the Affect and Avoidance study. During the preliminary test, I found that this procedure resulted in a much longer computer time. Additionally, the participant had a negative response to repeating the scale within a very short time frame and often did not change the scores he gave various emotions. Given that the Affect and Avoidance study had already validated the emotional impact of the hypothetical scenarios, I decided to run the second study with only one application of the PANAS, following introduction of the scenario.

3.5.1 Procedure and Instruments

Study sessions were conducted individually in various locations in the downtown area of a major city. Sessions were conducted in a private space, i.e., a private room located either in a public library or a community centre. Participants were asked whether they were comfortable in this space before the commencement of the session. After completing a consent form (see Appendix D), participants began the Interview and Interaction Study with a questionnaire (see Appendix B), presented to participants on a laptop computer. The questionnaire included demographic, health related, and information seeking questions similar to those in the Affect and Avoidance Study. Interview and Interaction Study participants were also asked to complete two scales, the Need for Cognition scale (NfC) and the Threatening Medical Situations Inventory (TMSI).

The NfC was used as this scale indicates one motivation for information seeking. The second scale, the TMSI, employs Miller's (1980) Blunting and Monitoring categories and serves as a general indicator of attitudes to medical threat related health information (Wakefield, Homewood, Mahmut, Taylor & Meiser, 2007; Nijhof, ter Hoeven, de Jong, 2008; Lindberg, 2012). Developed by van Zuuren and colleagues (van Zuuren & Hanewald, 1993; van Zuuren & Muris, 1993), the TMSI presents participants with four hypothetical scenarios involving varying degrees of medical threat (e.g., “Imagine you have suffered from headaches and dizziness for some time already. You visit your doctor. He or she tells you things don’t look good and refer you to a specialist for a rather trying medical exam.”) Threat varies according to two stress parameters, predictability and controllability (van Zuuren, Groot, Mulder & Muris, 1996). After each scenario, participants are presented with three statements having to do with Monitoring (e.g., “I plan to ask the specialist as many questions as possible.” “I plan to start reading about headaches and dizziness.”), and three concerning Blunting (e.g., “For the time being, I try not to think of unpleasant outcomes.” “I am not going to worry; such an examination is less worse than suffering from headaches all the time.”) These Monitoring and Blunting statements appear in a different order for each scenario; i.e., Monitoring statements are sometimes found in consecutive order and sometimes alternate with Blunting statements, in order to eliminate question fatigue. Participants are asked if these statements are applicable to them, measured on a five-point Likert scale ranging from “Not at all applicable to me” to “Strongly applicable to me.” The scale is considered reliable, with Cronbach’s alpha scores reported at between 0.70 and 0.90 (Muris, van Zuuren, de Jong, de Beurs & Hanewald, 1994).

After completing the scales, participants were given a hypothetical scenario, one of four similar scenarios encouraging participants to imagine that they had this condition. These scenarios, adapted from those used in the first study and based on responses from that study, are situations that might stimulate information seeking or avoidance (Williams-Piehota et al., 2009; Flight et al., 2012; Dawson, Savitsky & Dunning, 2006; Melnyk & Shepperd, 2012).

Next, Interview and Interaction Study participants returned to the computer, where they completed an information interaction session involving material that was related to the condition described in the scenario. They were permitted to retain the paper on which the scenario was printed and to refer to the scenario for reference and were instructed to behave as they “normally would,” i.e., to browse and consult the sources if faced with the condition in real life. A defined set of resources was provided for each scenario in a format simulating a web portal or resource page, here referred to as a MedBrowser. Participants were asked to interact with the resource collection for no more than 15 minutes but were allowed to stop at an earlier time if they felt they were done searching. Their sessions were recorded through screen capture and transaction logging using Morae (TechSmith, 2014) for Mac (Version 10.2.2 (1380)) (2014) software.

After the health information interaction, participants were again given the Positive and Negative Affect Schedule short form (PANAS), to measure their emotional state after reading the scenario and interacting with the condition-related health material.

They were then asked questions in a semi-structured interview format, recorded using a portable device. Interviews varied in length from 45 minutes to 1.5 hours.

3.5.2 Scenarios

The Interview and Interaction scenarios used in this study were selected based on the results of the Affect and Avoidance Study and were very similar to the scenarios used in that study.

Strong negative scenarios were employed for the more severe conditions, acoustic neuroma and meningioma, and weak negative scenarios for the milder conditions, Bell's palsy and Crohn's disease, in order to emphasize the division of severity between conditions. Lupus was omitted as the emotional impact of this scenario had proved to be less clear and consistent than that of the others. The threat of possible death was removed as it was felt to be unspecific to the situation; i.e., death can be caused by any condition, depending on the circumstances of the ill person. The conditions and scenarios used in this study are presented in Table 3-3.

Table 3-3

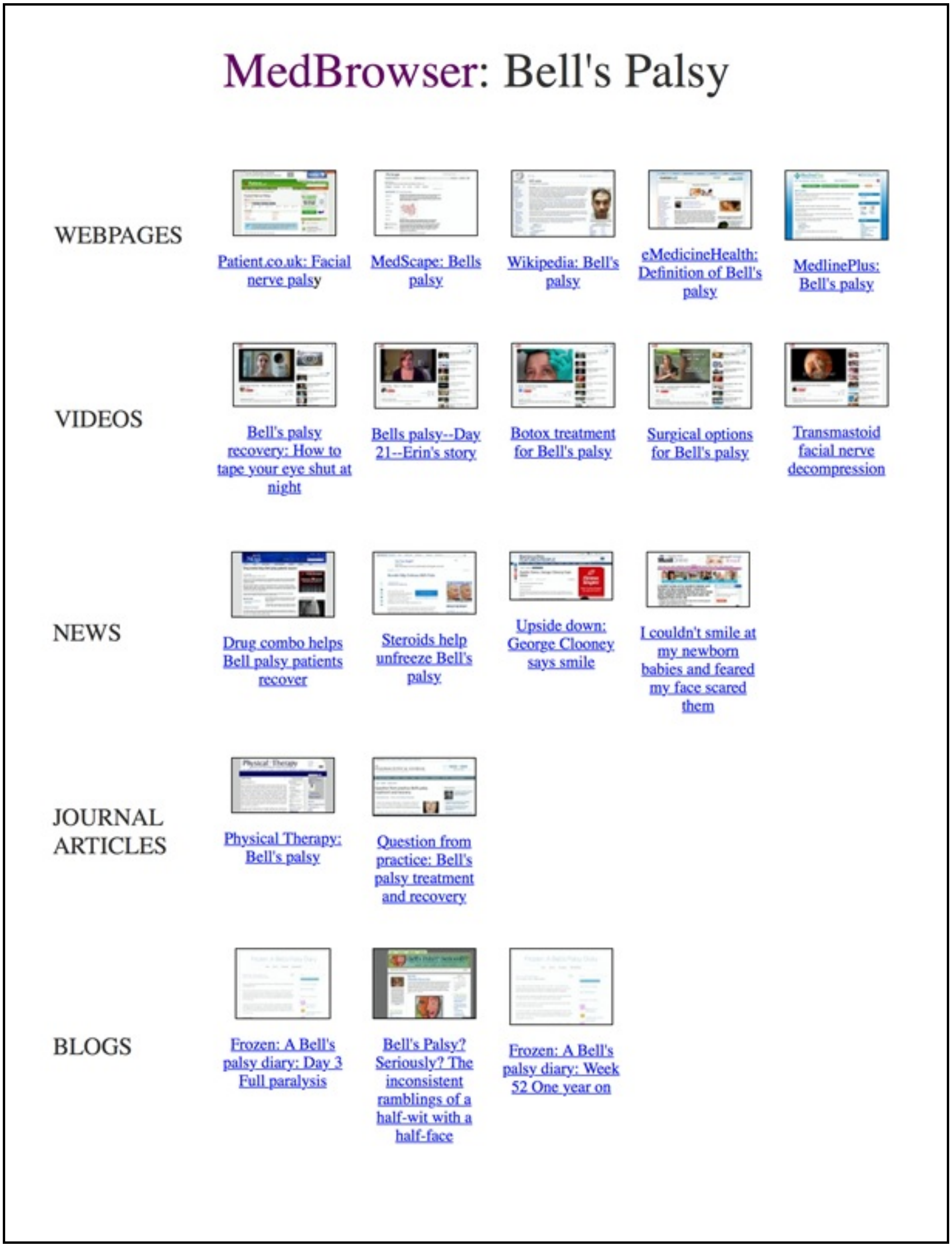
Scenarios for conditions in the I & I study

Condition	Scenario
Acoustic neuroma	Your doctor tells you that you have an acoustic neuroma: a tumour located close to your brain that requires immediate treatment. The doctor tells you that if the tumour is not treated, it will lead to a number of side effects including deafness in the ear, facial paralysis, and brain damage. Treatment options are surgery or radiation.
Bell's palsy	Your doctor tells you that you have Bell's palsy, in which a problem with the facial nerve results in difficulties in moving parts of the face. Bell's palsy has a number of side effects, including problems making facial expressions, winking, lifting one eyebrow, or smiling broadly. In most cases, Bell's palsy disappears in a few weeks. If treatment is needed, steroids, physiotherapy, and in very rare cases, surgery can all help.
Crohn's disease	Your doctor tells you that you have Crohn's disease, a form of inflammatory bowel disease in which your digestive system does not function properly. Crohn's has a number of side effects, which can include weight loss, low iron, and damage to your intestine. By and large, people who have this disease can live full and productive lives.
Meningioma	Your doctor tells you that you have a meningioma, a type of brain tumour that in your case requires immediate treatment. If untreated, meningiomas can lead to serious side effects, including problems with brain function. Treatment options are surgery and radiation.

Table 3-3 Scenarios for conditions used in the Interaction and Interview study

3.5.3 MedBrowser Portal

The MedBrowser portal for the Interview and Interaction Study contained health information material separated into five genres that were presented in one of two different arrangements to reduce order effects. Choice of material can be understood with reference to the literature review.



MedBrowser: Bell's Palsy

WEBPAGES

Patient.co.uk: Facial nerve palsy

MedScape: Bells palsy

Wikipedia: Bell's palsy

eMedicineHealth: Definition of Bell's palsy

MedlinePlus: Bell's palsy

VIDEOS

Bell's palsy recovery: How to tape your eye shut at night

Bells palsy--Day 21--Erin's story

Botox treatment for Bell's palsy

Surgical options for Bell's palsy

Transmastoid facial nerve decompression

NEWS

Drug combo helps Bell palsy patients recover

Steroids help unfreeze Bell's palsy

Upside down: George Clooney says smile

I couldn't smile at my newborn babies and feared my face scared them

JOURNAL ARTICLES

Physical Therapy: Bell's palsy

Question from practice: Bell's palsy treatment and recovery

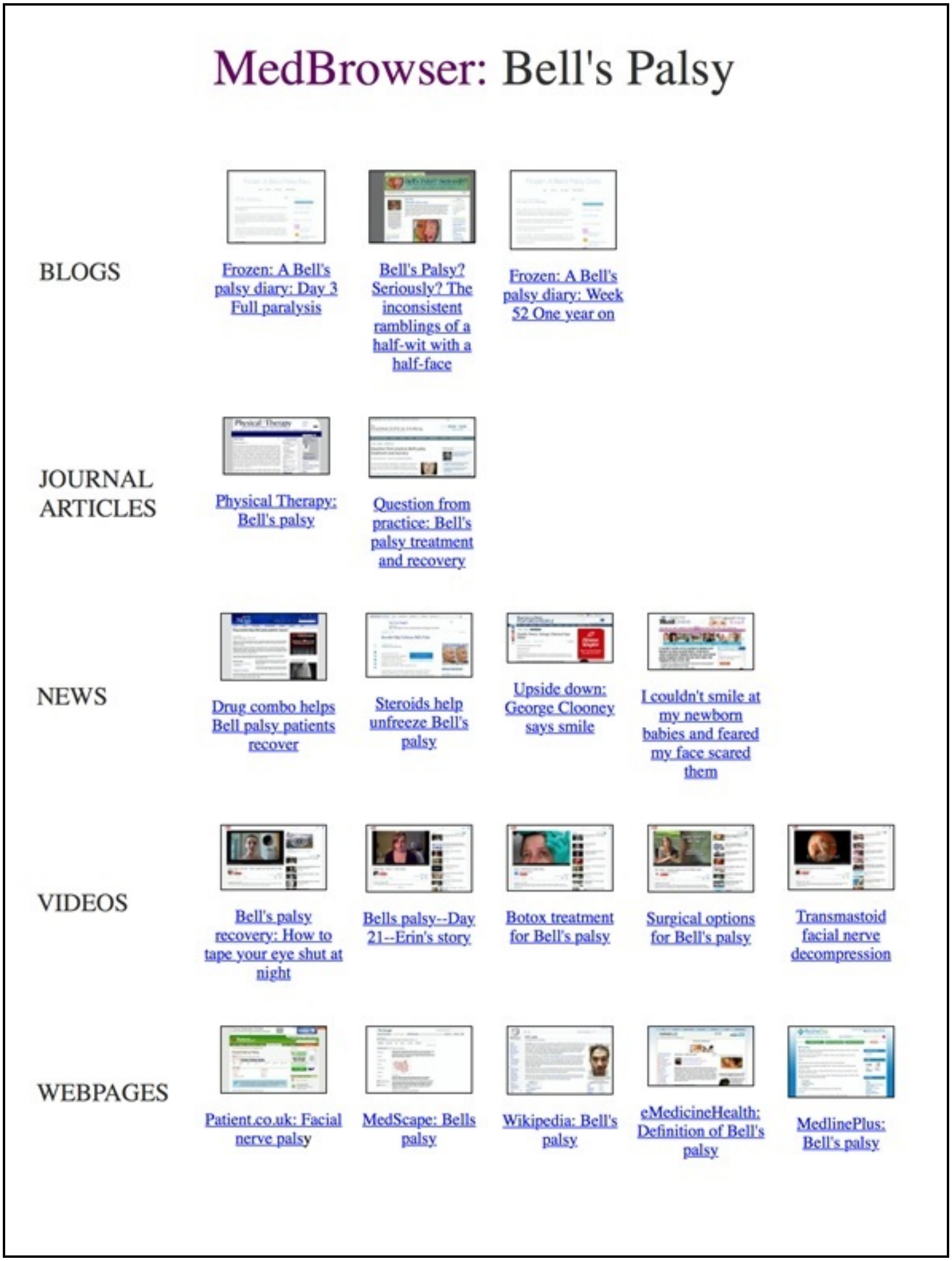
BLOGS

Frozen: A Bell's palsy diary: Day 3 Full paralysis

Bell's Palsy? Seriously? The inconsistent ramblings of a half-wit with a half-face

Frozen: A Bell's palsy diary: Week 52 One year on

Figure 3-1 Screen shot of Bell's palsy (order 1)


MedBrowser: Bell's Palsy

BLOGS
Frozen: A Bell's palsy diary: Day 3 Full paralysis
Bell's Palsy? Seriously? The inconsistent ramblings of a half-wit with a half-face
Frozen: A Bell's palsy diary: Week 52 One year on

JOURNAL ARTICLES
Physical Therapy: Bell's palsy
Question from practice: Bell's palsy treatment and recovery

NEWS
Drug combo helps Bell palsy patients recover
Steroids help unfreeze Bell's palsy
Upside down: George Clooney says smile
I couldn't smile at my newborn babies and feared my face scared them

VIDEOS
Bell's palsy recovery: How to tape your eye shut at night
Bells palsy--Day 21--Erin's story
Botox treatment for Bell's palsy
Surgical options for Bell's palsy
Transmastoid facial nerve decompression

WEBPAGES
Patient.co.uk: Facial nerve palsy
MedScape: Bells palsy
Wikipedia: Bell's palsy
eMedicineHealth: Definition of Bell's palsy
MedlinePlus: Bell's palsy

Figure 3-2 Screen shot for Bell's palsy (order 2)

Every effort was made to present consistent information across conditions; the website section, for example, always contained material from the same five sites:

patient.co.uk, MedScape, Wikipedia, eMedicineHealth, and Medline Plus. Attempts were made, too, to include material that ranged from potentially emotionally disturbing (e.g., details about surgeries) to less disturbing (e.g., people speaking about their past experiences and their life after being healed). Videos ranged from depictions of graphic surgeries (e.g., "Brain surgery removal of metastatic tumor high power surgical microscope") to personal narratives that represented either a short time after surgery and an uncertain outcome, (e.g., "24 hour post-op for de-bulking of my meningioma") to a long time after surgery and a positive outcome (e.g., "Acoustic Neuroma: Healing path 2013") to narratives by people who were merely describing the condition in a clinical manner (e.g., "Leonard Cerullo, MD, discusses meningiomas"). Blogs followed a similar path, ranging from "My seizure, finding the meningioma and my brain tumor surgery" to "3rd tumor-versary." Journal articles ranged from those written for medical experts (e.g., "Colonic adenocarcinoma revealing Crohn's disease") to those written for a more general audience (e.g., "New Crohn's disease treatment may result from 'bodyguard protein' discovery"). News articles chosen contained either personal stories (e.g., "I couldn't smile at my newborn babies and feared my face scared them"), stories about celebrities (e.g., "George Clooney says smile"), or explanations about new research or treatments (e.g., "Steroids help unfreeze Bell's palsy"). See Appendix E for a full list of online material and inclusion rationales.

3.5.4 Interview Questions

Interview questions (see Appendix F) for the Interview and Interaction Study were developed with reference to prior work, including McKenzie (2001) and Lambert, Loiselle, and Macdonald (2009). These questions were also shaped with the aid of the information-seeking question from the Affect and Avoidance study. For example, responses such as "I would take it with a grain of salt until I could discuss further with my doctor" alerted me that attitudes towards healthcare professionals might be an important element in health information behaviour and informed the creation of such questions as "Were there any features of the information that would make you feel better or worse? For example, the inclusion of material from doctors or other healthcare professionals?"

As Bosk (1979) notes in a metaphor, qualitative research is a "body contact" (p. ix) sport, in which importance is attached to the participant-researcher relationship; thus an interactive style of active interviewing (Holstein & Gubrium, 1995) was used, with meaning negotiated between interviewer and interviewee. An interview guide was utilised, but with reference to Maxwell (2011) and Sandelowski (2000, 2010), a flexible approach was employed, with the experimenter asking questions that arose naturally rather than strictly following that guide (see also Patton, 2002). I also took notes on participant behaviour while answering questions, taking care not to make judgments about this behaviour, e.g., "shifted in the seat while answering," rather than "looked uncomfortable."

Participants were asked to review their information seeking session prompted by the scenario. Questions focused on why they selected and did not select particular materials and genres; what information they were hoping or not hoping to obtain; whether or not this information was obtained; what caused them to stop searching; and their overall level of satisfaction with the material. Next, participants were asked about their own health behaviours. Here, questions encompassed topics such as any health problems they had experienced and their information searching and avoidance behaviours with reference to these problems.

3.5.5 Participation and Recruitment

Thirty-five members of the general public between the ages of 20 and 84 were recruited by convenience sampling, defined by Kelly (2009) as relying on available elements to which the researcher has access (p. 69) (Miles & Huberman, 1984; Miles, Huberman & Saldana, 2014; Maxwell, 2011). Recruitment was carried out by means of notices posted in coffee shops, community centres, libraries, and a hospital in the downtown area of a major urban centre. The website meetup.com, a social networking portal that supports networking and allows members to particulate in offline meetings was also used. These methods of recruitment were chosen in order to garner a broad cross-section of the population. The study was conducted in English and sessions were held in public locations in the downtown area, specifically in branches of the public library and in a community centre. (See Appendix C for the recruitment form.)

The study sample was almost equally split along gender lines, with 18 women and 17 men. Almost two-thirds, 21 or 59%, were 50 or older, with the rest, 14 participants, being between 20 and 49 (41%). 32 out of 34 participants possessed some post-secondary education past high school, and 11 (32%) having some graduate school. One person chose not to record their education. Few saw their health as less than good, 4 out of 35 (11%), and over half, 19, (54%) saw their health as very good or better. Only one person saw his/her health as having deteriorated from last year, while a third, 11 or 32%, saw their health as having improved. Over 60% of participants reported searching daily (19 or 54%) or a few times per day (7 or 20%) for online information regarding personal interests, entertainment, or news. Participants also reported frequent searching for health information, with over 80% searching monthly (8 or 24%) or more often, 8 or 24% searching a few times a month, 13 or 38% searching daily, and 2 or 6% searching a few times per day. When asked, one third of participants (10 or 31%) stated that they were "generally healthy," with some of these healthy participants later commenting on current or recent health problems. In the course of the interviews, almost all participants were able to draw upon personal experiences with health issues when describing their health-related information behaviour.

3.5.6 Data Analysis

Data analyses were conducted using SPSS Statistics for Windows (IBM, Version 20.0) (2011), MS Excel for Mac (Version 14.5.8) (2011), MS Word for Mac (Version 14.5.8) (2011), Morae (TechSmith, 2014) and NVivo (QSR International Pty Ltd, Version 10, 2014) for Mac (Version 10.2.2 (1380) (2014)). Demographics and health perception were summarized using frequency counts. Need for Cognition scores were determined as per the guidelines (Cacioppo & Petty, 1982), with the results indicating a positively skewed distribution, with an average of 3.88 (*SD* 6.46), and a median of 9. Threatening Medical Situations Inventory scores were calculated with Monitoring and Blunting scores measured separately, in accordance with van Zuuren and colleagues (van Zuuren, de Groot, Mulder & Peter, 1996), who consider them to be distinct characteristics. Positive and Negative Affect Schedule scores were also examined as per guidelines, with total scores for positive and negative affect being calculated separately in accordance with Cacioppo and Petty (1982). The video interaction sessions as recorded by Morae (TechSmith, 2014) were then examined using the Morae Observer component. Frequencies were tallied for the information seeking measures of number of items, and amount of time spent in general and on each item, and correlation analyses were performed comparing the different variables and the demographics with the information seeking measures.

Interaction data from 8 participants was not available due to technical difficulties, i.e., an unreliable Internet connection in the location of the interaction session; thus this section reports on 27 participants. The first 8 sessions were scheduled within a short time frame, and attempts to ensure that the Internet connection was functioning were initially unsuccessful. Thus these sessions went ahead even though the ability to use the MedBrowser was compromised. Full interviews were conducted with these participants. The decision was made to include the interviews conducted even though the interaction data was unavailable, as many questions focused on the general health information seeking of participants rather than on the seeking patterns in the interaction session.

Results from the 35 interviews were analyzed using qualitative content analysis (Sandelowski, 2000, 2010). Although this type of analysis is less interpretive than other forms of qualitative analysis such as phenomenology, "descriptions always depend on the perceptions, inclinations, sensitivities, and sensibilities of the describer" (Sandelowski, 2000, p. 335). Maxwell (2011) points out that the researcher is part of the world he or she studies; this "reflexivity" (p. 109) indicates that the interviewer and the interview situation influences interviewee behaviour and comments. Thus it is crucial to position myself in relation to this research.

Fifteen years ago, I had an acoustic neuroma that required emergency surgery (otherwise I would have died) and about which I did not seek much beyond minimal health information. My lack of health information seeking did not affect the outcome of this health concern; the surgery was (obviously) successful. Ten years ago, I returned to school to become a librarian. During this Master's in Library and Information Science degree, I encountered a negative bias against information avoidance in the information behaviour literature presented in my classes, a bias that contradicted my own experience. These various events inspired my choice of topic for this dissertation and also influenced the qualitative analysis. One aim of this project was to counter the bias in the field of library and information science against information avoidance. My interpretation of information avoidance is different than that of some other researchers; I see health information avoidance as less problematic, neutral, even positive, whereas the interpretations of others is more negative (Johnson, 2014; see also Williams-Piehota et al., 2009; Howell & Shepperd, 2013 for examples).

Analysis began after all interviews were completed. Interviews and observations were fully transcribed. As befitting qualitative content analysis, codes are both imposed by the researcher and data-derived. Examples of imposed codes were "information seeking" and "information avoidance;" however, I made certain to remain flexible and ensure all codes were in accordance with the data. The data was also summarized numerically; i.e., comments in each category were counted. Although efforts were made to uncover the latent content of the data, there was no mandate to re-present the data in any other terms but those of the participants (Sandelowski, 2000, 2010).

The material was examined line by line, using the coding software NVivo (QSR International Pty Ltd., 2014). Extraneous material was deleted with reference to the following questions: "Does it relate to the research concern? Does it help with better understanding the participants? Does it clarify experimenter thinking? Does it simply seem important, even if the reason is unclear?" (Auerbach & Silverstein, 2003, p. 48).

The following questions were then used to assist with analysis:

> What are people doing? What are they trying to accomplish?
> How, exactly, do they do this? What specific means and/or strategies do they use?
> How do members talk about, characterize, and understand what is going on?
> What assumptions are they making?
> What do I see going on here? What did I learn? (Emerson, Fretz & Shaw, 1995, p. 146)

Repeated ideas were then grouped together, according to the process outlined by Auerbach and Silverstein (2003). Initial ideas consisted of actual words used by the participants. For example, "[Doctors are] not kept up to date with current events, and the current health information" became "Doctors are not updated." Another idea, "Doctors not up to speed," stemmed from a quote "Doctors are not necessarily up to speed in very specific areas" (P33). All ideas were then examined as to similarity, and similar ideas were grouped together. Thus, in the example, both "Doctors are not updated" and "Doctors are not up to speed" were grouped together in "Doctors are not updated." I paid special attention to so-called "orphans," ideas that did not repeat, re-examining the texts to see if these ideas were indeed found in other places. The decision was then made as to whether these ideas were kept or discarded. The resulting list contained 85 ideas, approximately consistent with Auerbach and Silverstein's (2003) suggestion of between 40 and 80 ideas. Repeated ideas were then named with codes. Thus "Doctors are not updated" was grouped with other ideas involving healthcare professionals into the higher level codes "Doctors-healthcare professionals" and "Problems with doctors, medical system." Some ideas repeatedly mentioned by participants remained as lower level codes to indicate a strong element present in the code. Thus "Doctors are not updated" is present as a lower level code in the Code rationale (see Appendix G). The coding schema was developed over a number of weeks through an iterative process that included regular discussions with my research supervisor. Codes were also discussed and verified with members of the supervisory committee. An initial version of the Code rationale was circulated to all committee members, and subsequent versions were rewritten with input from the committee. Member checking was not performed. While member checking has been often cited as an important validation tool that supports both the science that researchers perform and participants' rights to know (Maxwell, 2011), Sandelowski (1993) points out that this technique can create difficulties in participants' lives. As participants alter the narratives of their lives in order to fit with differing situations, they may not wish to be confronted with earlier interpretations. For example, if participants viewed a certain situation in one way at the time of the interview and this view altered over time, it may not be ethical or practical to present them with the view they held in the interview (see also Sandelowski, 2000, 2010; Maxwell, 2011). Participants were invited to contact me regarding the results, if they wished, and one did so through email. Three more participants met me by chance at locations in my neighbourhood and asked for results and updates on my progress, which were provided verbally, with further information sent through email if desired.

The list of resulting codes was re-examined, then grouped into themes, with attention again paid to orphans. Themes were then examined to see how they fit, in order to establish a theoretical construct. The first theme from the list was chosen and the list read through to see how other themes connected with the first. Groups of themes were then put into theoretical constructs, with attention paid to orphan themes, and these constructs were named. Codes were re-examined at this stage as a form of intrarater reliability, to verify this analysis (Sandelowski, 2000, 2010). The re-examination functioned as an audit of analysis. The list of theoretical constructs was then examined to discern if a theoretical narrative could be created, using constructs that fit together.

Themes related to the research questions and thus had to do with mechanisms of information avoidance and the factors that influenced information avoidance behaviours. Some themes related directly to codes, while others emerged from closer examination of codes. The first two themes were two mechanisms that came from the results, delegation and self-regulation. Both mechanisms stemmed from examination of the coding category 6, search behaviour. The first, delegation, also arose from close inspection of the coding category, 10C People (as information source) and the coding category 8 Social, particularly with reference to code 8B Education of friends and family. The second mechanism, self-regulation, came from the coding category 3 Coping, especially code 3A-B Self-regulation (see Appendix G).

Themes regarding the factors influencing information avoidance consisted of three beliefs found in analysis of participant comments: a belief in health as a personal responsibility or in health as the responsibility of healthcare professionals or fate; a belief in healthcare professionals as trustworthy or not; and a belief or lack thereof in health information seeking as a social responsibility. All three themes were developed with the aid of coding category 1 Affect. "Belief in health as a personal responsibility" and its opposite, "the responsibility of healthcare professionals or fate" stemmed from an examination of codes in category 12 Social achievements, particularly codes G Self-efficacy and H Taking care of self, and codes in the coding category 10C People (as information source), especially 10C-A Doctor-healthcare professional. The coding category 10C People (as information source) also yielded the second theme, "Belief in healthcare professionals as trustworthy or not." The last theme, "Belief in health information seeking as a social responsibility," was found through examination of the coding category 12 Social achievements (see Appendix G).

3.6 Conclusion

A mixed methods approach was taken in which two studies, an online survey containing qualitative and quantitative elements and a user study including qualitative interviews were employed to answer the two research questions.

1. What factors contribute to information avoidance? More specifically, to what extent do personality traits, situational affect, and the nature of available information sources influence information avoidance?
2. What are the mechanisms of information avoidance?

The studies were conducted in 2015 and involved 198 participants and 35 participants, respectively. I chose the mixed methods approach as it corresponded both to my neopragmatist wish to find more practical solutions, and as it allowed me to examine information avoidance comprehensively from multiple angles.

The Affect and Avoidance study (Study 1), consisted of an online survey containing measurements of personality and affect and self-reported information seeking and avoidance questions that responded to ten hypothetical medical scenarios depicting five conditions at two levels of severity (see Appendix A for the full questionnaire used in this study). The crowd-sourcing software Amazon Mechanical Turk (2017) (MTurk) was used for recruitment, as it was deemed appropriate for the short nature of the survey and for the ability of MTurk (2017) to reach a large number of people quickly and efficiently. Care was taken regarding the ethical issues of this software, in particular with regards to payment. Instruments of measurement used were a questionnaire and two scales, the Need for Cognition Scale (NfC) and the Positive and Negative Affect Schedule (PANAS). NfC served to measure of a personality trait influencing information seeking and avoidance, and PANAS to measure affect. Scenarios were created with reference to previous studies and included much of the same wording, with dissimilar conditions. In this study, conditions were acoustic neuroma, Bell's palsy, Crohn's disease, lupus, and meningioma. The data from 198 participants, functioned as the base for analysis, in which characteristics were tested for associations with reported information seeking and in which the effect of scenarios in general and the two levels of severity in particular were also examined.

The Interview and Interaction study (Study 2) was a user study in which participants interacted with health information material relating to a hypothetical medical scenario and were then interviewed as to this interaction and to their past health information behaviour. Three scales were employed in this study, the NfC scale, the Threatening Medical Situations Inventory (TMSI), and the PANAS scale. The NfC and TMSI served to test for personality traits related to information seeking and avoidance in general and health information seeking and avoidance in particular. PANAS was employed to test for affective factors. Scenarios used in this study were based on those used in the Affect and Avoidance study; these were the strong negative scenarios for acoustic neuroma and meningioma and the weak negative scenarios for Bell's palsy and Crohn's disease. A

MedBrowser website was created with health information material with reference to the literature (see Appendix E), and interview questions were created with reference to responses from the Affect and Avoidance study as well as to the literature as well (see Appendix F). Data from 35 participants were analyzed, with descriptive statistics used for responses to the scales and to data from the interaction session. Data from the interviews were analyzed by means of qualitative content analysis.

4 Affect and Avoidance Study

The following chapter will present the results of the Affect and Avoidance study, which examined the influence of affect and personality factors on participants' stated intent to seek health information, and to test the influence of hypothetical medical scenarios on participants' emotional states. I will begin by looking at evidence of information seeking and avoidance in the study and progress to an examination of the personal characteristics of participants and their influence on participants' information seeking. I will then look at the situational affect demonstrated by participants after their reading of hypothetical medical scenarios.

4.1 Participants

The study sample consisted of 198 participants, of whom 56% (*n*=110) were men and 44% (*n*=88) were women. Education levels varied, with 39% (*n*=76) possessing high school or less than high school; 21% (*n*=42) having a college level education, some college or an associates degree; and 40% (*n*=80) holding an undergraduate degree or higher. Participants were experienced Internet searchers, and many looked for subjects such as research and studies, news and current events, and personal interests and entertainment a great deal. Many participants reported especially frequent searching for news and current events, with 54% (*n*=107) reporting daily searching and 28% (*n*=54) reporting searching a few times per day, 28% (*n*=54); and personal interests and entertainment with 46% (*n*=92) searching daily and 36% (*n*=71) reporting searching a few times per day. Reported health information searching was slightly less frequent, with the majority of participants looked for health information a few times per month, 40% (*n*=80), a few times per year, 27% (*n*=54), or monthly, 22% (*n*=43).

Participants' age, general health perception, and current health perception are summarized in Table 4-1.

Table 4-1

Age, general health perception and current health perception of participants in the Affect and Avoidance study

Characteristic	Category	Percentage (number)
Age	19-29	31% (*n*=61)
	30-39	36% (*n*=71)
	40-49	15% (*n*=30)
	50-59	13% (*n*=26)
	60-69	5% (*n*=10)
General health perception	Poor	3% (*n*=5)
	Fair	14% (*n*=27)
	Good	43% (*n*=86)
	Very good	31% (*n*=61)
	Excellent	10% (*n*=19)
Current health perception	Much worse than last year	0%
	Somewhat worse than last year	9% (*n*=18)
	About the same	68% (*n*=135)
	Somewhat better than last year	20% (*n*=39)
	Much better than last year	4% (*n*=6)

Table 4-1 Age, general health perception, and current health perception of participants in the Affect and Avoidance study

4.2 Information Seeking and Avoidance

Upon exposure to a hypothetical scenario in which they were diagnosed with a medical condition, an overwhelming amount of participants reported that they would seek a large amount of health information (Table 4-2 and Figure 4-1). The majority of participants (75%) indicated that they would search extensively, regardless of the medical condition or the relative severity of this condition; they all selected option 6: "I would look for as much information as I could find" (Table 4-2 and Figure 4-1). The number of participants who indicated they would seek minimal information or would not seek at all (Options 1 or 2 in Table 4-2 and Figure 4-1) was very low, 2.5% overall.

Table 4-2

Reported likelihood of information seeking of participants in the Affect and Avoidance study

Information seeking	Percentages (*n*)
1 I would avoid information about this disease.	1% (*n*=1)
2 I would not avoid information but would not actively look for it.	2% (*n*=4)
3 I would look for a small amount of information.	2% (*n*=3)
4 I would look for a moderate amount of information.	8% (*n*=15)
5 I would look for a great deal of information.	12% (*n*=24)
6 I would look for as much information as I could find.	75% (*n*=148)

Table 4-2 Reported likelihood of information seeking of participants in the Affect and Avoidance study

4.3 Personal Characteristics

I examined a number of personal characteristics including Age, Gender, Level of Education, Internet usage, General Health Perception, and Need for Cognition (NfC). All characteristics were tested for associations with the level of information seeking that participants reported they would undertake in response to the scenarios. Spearman's correlations were calculated for Information Seeking and the factors Age, Level of Education, General Health Perception, and NfC, for which participants in this study obtained a mean NfC score of -0.09 (*SD* 5.84) and a median of 0. I used Spearman's correlations because the data were not normally distributed and performed Bonferroni corrections, leading to a significance threshold of .0125. A weak positive correlation was found between Information Seeking and General Health Perception (r=.206, p=.004, n=196), as well as a correlation that is close to being significant between Information Seeking and Age (r=.148, p=.037, n=198). Spearman's correlations were also performed on Information Seeking and Gender; no correlations were found. These correlations suggest that individuals who perceived their health to be better were also more likely to claim they would search for more information. Age was also close to being significantly correlated with NfC (r=.173, p=.015, n=197), while neither Education Level nor NfC were correlated with Information Seeking.

4.4 Situational Affect

I also examined the role of situational affect on information seeking. The Positive and Negative Affect Schedule (PANAS) was administered before and after scenarios were shown to participants and results indicate that the scenarios were successful in engendering affective responses among participants. Pre-scenario participant PANAS scores were similar to other reported results (Watson, Clark & Tellegren, 1988). The overall mean positive affect (PA) score of 29.5 (*SD* 8.56) is consistent with Watson, Clark & Tellegren's (1988) mean score of 29.7 (*SD* 7.9). The overall negative score (NA) for participants was 12.9 (*SD* 8.49), which is slightly below the mean of 14.8 found by Watson et al., but given the standard deviation of 5.4, it is in the same range. To assess the impact of the scenarios, I compared the pre- and post-scenario PANAS scores using Related Samples Wilcoxon Signed Rank tests, as data were not normally distributed. This test rejected the null hypothesis that the difference between these two measurements for both positive and negative affect was 0; I concluded that the scenarios influenced participants' affect (z=-8.355, p=.000 for positive; z=-7.969, p=.000 for negative). Results for individual diseases showed significant differences in affective state before and after exposure to the scenario as well (acoustic neuroma: z=-3.672, p=.000 for positive, z=-4.026, p=.000 for negative; Bell's palsy: z=-3.466, p=.001 for positive, z=-3.127, p=.002 for negative; Crohn's disease: z=-3.967 for positive, z=-3.804, p=.000 for negative; lupus: z=-3.666, p=.000 for positive, z=-2.859, p=.004 for negative; meningioma: z=3.851, p=.000 for positive, z=-3.851, p=.000 for negative).

Mean PA and NA scores are summarized in Tables 4-2 and 4-3, for the 5 disease scenarios and overall, showing that following reading of the scenarios, positive emotion scores dropped and negative emotion scores rose. The different scenarios, therefore, influenced participants' negative and positive affect, i.e., a lowering of positive affective scores and a rise in negative affective scores. This impact of the scenarios also varied somewhat according to the severity of the health conditions presented in the scenarios, with higher average changes in pre and post-scenario scores occurring for acoustic neuroma and meningioma, the more serious conditions. Table 4-2 and Table 4-3 list the scenarios in order of severity from lowest to highest, beginning with Bell's palsy (n=42), and Crohn’s disease (*n*=40), next following with lupus (*n*=38), and continuing to acoustic neuroma (*n*=39) and meningioma (*n*=41).

Table 4-2

Pre- and post-scenario PANAS scores for positive affect by disease

Condition	Mean Positive Affect (*SD*)		
	Pre	Post	Change
Bell's palsy	25.8 (*8.9*)	23.1 (*6.0*)	-2.6 (*5.6*)
Crohn's disease	29.3 (*11.0*)	25.2 (*8.3*)	-4.1 (*6.3*)
Lupus	31.1 (*9.4*)	27.9 (*10.2*)	-3.6 (*5.8*)
Acoustic neuroma	29.8 (*8.6*)	27.1 (*8.7*)	-2.7 (*4.4*)
Meningioma	31.0 (*9.0*)	20.5 (*11.3*)	-6.8 (*7.4*)
Overall	29.5 (*9.3*)	23.0 (*8.5*)	-3.6 (*6.0*)

Table 4-2 Pre- and post-scenario PANAS scores for positive affect by disease

Table 4-3

Pre- and post-scenario PANAS scores for negative affect by disease

Condition	Mean Negative Affect		
	Pre	Post	Change
Bell's palsy	13.0 (*7.0*)	16.8 (*9.6*)	+3.7 (*7.9*)
Crohn's disease	12.6 (*8.1*)	16.1 (*8.9*)	+3.6 (*6.4*)
Lupus	12.9 (*3.4*)	14.9 (*6.0*)	+2.2 (*4.5*)
Acoustic neuroma	12.4 (*6.4*)	18.4 (*8.7*)	+4.7 (*8.7*)
Meningioma	10.5 (*6.2*)	24.5 (*8.3*)	+4.3 (*10.4*)
Overall	12.9 (*6.2*)	17.5 (*9.2*)	+4.2 (*8.0*)

Table 4-3 Pre- and post-scenario PANAS scores for negative affect by disease

I had anticipated a difference between the emotional impact of the strong negative and weak negative versions of the scenarios; however, that did not prove to be the case (see Table 4-3). These scores were compared using Kruskal-Wallis tests. Significant results were not found between these strong and weak negative versions, either in scores for positive affect (r=0.666, p=.186) and for negative affect (r=0.356, p=.850) overall. As evidenced by Table 4-4, the difference between strong and weak scenario tones was often found to be similar (Bell's palsy) or having an opposing effect than predicted (acoustic neuroma and meningioma). For this reason, the strong negative and weak negative scenarios were combined and the distinctions were not considered in further analysis.

Table 4-4

Pre- and post-scenario emotional states by scenario tone

Condition and scenario tone	Emotional states					
	Mean Positive Affect			Mean Negative Affect		
	Pre	Post	Change	Pre	Post	Change
Bell's palsy: Strong negative	24.7	22.1	-2.6	14.1	18.6	+5.1
Bell's palsy: Weak negative	26.9	24.3	-2.6	11.8	14.9	+3.1
Crohn's disease: Strong negative	29.7	23.8	-5.9	13.0	18.9	+5.9
Crohn's disease: Weak negative	29.4	26.6	-2.8	13.2	15.0	+1.8
Lupus: Strong negative	32.8	29.1	-3.7	14.0	16.4	+2.4
Lupus: Weak negative	30.3	27.1	-3.2	11.6	13.7	+2.1
Acoustic neuroma: Strong negative	29.2	27.5	-1.5	12.5	17.0	+4.5
Acoustic neuroma: Weak negative	30.5	26.6	-3.9	14.7	19.8	+5.1
Meningioma: Strong negative	31.2	29.1	-2.1	11.6	17.2	+5.6
Meningioma: Weak negative	30.8	25.0	-5.8	15.0	22.9	+7.9
Overall: Strong negative	29.5	26.3	-3.2	13.0	17.6	+4.6
Overall: Weak negative	29.6	25.9	-3.7	13.6	17.3	+3.7

Table 4-4 Pre- and post-scenario emotional states by scenario tone

There does seem to be some differential impact on Information Seeking between the disease scenarios. Table 4-5 summarizes the Information Seeking responses by disease scenario. For the more severe diseases, Meningioma and Acoustic Neuroma (two types of brain tumours), most participants indicated the highest levels of Information Seeking. Responses for the less serious conditions, Bell's Palsy and Crohn's Disease (a temporary form of facial paralysis and a chronic inflammation of the intestines), included a broader range of responses. This distinction may suggest that some people envision themselves more likely to seek greater amounts of information when faced with more serious conditions. Interestingly, though, the sole study participant claiming that s/he would completely avoid information had received the most serious condition, Meningioma. Here, the seriousness of the disease seems to have prompted an opposite effect, although for one participant only.

Table 4-5

Likelihood of information seeking by disease scenario, frequencies and percentages

Information seeking	Diseases					
	Acoustic neuroma	Bell's palsy	Crohn's disease	Lupus	Meningioma	Overall
1	0	0	0	0	1 (2%)	1 (1%)
2	0	2 (5%)	1 (3%)	0	1 (2%)	4 (2%)
3	0	0	3 (8%)	2 (5%)	1 (2%)	6 (3%)
4	2 (5%)	6 (15%)	1 (3%)	5 (13%)	1 (2%)	15 (8%)
5	5 (13%)	8 (20%)	6 (15%)	4 (11%)	1 (2%)	24 (12%)
6	32 (82%)	24 (60%)	29 (73%)	27 (71%)	36 (88%)	148 (75%)
Total	39 (100%)	40 (100%)	40 (100%)	38 (100%)	41 (100%)	198 (100%)

Table 4-5 Likelihood of information seeking by disease scenario, frequencies, and percentages

Figure 4-1 represents the same data in a chart format.

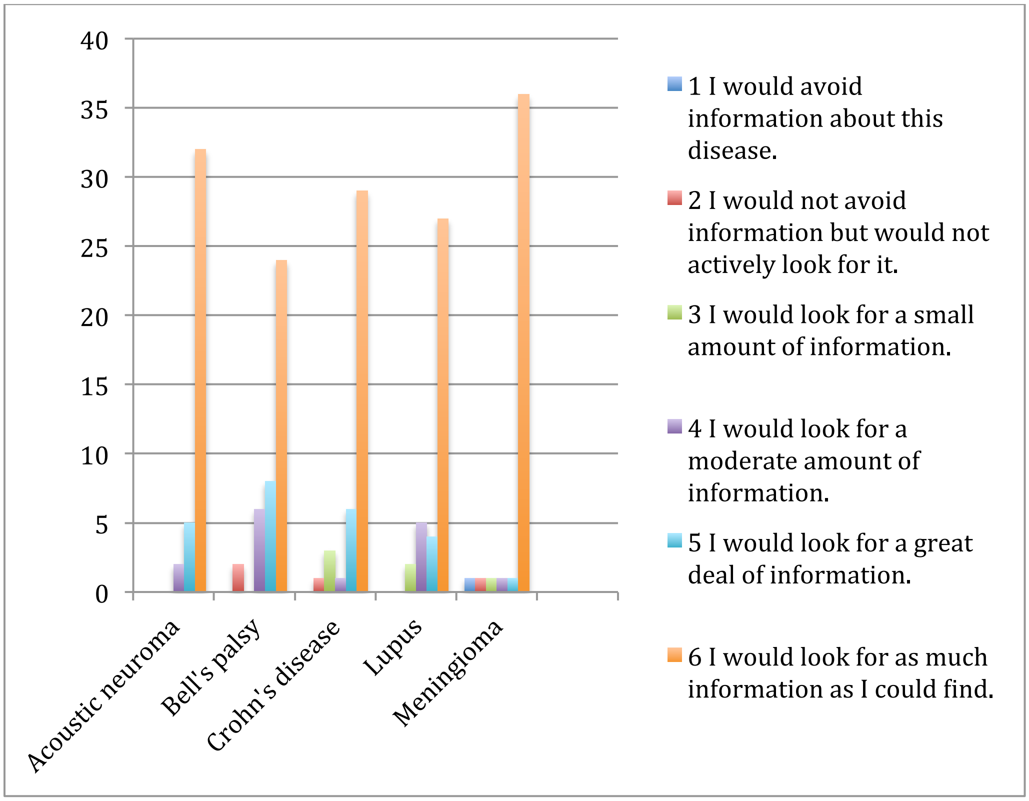


Figure 4-1 Information seeking and avoidance of participants by condition

To test for a possible relationship between emotional state and Information Seeking, Spearman's correlations were employed. For this analysis, I considered the overall pre- and post- positive and negative PANAS scores as well as scores for the individual emotions included in the scale. The overall positive and negative affect scores were not correlated with information seeking. There were weak positive correlations between three of the PANAS scale positive emotions and Information Seeking: alertness, r=.215, p=.002, n=197; attentiveness, r=.199, p=.005, n=194; and interest, r=.188, p=.008, n=198. However, given the large number of tests, these would not be considered significant using a Bonferroni correction. No correlations with negative emotions were found.

4.5 Qualitative Data

Two sets of results were analyzed qualitatively: a small set of questions testing participants' familiarity with the diseases in question and a follow up optional comment box after the question regarding how likely they were to seek information about the condition. All participants answered the questions concerning familiarity; 79% or 157 out of 198 participants answered the optional question looking at likelihood of seeking information, with approximately 30 participants from each condition responding to the question. Results indicate that personality, affect, and source format were all influencing factors in participants' health information behaviour.

Responses to the question about disease perception represent some negative affective connotations. Responses to the question "what do you think of when you hear the word(s) ___________?" ranged from 1 to 49 words, with an average of 10.49 words (*SD* 21.26) and a median of 7. Many comments signalled negative affect. This affect was due less to worry about the prognosis of the disease and more to what participants appeared to believe or assume about the condition. More participants connected words present in the name or description of the conditions with severe diseases. "Acoustic neuroma" and "meningioma," for example, were related to cancers due to the "oma" sound in their names. Many participants linked these conditions with, for example, "bad cancer, often fatal," and, in the case of meningioma, "tumor of the meninges," or "a deadly tumor in the lungs or heart." "Meningioma" also drew associations with "meninges" in the brain, with "membranes," and with "meningitis." One participant noted, regarding "meningioma," "It's something having to do with membranes. It doesn't sound too good." Although the majority of these connections appeared in conjunction with acoustic neuroma and meningioma, connections were present also in the less severe conditions, as "Bell's palsy" was linked with "cerebral palsy." "I think of someone with shriveled [*sic]* hands and pain/difficulty with their joints," wrote a participant about "Bell's palsy."

However, not all connotations of the conditions inspired negative affective reactions in participants. Other forms of affect, neutral and even positive, were also present. Some participants drew conclusions between words in the conditions and possible meaning, inferring that the "acoustic" in "acoustic neuroma" for example, meant that the condition had to do with the ear or with hearing difficulties. A few participants also mentioned humourous or incongruous connotations, particularly in connection with the less severe conditions: "a cow bell" (BP); "a werewolf" (LP). Many wrote of links between "lupus" and a popular televised medical drama, "House." This may have served to mitigate unpleasant associations with the disease, as one particular participant also adds, in an incongruous connotation, "I think of wolves and of the show House." It is tempting to link these negative and positive affective connotations with differing levels of information seeking, in that participants writing about humourous associations may seek less information as they might not take the condition seriously. However, one participant, writing about meningioma, also expressed a positive affective reaction, here curiosity, which might inspire more information seeking: "That's interesting. I wonder what it is."

Out of the participants who took the opportunity to comment on their Information Seeking responses, 16 participants made mention of some form of information avoidance, while 141 indicated that they would search. Comments were brief, with an average of 20.24 (*SD* 10.25), a median of 21, and a range of 1 to 55 words. Analysis of these comments revealed a number of themes: information behaviour (which included information seeking and information avoidance as subcodes); sources consulted (including healthcare professionals, libraries and library staff, the Internet, patients); and reasons for information behaviour (including negative affect, positive affect, personality, duty, and improvement of doctor-patient relationship).

Comments indicated that affect was a component of the decision to look for or avoid information. Both negative and positive affective reasons were shown. Fear was a component of both information seeking and information avoidance, with some participants saying that fear would stimulate their health information seeking and others indicating that fear would lead to avoidance. One participant, for example, wrote of Bell's palsy that s/he would be "scared to death and [would] want to find something positive about it," while another wrote of lupus that s/he would be "scared and looking for answers." Other participants indicated that information seeking needed to be curtailed to prevent fear; they viewed searching as an activity that might lead to fear or loss of control. Four participants with various conditions noted that although they would search for information, their information searching would be limited, for they didn't want to make themselves "crazy" or "consume" themselves by looking up too much. Several participants mentioned that they would delay information seeking as they would be initially frightened, perhaps after diagnosis, and in an extreme case, regarding meningioma, one participant announced that fear would prevent all information seeking, although, interestingly, not fear of health outcomes:

> I would be too scared to look for information. Since I don't have insurance, I'd be stuck with some very expensive bills for the next year at least. I'd be very scared and wouldn't go looking for any more information.

Financial worries, then, would cause an added burden too great for the participant to handle.

Some participants signalled that they felt disinterest, a form of negative affect that would hinder information seeking. These participants, often those responding to the milder condition Bell's palsy, stated that the condition was temporary or not serious and thus required little action on their parts. As the problem was expected to go away, these participants felt no need to "delve" or "dig up" information about it. "Since it is expected to go away, I wouldn't delve into it a great deal," explained one. For these participants, health outcomes were thus not serious enough in this condition to warrant health information seeking about it. Some participants, though, noted that interest or curiosity would stimulate searching. "I would be curious to know everything," wrote one participant about Bell's palsy. Another participant, also describing Bell's palsy, noted the lesser severity of this condition.

> It isn't a life-threatening disorder and it would go away in a few weeks, thus I wouldn't need to dig up every piece of information possible. But I would be rather curious as to what causes it and what it entails, so I would look up some information.

Here the participant clarified his/her lack of need to search and the curiosity that would partially overcome this information disinterest.

Trust in medical authorities was also a factor cited in participants' comments. Some participants indicated that healthcare professionals were the primary health authority, and that all information should be checked with them, thus limiting outside information searching. "I would take it with a grain of salt," said one participant of online information about Bell's palsy, "until I could discuss further with my doctor." A few others stated that they would allow their healthcare professional full responsibility, trusting him/her completely: one participant with Bell's palsy would "listen but not look it up," while another with the condition lupus would just turn to "trusted healthcare professionals." Others mentioned doctors but stated that information seeking was an individual activity, happening independently from doctors and often stimulated by distrust. As an example, one participant stated that s/he needed to find information about acoustic neuroma, to discover "what the doctors aren't telling me."

Some participants made comments that indicated a sense of personal responsibility for their health and their health information searching. These participants, with varying conditions, tended to use the personal pronoun "I": "If I had it I would want to know as much about it as possible;" "I like to find out for myself." Treatment for these participants was in their own hands; as one participant expressed, s/he had to "deal" with the condition:

> I always look up any problem or disease I have online to find as much information as possible to be able to deal with the condition in the best way possible, find alternative ways to deal with it, etc., and find others with the same problem. So I would do it in this case too.

Participants thus usually indicated affective reasons for their health information behaviour. Affect included both negative affect, such as fear, distrust, and disinterest, and positive affect, such as trust and curiosity. Fear functioned as a hindrance and stimulant to information seeking, while distrust in doctors worked to encourage and disinterest to discourage searching for health information. In terms of positive affect, trust in doctors functioned to somewhat limit participants' information seeking, while curiosity was a stimulus to participants to look for information. Participants also expressed beliefs about their responsibilities with respect to their health and health information seeking, which influenced their information seeking and avoidance behaviours.

4.6 Conclusion

This chapter presented and examined the results of the Affect and Avoidance study, an online survey that tested participants' responses to hypothetical medical scenarios in light of personality and affective characteristics. Reported information seeking in this study was very high, with three quarters of participants claiming they would search for the maximum amount of information possible. Reported instances of information avoidance were low (2.5%). There was some evidence to suggest that, when they received the hypothetical scenarios depicting more serious conditions, participants may have envisioned seeking more information in response. Results also indicated that affect may have had an influence on participants' stated intent to look for information; those participants who felt more alert, attentive, and interested were also more likely to claim they would seek more information, although the correlations are weak. There were no overall correlations between positive or negative emotional state and likelihood to seek information. Analysis of the brief comments did identify both negative and positive affect and personal responsibility as motivations for the health information behaviour claimed by participants. One limitation of this study was that the lack of variation in the responses to the information-seeking question curtailed the usefulness of this measure as an outcome variable.

Aspects of this study informed the design and implementation of the Interview and Interaction study. The hypothetical medical scenarios had a clear influence on the emotional state of participants and were used in the second study. Changes in the wording of the scenarios to create strong negative and weak negative versions, however, had no apparent effect; thus the distinction between these versions was omitted from the second study. Findings from this study informed the interview guide employed in the second study. For example, comments referencing participants' affect as well as the findings regarding positive affect and its influence on information seeking were influential in creating questions regarding how participants' emotions related to their information seeking. The overwhelming response regarding information seeking, i.e. that the majority of participants in the Affect and Avoidance study claimed they would seek the maximum amount of information, was also useful. This response informed the interview guide in that further questions were asked regarding participants' health information seeking with relation to the scenarios, to verify this striking response. Results of the second study are presented in Chapter 5, followed by a discussion of the results of both studies.

5 Results from the Interview and Interaction Study

This chapter presents the results of the Interview and Interaction study. This study built on the Affect and Avoidance survey, which previously examined the influence of affect and personality factors on participants' stated intent to seek health information and tested the influence of hypothetical medical scenarios on participants' emotional states. This Interview and Interaction study continued this work by employing the same scenarios and asking participants to search for information using a customized online collection of documents. An in-depth interview on personal health information seeking behaviour followed the interactive session.

The purpose of the second study was to triangulate findings such as the stated response of most Affect and Avoidance study participants regarding information seeking and the influence of positive and negative affect on information seeking, as well as to provide more in-depth information about how participants avoided and sought information. This study thus aided in responding further to the research questions:

1. What factors contribute to information avoidance? More specifically, to what extent do personality traits, situational affect, and the nature of available information sources influence information avoidance?
2. What are the mechanisms of information avoidance?

I will begin this chapter by portraying quantitative and qualitative results from the interaction session and from the scales. A section presenting the themes resulting from the qualitative analysis of the interviews will follow.

5.1 Demographic Data

The study sample consisted of 35 participants, of whom 51% (*n*=17) were men and 49% (*n*=18) were women. Education levels varied, with 6% (*n*=2) at or below high school level; 26% (*n*=9) having a college diploma, some college or an associates degree; and 68% (*n*=23) holding an undergraduate degree or higher. One person chose not to record their education. All participants reported searching for health information. The majority searched monthly, 24% (*n*=8), a few times per month, 24% (*n*=8), or daily, 38% (*n*=13). Other participants searched a few times per day 9% (*n*=3) or a few times per year, 6%

(*n*=2). These amounts of searching are much higher than those reported in the Affect and Avoidance study and may indicate self-selection for a health information seeking study.

Participants' age, general health perception, and current health perception are summarized in Table 5-1.

Table 5-1

Age, general health perception and current health perception of participants in the Interview and Interaction study

Characteristic	Category	Percentage (number)
Age	19-29	11% (*n*=4)
	30-39	20% (*n*=7)
	40-49	11% (*n*=4)
	50-59	37% (*n*=13)
	60-69	11% (*n*=4)
	70+	9% (*n*=3)
General health perception	Poor	3% (*n*=1)
	Fair	9% (*n*=3)
	Good	34% (*n*=12)
	Very good	28% (*n*=10)
	Excellent	26% (*n*=9)
Current health perception	Much worse than last year	0
	Somewhat worse than last year	3% (*n*=1)
	About the same	66% (*n*=23)
	Somewhat better than last year	26% (*n*=9)
	Much better than last year	6% (*n*=2)

Table 5-1 Age, general health perception, and current health perception of participants in the Interview and Interaction study

In the course of the interviews, many participants described health conditions that prompted information searching or avoidance. Please see Table 5-2 for a list of the conditions discussed, which vary from severe to mild. This table uses participants' own words; thus when participants described themselves as "generally healthy," this is noted. Additionally, conditions are listed as indicated by participants; thus Participant 11 has "HIV," while Participant 20 is "HIV positive).

Table 5-2

Health of participants

Participant	Health
Participant 1	Goitre
Participant 2	Early onset of deafness (cured), hernia
Participant 3	Thyroid difficulties; hysterectomy when younger
Participant 4	Pregnancy
Participant 5	Itchy scalp condition
Participant 6	Generally healthy (deviated septum)
Participant 7	Generally healthy (cystitis, potential for stroke, IT band issues)
Participant 8	Benign tumour on finger
Participant 9	Generally healthy (gave up sugar)
Participant 10	Severe arthritis
Participant 11	HIV, drug-induced schizophrenia
Participant 12	Heat stroke
Participant 13	Generally healthy (past problems with concussions and tropical fever)
Participant 14	Runner's knee (believed it to be necropsis)
Participant 15	Arthritis and hip replacement
Participant 16	Bipolar disorder, lithium-related problems with kidneys, osteoporosis
Participant 17	Childhood scoliosis
Participant 18	Post-Traumatic Stress Disorder and accompanying anxiety and depression, learning disorder
Participant 19	Generally healthy (rash on chest, backaches)
Participant 20	Generally healthy (HIV positive)
Participant 21	Chronic pain in stomach, back
Participant 22	Generally healthy (hypothyroidism)
Participant 23	Transient ischemic attack (mini-stroke), depression, hypertension
Participant 24	Cardiac issues (arrhythmia)
Participant 25	Genetic potential for diabetes, overweight
Participant 26	H pylori bacteria in stomach
Participant 27	Detached retina (4 times) and glaucoma
Participant 28	Anxiety and depression
Participant 29	Myopic degeneration
Participant 30	Generally healthy (colonoscopy with undiagnosed digestion problems; low iron; discoloured toe)
Participant 31	Generally healthy (vegetarian, hypothyroidism)
Participant 32	Food intolerances
Participant 33	Post-Traumatic Stress Disorder
Participant 34	Generally healthy (lost tooth when younger, scraped knee)
Participant 35	Generally healthy (bad experience with tetracycline)

Table 5-2 Health of participants

5.2 Health Information Seeking and Avoidance

Participants were presented with a health scenario indicating that they had just been diagnosed with a particular health condition and were then provided access to a customized collection of documents relating to the condition and asked to interact with this collection, if they wished, for a maximum of 15 minutes. Measures from this session thus include time spent browsing each item of health information material, time spent browsing the health information material overall, and number of items looked at overall. Difficulty with Internet connections resulted in lower numbers of participants (see section 3.5.6.); thus this section reports on data from 27 participants.

Table 5-3 reports on the measures in the interaction session.

Table 5-3

Interaction session measures

	Mean	St Dev	Median	Mode
Time spent per item (mins: secs)	1:19	1:02	1:35	N/A
Total time spent	12:06	5:36	10:17	N/A
Number of items	7.23	3.18	6.5	8

Table 5-3 Interaction session measures for the Interview and Interaction study

On average, participants spend 10 to 12 minutes interacting with items, viewing 6 to 8 items and spending a little more than a minute per item. As revealed by analysis of the screen-capture videos and of the interviews, participants followed several patterns in their selection of materials. Some participants searched for health information from patients, while others looked for information they associated with traditional medical authorities, such as healthcare professionals or associations. Many participants relied on the genre groupings provided in the MedBrowser interface to aid their selection. Some genres were seen as indicative of patients' viewpoints and others as representing medical opinions. The most popular genre of material was websites, followed by videos, then blogs, and finally, news and journal articles; however, participants' comments noted that genres were perceived as indicative of either patients' viewpoints or traditional medical authoritative viewpoints and reacted to accordingly. Blogs, videos and news stories were seen as indicating patients' viewpoints, and were selected by participants who wanted this type of information. Participants who wanted more medically authoritative knowledge sought out websites, journals, and sometimes videos. A small number of participants also linked to material outside of the MedBrowser site.

Table 5-4 shows the number of items of health information material viewed and the genre distributions of items for all participants.

Table 5-4

Number of items of health information material viewed per genre category per genre category per session

	Mean	St Dev	Median	Mode
Blogs	1.81	0.83	1.5	2
Journal articles	1.53	0.74	1	1
News articles	2.00	0.71	2	2
Videos	2.06	1.11	1.5	1
Websites	2.52	1.21	2.5	2
All genres	7.11	3.18	8	8

Table 5-4 Number of items of health information material viewed per genre category per session

5.3 Need for Cognition (NfC), Threatening Medical Situations Inventory (TMSI) and Positive and Negative Affect Schedule (PANAS)

Participants' Need for Cognition (NfC), Monitoring and Blunting coping styles, and situational affect in response to a hypothetical medical scenario and related health information were all measured. Three scales were used, the NfC, the Threatening Medical Situations Inventory (TMSI), and, after participants read a hypothetical scenario and interacted with the health information material, a Positive and Negative Affect Schedule short form (PANAS) (see Table 5-5). Descriptive statistics are reported, as the number of participants was deemed too low for inferential statistics; comments are used to illustrate interpretations. Table 5-5 reports the summary descriptive statistics for the three scales used.

Table 5-5

Interview and Interaction study scales

	Mean	St Dev	Median	Mode
Need for Cognition	3.88	6.46	2.5	0,7
Monitoring	43.76	7.29	48.5	51
Blunting	38.18	7.49	38	40,50
Positive affect	20.06	6.88	18.50	13,15
Negative affect	15.76	7.00	13.50	10

Table 5-5 Interview and Interaction study scales

The following sections examine these results more closely, along with representative comments from the participants.

5.3.1 Need for Cognition (NfC)

The following table shows NfC scores compared with the measures used in the Interview and Interaction study (see Table 5-6). As the scores were positively skewed, I divided the participants into three equal groups. Scores were deemed low, middle and high according to their place in this scheme, with low scores ranging from -4 to 0, middle scores from 1 to 7, and high scores from 8 to 21.

Table 5-6

NfC scores compared with the time spent per item of health information material, the total time spent, and the number of items of health information material viewed

	Time spent per item	Total Time spent	Number of items viewed
Low NfC	2:12 (1:10)	13:14 (5:55)	7.22 (3.23)
Middle NfC	1:44 (0:53)	11:33 (4:48)	7.33 (3.02)
High NfC	2:06 (1:04)	11:20 (3:52)	6.57 (3.51)

Table 5-6 NfC scores compared with the time spent per item of health information material, the total time spent, and the number of items of health information material viewed

There is no evidence that participants with high NfC scores were more likely to interact more fully with the collection of health information material given. The means in this table are quite similar, and the highest mean time per item, and time spent in total were found in the low NfC category. The analysis of participants' comments raises further doubts that a relationship between NfC and the information behaviour of these participants exists, as well. Participant 13 (generally healthy; past problems with concussions and tropical fever) illustrates some of those concerns. This participant had a high NfC score of 8. He believed strongly that he could overcome most health problems, negating the need for health information searching or consulting a healthcare professional. He described his reaction to a potential concussion: "If you're knocked out, and you come to; you get a ringing for a few hours and then you're okay [laughs]. I do, and I seem fine. I'm a pretty healthy guy…I'm pretty in touch with my body.“

This participant did reveal that he would seek some health information; however, this information would be more directed at the experience of other patients, rather than traditionally medical information. He explained, "This is someone who's gone through it, so I'm very interested in their experience. And maybe some of that is some distrust of medicine."

Trust was also a factor in another example of a participant whose NfC score did not seem to influence her health information searching. Participant 21 (chronic pain in stomach, back) possessed a NfC score of -1 and indicated a strong desire to look for health information. She browsed for 16 minutes 52 seconds, slightly longer than the time allotted and looked at 9 items. The following quotation also illustrates her stated desire to search:

> If it was something that I had or someone in my family had, I would spend probably hours researching: what causes it; what different kinds of treatments there are; different people who've had it; what they've said about it; what the outcome was. I think that's normal. To me it is.

She attributed this desire to search to a lack of trust in healthcare professionals, expressing her belief that doctors are not trustworthy, due to their experimental techniques. She spoke of people she met who did not search for health information, pointing to what she saw as their lack of responsibility and misplaced trust in healthcare professionals:

> You're taking pills and you don't know what it is…Wow, you really trust doctors a lot. You have no initiative to look after your own health? I find it's everybody's responsibility to do that. I've seen many doctors in my life and doctors only do trial and error.

5.3.2 Monitoring and Blunting (Threatening Medical Situations Inventory or TMSI)

The following tables show TMSI scores compared with the measures used in the Interview and Interaction study (see Table 5-7, 5-8). Here the scores are again divided into three groups of equal intervals for monitoring and three for blunting. In this grouping, low monitoring and blunting scores range from 29 to 39, middle monitoring and blunting scores from 40 to 49, and high monitoring and blunting scores from 50 to 59.

Table 5-7

Monitoring scores and the time spent per item of health information material, the total time spent, and the number of items of health information material viewed

	Time spent per item	Total Time spent	Number of items viewed
Low Monitoring (*n*=6)	1:36 (0:54)	10:34 (4:09)	8.00 (4.30)
Middle Monitoring (*n*=8)	2:00 (0:58)	14:21 (4:41)	8.14 (3.08)
High Monitoring (*n*=13)	2:05 (0:59)	11:29 (4:57)	6.33 (2.82)

Table 5-7 Monitoring scores and the time spent per item of health information material, the total time spent, and the number of items of health information material viewed

Table 5-8

Blunting scores and the time spent per item of health information material, the total time spent, and the number of items of health information material viewed

	Time spent per item	Total Time spent	Number of items viewed
Low Blunting (*n*=8)	2:23 (1:13)	14:25 (4:48)	7:38 (3.66)
Middle Blunting (*n*=11)	1:35 (0:40)	9:15 (3:21)	6.80 (3.01)
High Blunting (*n*=8)	1:39 (0:34)	11:23 (5:24)	6.20 (2.77)

Table 5-8 Blunting scores and the time spent per item of health information material, the total time spent, and the number of items of health information material viewed

Some of the monitoring and blunting data aligns with expectations. High monitors, that is, those people who are most likely to concentrate on finding a solution to a problem in a situation of stress, have the highest mean time for item score, as well as a high time spent overall. Blunters in the lowest category, that is those people who are least likely to concentrate on their emotions when in a situation of stress, had the highest mean scores in all categories; on average, they spent the most time per item, the most time overall, and viewed the greatest number of items. High blunters, those people who were most likely to concentrate on their emotions, viewed the lowest number of items on average.

This pattern, that of high monitors and low blunters looking at more information, echoes that in comments made by participants about their health information seeking and avoidance behaviours. Participant 20 (generally healthy; HIV positive) provides one example. This participant had a high Blunting score of 50 and browsed the given health information for a total of 7 minutes 33 seconds, looking at 5 items of health information. He spoke about wanting to limit his health information searching:

> At some point, my time becomes more valuable, and I don't want to just spend three hours to learn two new things; I've had enough. A saturation point. [Anything else] might influence my interpretation of experience and not make me worry, but it'd make me maybe blame the wrong thing for what I'm experiencing.

Here this participant indicated that after a significant period of time with a chronic illness, HIV, he had become tired of searching. He explained: "I look a little bit. Initially, I did. [Now] I just plod along, and I have no reason to investigate anything. I trust the medicines that I'm taking."

However, participant 9's (generally healthy; gave up sugar) results show some contradictions. This participant also had a high Blunting score of 50; he searched for a total of 9 minutes 20 seconds, looking at a total of 13 items of health information. However, he spoke of wanting to look for alternative health information over medically authoritative material. He declared that the

> menu here was insufficient; I thought there'd be more stuff…there wasn't no shaman; there wasn't no witch doctor…in my own line of thinking there's always more…There's a lot of things that seem illogical, but then when you look at the real world there's effects, E-ffects, real world effects.

Here the participant's lack of trust of healthcare professionals had led to a rejection of medically authoritative information. He commented: I don't believe anything the doctors say. I don't think some doctors are out to deliberately deceive you. It's just that some of them have bad datasets." Rather than depend on healthcare professionals and their potentially incorrect knowledge, the participant would rather see a range of health information; anything, he said, that had an "effect."

5.3.3 Situational Affect

The following tables show positive and negative affect scores based on the PANAS scale compared with the measures used in the Interview and Interaction study (see Table 5-

9, Table 5-10). These scores are divided into three groups. Low positive and negative affect scores range from 0-10, middle scores from 11 to 19, and high scores from 20 and higher.

Table 5-9

Positive affect compared with time spent per item of health information material, total time spent, and number of items of health information material viewed

	Time spent per item	Total Time spent	Number of items viewed
Low positive affect (*n*=2)	4:03 (0:55)	13:53 (4:21)	3.50 (0.71)
Middle positive affect (*n*=14)	1:40 (0:42)	11:44 (4:54)	7.71 (2.73)
High positive affect (*n*=11)	1:59 (0:59)	12:08 (5:28)	7.00 (3.56)

Table 5-9 Positive affect compared with total time spent per item of health information material, total time spent, and number of items of health information material viewed

Table 5-10

Negative affect compared with time spent per item of health information material, total time spent, and number of items of health information material viewed

	Time spent per item	Total Time spent	Number of items viewed
Low negative affect (*n*=8)	1:48 (1:04)	12:20 (5:10)	7.87 (3.52)
Middle negative affect (*n*= 15)	2:12 (1:09)	11:31 (6:16)	5.61 (2.59)
High negative affect (20+) (*n*=4)	1:58 (1:02)	11:56 (4:55)	7.63 (4.25)

Table 5-10 Negative affect compared with time spent per item of health information material, total time spent, and number of items of health information material viewed

Participants with low positive affect spent the highest total time and had the highest time spent per item; however, these participants also had the lowest number of items viewed. There were no clear patterns relating to negative affect.

The analysis of comments may also shed some light on how affect influences information seeking. Participant 29 (myopic degeneration), who possessed the highest positive affect score (37), also held high scores of 5 for interest, alertness and attentiveness. Her comments indicated that interest functioned as a strong motivator for information seeking. She declared that she sought information because her interaction with her healthcare professional did not provide enough medical information.

> I'm far more interested in all of the angles of it than my doctor has the time to explain to me… I should have been a doctor, actually, in another lifetime but because I got born in the wrong age, in the wrong place, nobody ever suggested it to me or it was never a possibility, but I'm really interested in this stuff.

However, the interviews also suggested other interpretations for the positive and negative affect scores. Participant 28 (anxiety and depression), who achieved the lowest positive affect score (9) also cited her numerous problems with depression and anxiety. Participant 8 (benign tumour on finger), who scored a high negative affect score (35), commented that his searching would be limited, but that he did seek out some information. When given his hypothetical scenario, this participant declared: "I would, first of all, want to know about the disease just general, medically grounded information." Later he did add that this searching would not be extensive: "I don't need to know everything." He gave several reasons for searching, i.e., curiosity, the current health climate (an abundance of resources), and distrust of healthcare professionals:

> I'm just curious by nature, and I like to have the best information. We're in an era of health literacy where there's a lot of resources out there. I'm hesitant too, off the bat, to talk to the doctor too much about it 'cause I don't know what he knows.

These preceding sections gave details about the demographics, scales and interaction session measures from the Interview and Interaction study. Participants showed patterns in material selection, with some participants searching for information from patients, while others searched for information associated with more traditional medical authorities. There was very little indication that participants' NfC scores had an effect on health information seeking. With respect to Monitoring and Blunting, there does seem to be some effect, particularly at the high and low ends of the TMSI scale. However, attitudes about health and healthcare systems also play a role and seem to confound these results. In terms of affect, there is some evidence that those participants with low positive affect spent more time per item, but it is not clear whether this is the result of a general mood.

5.4 Themes Identified in the Interviews

This next section presents results from the interview portion of the Interview and Interaction study. Data from all 35 participants was included in this analysis. As described in Chapter 3, the interview transcripts underwent an extensive coding process, leading to the identification of a number of high-level themes in response to the research questions. The full set of codes is provided in Appendix G. I will begin by examining two methods of information avoidance, self-regulation and delegation, revealed by the analysis of participants' comments. I will then move to the factors that influence these behaviours, again unveiled by the analysis of participants' comments. These factors consist of beliefs and attitudes conveyed by participants about their own health, the role of healthcare professionals, and health information seeking.

For clarity, the themes and sub-themes presented in the sections to follow, are summarised here in point form:

- Self-regulation
- Delegation
    - Delegation to family members
    - Delegation to healthcare professionals
- Factors that influence information avoidance
    - Belief in one's health as a personal responsibility
    - Belief that one's health is in the hands of healthcare professionals or fate
    - Belief in healthcare professionals as trustworthy
    - Belief in healthcare professionals as not trustworthy
    - Belief in information seeking as a social responsibility
    - Belief in information seeking as not a social responsibility

5.5 Self-regulation

Twenty-one participants described themselves as avoiding *some* information. This avoidance typically took the form of self-regulation, in which participants limited or curtailed looking at some (usually online) information. Codes associated with this theme were the coding category 3 Coping, particularly code 3A Managing emotions, with subcodes 3A-A Avoidance of regret, and especially 3A-B Self-regulation, with 3A-B-a Preference for easy information. Code 3B Planning and preparation also clarified details about the opposite coping preference (See Appendix G for full codebook).

Participant 33's (Post-Traumatic Stress Disorder) comments were typical, in that she applied "very specific parameters…because you could search forever, but then you have to decide, alright, is it this? Is it that? Or is it open ended?" Eight of these participants specifically stated that these limits enabled them to avoid distress. Participant 33 noted that "you can see how, you can dig, dig, dig, dig, dig yourself into a hole," a problem her limits are designed to prevent. Participant 20 (generally healthy; HIV positive) stated that limits on his searching for information about his HIV constituted

> a heavy dose of ignorance as a coping strategy. So when I'm told that there's a difference between viral load and detectability, I don't really care. Are things okay? Yes, they're okay, and I feel okay, that's great.

Participants' comments pointed to the emotional stress resulting from interactions with health information, especially when coping with actual health concerns, and emphasized the care that some individuals took to balance out the benefits and negative effects of exposure to this type of information. When participants indicated, for instance, that they would limit the amount of online searching, they often gave as the explanation their impression that too much searching would result in extreme negative affective reactions: getting "freaked out" (P19 (generally healthy; rash on chest, backaches)), "overwhelm[ed]" (P13 (generally healthy; past problems with concussions and tropical fever), P27 (detached retina (4 times), glaucoma)), or "crazy" (P23 (transient ischemic attack (mini-stroke), hypertension, depression)), reaching the point of confusion and "throw[ing] up" further information (P33 (Post-Traumatic Stress Disorder)). Participant 19 (generally healthy; rash on chest, backaches) spoke of the joys of ignorance.

> Because by the time you read so much medical stuff, sometimes you get freaked out because you have all this conspiracy theories that everything will keep getting worse so sometimes, the less you read about the fine prints, the better.

Participants spoke of using a number of approaches to self-regulation. Participants limited the time spent on searching or avoided certain types of content. Five participants spoke of limiting information searching by time. Participant 7 (generally healthy; cystitis, potential for stroke, IT band issues) specified that she would do a large amount of searching all at once, "until I'd tired myself or upset myself enough." The other four participants spoke about regulating the time spent searching, so as to avoid this final break. Participants 3 (thyroid difficulties, hysterectomy when younger), 5 (generally healthy; deviated septum), and 27 (detached retina (4 times), glaucoma) declared that they would do only a small amount of searching at one time. Participant 31 (generally healthy; vegetarian, hypothyroidism), more explicitly, stated that she would search "forty minutes at a time...I would probably spread it out over a week, and a half an hour at a time, and make a few notes. Otherwise, it would be just too heavy." Three participants attributed this limited searching to a need for time away from the computer, to process the affective elements of health information. Participants 3 (thyroid difficulties, hysterectomy when younger) and 31 (generally healthy; vegetarian, hypothyroidism) spoke of needing to "absorb" the information. Participant 31 explained: "I don't think I learn or take it in as effectively if I'm sitting there for hours. Breaking it down, partly, it's upsetting, but it's also, I want to really absorb it properly." Participant 5 (itchy scalp condition) spoke more explicitly about the process of absorption and why she chose to take time between searching sessions:

> I know about emotional health…and how you have to pace yourself...I expect most of this information is gonna be negative? (laughs) So, if I'm diagnosed with the illness, I'm already feeling really blue. It's good to get information…but then you have to go sit with it…It gets out of my head and gets more into my bones (laughs).

Seven participants also limited their information searching by content. These participants also cited the affective elements of health information and attempted to select that information which was less affectively burdensome. Participant 11 (HIV, drug-induced schizophrenia) declared that he would "get always the names of the easy things. But I will never go into the real thing. I will never read the whole thing; maybe I will be so afraid." Participant 16 (bipolar disorder, lithium-related problems with kidneys, osteoporosis), too, reported that she did not plan to search for a lot of information about her recently diagnosed kidney condition; she said she would "probably look up, as well, but I just don't want to scare myself." Participant 19 (generally healthy; rash on chest, backaches), too, asserted,

> I believe getting negative information can make you to react negatively to a situation…If somebody said, if you had Bells Palsy, you're gonna die in two months and you've had Bells Palsy for a month that would freak you out…That would be scary.

Participant 24 (cardiac issues (arrhythmia)) explained that this need to limit negative information might change over time:

> I might check out what's gonna happen…but maybe not my first go around. I'm probably still in shock. Might be too frightening. I might not be ready for it: "whoo, don't tell me yet; I'll tell you when I'm ready to go into that room."

Three of the seven participants gave examples of information they believed would cause negative affective information, commenting that this information would usually take the form of participants' stories found in blogs. Participant 20 (generally healthy; HIV positive) commented on blogs: "I don't want that to plant seeds in my mind about what may or may not go right or wrong…. In some ways, I stick my head in the sand." Participant 21 (chronic pain in stomach, back), too, demurred when asked about blogs, saying that she would prefer not to listen to "someone rant about how difficult it is…I think that would make me feel worse…oh, my God, I'm going to be like this for six months…and then I would get quite upset." Participant 26 (H pylori bacteria in stomach) did not look at information that he felt might contain unpleasant outcomes of his condition, bacteria in his stomach. "'Cause there can be a bad outcome…you can get stomach cancer from it. I knew that that was one of the outcomes, and I didn't want to find out more about it."

Three of the seven participants noted preferences for information that would cause positive affective reactions over more negative reactions. Participant 24 (cardiac issues (arrhythmia)) stated that she always ended a health information search on a positive note:

> I always want to end my time at the golf course, after having hit a really good shot; you never leave when you've just duffed one. Same thing here – I don't want to leave, shut my computer with some negative note.

Participant 19 (generally healthy; rash on chest, backaches) and 34 (generally healthy; lost tooth when younger, scraped knee) gave further examples of the benefits of health information that generated positive affective reactions. Participant 19 believed that this positive information would help patients to get better: "being able to have a positive view of the problem, puts me in a better situation to solve it." Participant 34 commented that such information would give her a sense of confidence and "help me engage in…my own health," rather than information which caused negative affective reactions.

The most extreme example of avoidance by self-regulation due to potential negative affective reactions was the refusal by eleven participants to look at videos of surgeries. Rather than fear, though, this negative affective reaction was disgust. "I'm a little squeamish," said Participant 29 (myopic degeneration). "I don't like gore." Similarly, participants 13 (generally healthy; past problems with concussions and tropical fever), 16 (bipolar disorder, lithium-related problems with kidneys, osteoporosis), and 33 (Post-Traumatic Stress Disorder) described surgeries as "yucky" (P13), "graphic," (P16), and "gory" (P33). Participant 12 (heat stroke) spoke of a physical reaction to the unpleasantness of videos: "I definitely wouldn't watch anything on Mt Sinai. They got pictures of operations. And I'd throw up." Participant 23 (transient ischemic attack (mini-stroke), hypertension, depression), too, expressed disgust: "The videos? I don't want to see photography of someone's troubled anus." Participant 7 (generally healthy; cystitis, potential for stroke, IT band issues) was in accord.

> I don't know how I'd feel watching someone's head being cut open knowing that their heart is still beating; they're still awake in there. I don't know if I'd really want, and especially knowing that I'd go through that.

Three participants did add that, although they too found the videos unpleasant, they would overcome this reaction if surgery could not be averted. Participant 6 (generally healthy; deviated septum) declared that if he had to get his head operated on, and initial questions were over, then "yes, I'd probably be interested. Just to see what would happen." Participants 27 (detached retina (4 times), glaucoma) agreed, saying that he would watch the video, "if this is what's going on right now."

Participants 22 (generally healthy; hypothyroidism), 26 (H pylori bacteria in stomach), 30 (generally healthy; colonoscopy with undiagnosed digestion problems, low iron, discoloured toe) and 34 (generally healthy; lost tooth when younger, scraped knee) were also exceptions, saying they would watch the surgeries. Participants 26 and 30 seemed drawn in by the disgusting elements. Although Participant 26 found surgeries "gross" she wanted to watch: "It is disturbing. It's gross, but I also wanted to see what was happening." Participant 30 also evinced this fascination: "it's just like carving a turkey," he said of a video depicting brain surgery. Other participants indicated that this interest in watching surgical videos was a common occurrence in their lives. Participants 22 and 34 (generally healthy; lost tooth when younger, scraped knee) said they were not disgusted. "I am fine with it…I don't get scared or have any objections to it. I'm fine with looking at things from a gross level." Participant 22 explained that she enjoyed watching surgeries: "I probably should really have been a clinician."

While much of this self-regulation was due to fear, five participants discussed avoiding detailed medical information out of boredom or disinterest. Four participants expressed preferences for Wikipedia, as it is written in "layman's terms" (P15 (arthritis and hip replacement)), in a "basic" (P19 (generally healthy; rash on chest, backaches)) language, or in "English," i.e., not as complex and detailed as other more medical sites (P18 (Post-Traumatic Stress Disorder with accompanying anxiety and depression, learning disorder), P23 (transient ischemic attack (mini-stroke), hypertension, depression)). Participant 18 declared that in Wikipedia, there's "no [*sic*] too much jargon and plain English." Participant 19 emphasized that in Wikipedia, "I'll get the most general information which wouldn't particularly be anybody's point of view but just try to describe all the basic stuff about the disease or the condition. The most basic thing." Participant 23's comments were also typical here: "The other ones slow me down. Because I don't speak in six-syllable words, and I trip over drug names."

Ten participants spoke about information that they would avoid due to anticipation of boredom. Eight of those participants referred to journals, described as "dry" (P5 (itchy scalp condition), P18 (Post-Traumatic Stress Disorder with accompanying anxiety and depression)), "very wordy" (P5 (itchy scalp condition)), "specialized" (P26 (H pylori bacteria in stomach)), "gibberish" (P23 (transient ischemic attack (mini-stroke), hypertension, depression)), and the opposite of plain language or "shit as shit" (P15 (arthritis and hip replacement)). Participant 5 commented on this notion of boredom to explain his refusal to choose a journal article as a health information source: "it's too busy right off the bat…I'm thinking, oh my God,…ten million pages of that." "I think it's very detailed;" noted Participant 34 (generally healthy; lost tooth when younger, scraped knee), commenting on the avoidance of journal articles by others.

> I think that people…when they read about very, very long detailed information, they tend to get lost; they can get their self lost, and they may not want to go any further

> reading for the information…When you're given large amounts of information, you tend to drift off.

One participant (P7 (generally healthy; cystitis, potential for stroke, IT band issues)) commented that she was unable to comprehend the medical jargon. "I would probably get bored and frustrated with the fact that I don't understand," she said. However, two participants spoke about how they could understand; they were simply unwilling to do so. "While I claimed to like thinking in the other interview," said Participant 23 (transient ischemic attack (mini-stroke), hypertension, depression), speaking about the Need for Cognition scale, "that's not the kind of thinking I like to do." Similarly, Participant 18 (Post-Traumatic Stress Disorder with accompanying anxiety and depression, learning disorder) said,

> I do have the academic background. I have a degree so I know you have to depend on journal articles for a paper. I don't usually go for those when it comes to medical disease because it's too dry [laughs].

Three participants also cited blogs as being uninteresting and causing boredom. Blogs were described by these participants as overly lengthy and detailed: "flowery", "very wordy," (P3 (thyroid difficulties, hysterectomy when younger)), written by people who tend to "run off at the keyboard" (P23 (transient ischemic attack (mini-stroke), hypertension, depression)), and lacking a good writing style (P2 (early onset of deafness (cured), hernia)) all of which would cause participants to avoid this material. Participant 3's (thyroid difficulties; hysterectomy when younger) comments were typical here: "I want to go in there and look around a bit but if it gets too flowery for me, then I lose interest. I lose interest very quickly in things like the blog."

5.6 Delegation

Delegation was one of the information avoidance mechanisms that emerged from analysis of participants' comments. Delegation was one of the information avoidance mechanisms that emerged from analysis of participants' comments. In delegation, participants reported behaviours in which others were allowed to act on behalf of patients, performing health information seeking and other duties. Delegates were both family members and healthcare professionals.

Codes associated with delegation were the coding category 10C People (as information source) and the coding category 8 Social. With regards to 10C, the following subcodes also indicated further information about participants' opinions and ideas about people: 10C-A Doctor-healthcare professional, with further divisions into subcodes 10C-A-a Doctor as authority, Conversation with doctor, and Friend as authority; 10C-A-b Problems with doctors, medical system, with divisions Conflict between doctors, Doctors have inadequate info, No life info, Not updated, and Doctors have suspect motives. In category 8 Social, subcodes that elucidated participants' viewpoints were 8A Connection with others, 8C Independence, 8D Maintenance of social norms, and especially 8B Education of friends and family (See Appendix G for full codebook).

5.6.1 Delegation To and On Behalf of Family Members

Eight participants noted that family members are often the delegates chosen or self-appointed to seek health information on behalf of others. In two of those cases, the participants themselves delegated; in the rest, they acted as delegates. Participants 7 (generally healthy; cystitis, potential for stroke, IT band issues) and 11 (HIV, drug-induced schizophrenia) delegated to family members. The mother of Participant 7 made appointments: "I was depressed, essentially when I was at home. So she booked me in for an appointment. And then she'd just come back and tell me about these appointments." Participant 11 said of his ex partner:

> He was the one…I been lucky…Very lucky to have always somebody who knows more than me or who goes and do the research for me and say "look at this" and I say "oh." "See? So you have to do this and then do this." And I say, "Okay, so I will do it."

Six participants spoke of being the delegate. Here health information seeking could be considered an extension of the role of caregiver taken on by a partner, parent or child. The caregiving role was illustrated by several examples given by participants. Participant 6 (generally healthy; deviated septum) spoke of his mother, who was diagnosed with lupus. She "didn't read anything about it…my dad probably went with her [to the doctor] and asked everything." Participant 3 (thyroid difficulties; hysterectomy when younger) told of acting as the delegate for her elderly mother; this participant searched for information when her mother was diagnosed with breast cancer. "My mom's 88, so she doesn't do any of that…I do that for her. Her medication and her health care searching and things like that. I write letters to her doctor." Participant 20 (generally healthy; HIV positive) searched for information for his parents, "to inform myself in order to educate them. And to make sure that they were asking the right questions. That they were interpreting the information the correct way."

Four participants gave examples of informed caregivers who provided informational support for ill people. Delegation thus can allow the ill person to practise information avoidance in order to deal with his/her emotions, usually fear. Participant 6's (generally healthy; deviated septum) father learned all about his mother's lupus,

> because he wanted to know everything he possibly could about lupus so that he could talk to the doctors and know how to take care of her. Whereas, mom was "I'm gonna do what the doctor tells me, and I don't need to know" and find out anything that might scare me or make me unhappy.

Participant 5 (itchy scalp condition), too, searched for information for her mother:

> I had to do all the research for her about what her options might be and she doesn't even want to hear the word 'cancer' said out loud. She's an extreme case of someone who believes, the more you talk about it, the worse it's gonna get -- the condition.

Information given by caregivers was often carefully selected so the recipients were better able to manage it; this information thus became, as Participant 20 (generally healthy; HIV positive) portrayed it, a "filter between the numbers and the science and…experience." Participant 11 (HIV; drug-induced schizophrenia) spoke about reading only material selected by his ex-partner and his friends: "I don't read anything so most of the time people looking and saying look, read this. And then I read it." Similarly Participant 20 spoke of finding positive information for his parents, who he described as being overwhelmed with depression over his father's Parkinson's disease. This participant searches for information "that would contradict that picture. Because what they're telling me is pretty much a death sentence." Similarly, this participant searches for information about his own HIV status to give to his parents. Both sets of information, this participant noted, were selected for factual veracity but also to give his parents hope. The participant, in choosing information about Parkinson's, attempted to choose positive information; the information he reported sending about his own HIV status was equally hopeful. "I'm gonna give them a picture that is gonna fly in the front of something tragic that they may have read."

Delegation, participants explained, thus took place when people were too fearful to search or could only search in a limited fashion; however, other reasons for delegation were present as well. A delegate might, declared participants, have stepped into this role because of better information skills or knowledge. Participants 3 (thyroid difficulties; hysterectomy when younger), 5 (itchy scalp condition), and 25 (genetic potential for diabetes, overweight) both spoke of searching for parents who are part of a different, less technologically able generation. Participant 25's comments are representative:

> I feel like I have more expertise. And I know who to look for, because they would probably be…looking at Wikipedia and stuff. Why would you do that if we can do a better search now just through me?

Here this delegation seemed less a result with the parents' fear and more to do with the participants' own better knowledge. In some cases, this form of delegation implied a lack of interest in searching for health information. Participant 25 reported that her parents are disinterested in learning how to search for health information, even in a situation where they were personally affected. "There's also social media and my parents see a lot of it – let's say Twitter -- and then my parents would say, 'Oh, I saw this and can you look it up?'" The participant noted that she had taught her parents how to use Twitter, at which they were now skilled. Her parents, though, did not want lessons in how to "look [things] up," as their daughter could accomplish this task for them.

5.6.2 Delegation to Healthcare Professionals

Delegates could also be healthcare professionals who were in this case allowed to perform all healthcare duties for the patient without much patient input. Three participants told stories that illustrated this sort of delegation on the part of others to healthcare professionals. Delegation in this format may be likened to the traditional model of medicine; however, patients practising delegation to healthcare professionals avoided searching for outside information or refused information offered by others. Thus although this delegation could represent deference to the knowledge and experience of healthcare professionals, it might also indicate information avoidance due to fear on the part of the ill person. Participant 15 (arthritis and hip replacement) spoke of his brother who, when faced with the prospect of bypass surgery, followed medical guidance without question. "Once they'd diagnosed it," said the participant of his brother, "he found that this was what was needed, and he went forward with it." The parents of Participant 20 (generally healthy; HIV positive) "rely solely upon the messenger being their primary physician." Participant 2 (early onset of deafness (cured), hernia) spoke of his brother, who accepted treatment from healthcare professionals for a tendon problem but refused all other information.

> I tell him there's really easy exercises you can do to get blood moving down there, and he totally doesn't want to hear about it. I think he sees it as a life sentence and the doctors know best, and he's going to do what the doctor tells him to do.

Three participants explained that they themselves, like the family members of participants above, also rely on healthcare professionals, usually general practitioners ("doctors") and specialists, seeking independently only minimally or not at all. These participants were more explicit about the fear they felt. Participant 11 (HIV, drug-induced schizophrenia) spoke of being "guided a very little" by the doctor during his experience being treated for his HIV. Participant 11 said elsewhere that his experience with HIV was very frightening: "it was hard at the beginning; it was just terrible. It was very scary." Participant 23 (transient ischemic attack (mini-stroke), hypertension, depression), too, stated that for various difficulties, appointments with doctors would replace extensive searching. Instead, he "would look but…wouldn't spend days. It would make me crazy." Participant 16 (bipolar disorder, lithium-related problems with kidneys, osteoporosis) declared of her as-yet-undiagnosed kidney difficulty: "I do have a follow-up with the nephrologist and I'm gonna write more questions (laughs) to ask him, and I'll probably look up, as well, but I just don't want to scare myself." Her information searching, she implied, would be limited.

This association between this form of delegation to healthcare professionals and situations of extreme fear is reinforced by other examples from participants. Five other participants spoke of similar delegation in reference to hypothetical situations that might generate fear. When given the scenario of meningioma, Participant 4 (pregnancy) declared that her searching about this condition would be limited only to alternative medicine, as she would "just let the doctor do the thinking for the medical side. 'Cause I feel that they have the most knowledge, and that they're going to give you the best answer." Four participants claimed that they would delegate information seeking if they were faced with the possibility of having surgery. Participant 20 (HIV positive) declared that he would not search for information about surgery: "I'm not concerned about the process of surgery…I just will go with the flow." Participant 7 (generally healthy; cystitis, potential for stroke, IT band issues) talked of a television program in which young women were shown breast implantation surgeries in their entirety, so they would understand what the procedure involved. The participant asserted that she herself thought, "ignorance is bliss…I think I'd rather go in and blindly have it done. Just entrust that whatever the doctors were doing was what needed to be done." Participant 11 (HIV, drug-induced schizophrenia) echoed this passivity, continually repeating the word "wait:" "for me, if you say I'm going to do an operation right now, I will just sit and wait. I will not go looking; I will just sit and say I will wait. And say I will wait."

Two participants told of not contributing to their healthcare out of satisfaction with the healthcare professional(s) rather than out of fear. Participant 23 (transient ischemic attack (mini-stroke), hypertension, depression) said he did not look for information regarding his repeated small strokes because he trusted his doctor and specialists. "The neurologist he referred me to, I was comfortable with. And so once I met him, I don't think I've been back online to look for stuff." Participant 30 (generally healthy; colonoscopy with undiagnosed digestion problems, low iron, discoloured toe), who had low iron, measured the doctor's thoroughness in considering all possibilities as to the nature of the problem. This participant did not look for information outside of the doctor-patient communication. "No, I didn't look it up that way, because I did feel that the GP was helping consider all the possibilities, and she was flummoxed as well (laughs)…I was satisfied with that."

Two participants also discussed times when they felt their attendant healthcare professional did not display enough expertise or attention to serve as the sole information source. Participant 11 (HIV, drug-induced schizophrenia) spoke of a time when he demanded more information after his doctor commented on his weight loss. He said:

> And if she say, oh, you're okay; I'll get upset and I'll say no, no, I want you to look, because you tell me that I look so skinny…you told me something and now you have to pay attention; what is the next comment, and you have to tell me what is the next comment.

This participant later received the response he wanted from his doctor, her attention and information as to whether his weight gain plan had worked. Participant 26 (H pylori bacteria in stomach), by contrast, after years of seeing his doctor's uncertainty about a digestive difficulty the participant was having, began to search for alternative explanations, albeit not online. "I was disappointed about the care I was receiving, and then that's why, at the beginning of this year, I started seeing a naturopath as well."

5.7 Factors that Influenced Information Avoidance

Thematic analysis of the interviews and comments made while interacting with online information identified a number of factors that seem to influence the decisions of participants to avoid or seek health information. Principal among these factors were three sets of beliefs held by participants in part or in whole. The first set of beliefs centred on health and responsibility; some participants felt that health was their own personal responsibility, a belief that often changed when conditions were more serious. Others expressed the belief that their health was in the hands of others, either healthcare professionals or fate. A second set of beliefs had to do with trust in healthcare professionals: some participants reported feeling healthcare professionals to be trustworthy and other participants reported the opposite, that healthcare professionals lacked trustworthiness. Again, comments from participants clarified that this second belief could be situation-specific. A third belief focused on the position of health information seeking in society, in which some participants expressed the belief that health information seeking is a social responsibility and that seeking made one a good patient and often a good citizen, while others did not express this belief.

These themes were associated with the codes in category 12 Social achievements, with codes 12D Information seeking, 12G Self-efficacy, and 12H Taking care of self being associated with the first belief, in health as a personal responsibility. The category 12 Social achievements was also used in connection with 10C People and 10C-A Doctor-healthcare professional to result in the second belief, in the trustworthiness of healthcare professionals. The third belief, in the social responsibility of health information seeking was developed in association with 12 Social achievements, particularly codes 12A Abuse of system, 12C Gender, and 12D Information seeking (see Appendix G for the full codebook).

5.8 Belief in One's Health as a Personal Responsibility

Twelve participants made statements indicating they saw their health as a personal responsibility, in which they themselves were responsible, at least in part, for maintaining their own health. These participants often reported performing various health tasks, including exercising and eating healthily, tasks that eliminated or reduced to many the need for health information seeking.

Ten participants talked of their "preventative" (P8 (benign tumour on finger)) lifestyles, designed, at least in part, to ensure their health. These participants talked of exercising (P8, P20 (generally healthy; HIV positive), P27 (detached retina (4 times), glaucoma), P29 (myopic degeneration), P31 (generally healthy; vegetarian, hypothyroidism), P33 (Post-Traumatic Stress Disorder), P34 (generally healthy; lost tooth when younger, scraped knee), P35 (generally healthy; bad experience with tetracycline)); eating healthily (P19 (generally healthy; rash on chest, backaches), P20, P35); and maintaining their emotional health by reducing their stress (P24 (cardiac issues (arrhythmia), P35), staying confident (P19) and positive (P19, P20), and by building and maintaining social networks (P19, P20, P35). Participant 20's comments are representative:

> I go the gym; I eat perfectly well; I maintain an optimistic attitude; I have a strong work ethic; I keep myself busy; I keep myself socially active. I know I'm a little bit reckless but I do wear a helmet (laughs)…I don't do drugs. That's what I do to keep myself healthy.

Three of these ten participants also searched for wellness information, here defined as information about healthy lifestyles, healthy food, and exercise, as part of their healthy behaviours. Participant 24 (cardiac issues (arrhythmia) was planning on searching for information about meditation: "I must say that what I would like to do more of – and, once again, this is just choice -- is find out more about the neuroscience of meditation." Participant 19 (generally healthy; rash on chest, backaches), too, sought information: "I look at a lot of things online…more of how to live a healthy life or how to eat healthy…I look up things like benefits of oranges, strawberries." Participant 34 (generally healthy; lost tooth when younger, scraped knee), too, searched for wellness information. "I do find out things that will help me to better my lifestyle...have better sleep or sometimes to decrease stress levels…[I] look at websites, health websites."

Seven participants gave comments that described these activities as effortful, "work" (P29 (myopic degeneration), P30 (generally healthy; colonoscopy with undiagnosed digestion problems, discoloured toe)), an "effort" (P8 (benign tumour on finger)), something people "have to do" (P20 (generally healthy; HIV positive)), linking these good health behaviours with the concept of "healthwork" (Mykhalovskiy & McCoy, 2002). "I try to work two hours a day on physical activity," said Participant 29, while Participant 30 echoed this emphasis on "work": "I need to work at it, be vigilant about what I eat and be somewhat vigilant about exercising." Participant 11 (HIV, drug-induced schizophrenia) discussed his labour-intensive attempts to gain weight. He spoke of the discomfort he feels from eating more.

> I have my goal…And the fact is that I'm eating more than I can; there's nothing funny at all…I've been eating like crazy, you know? Yeah, it's very discomforting…I been pushing myself; I been eating and eating.

Two of these seven participants referenced this notion of healthy activities as work as they discussed their guilt over not performing important health tasks, eating healthy food and exercising. Participant 25 (genetic potential for diabetes, overweight) talked of how her laziness stops her from following health dictates she finds online.

> Interviewer: So you mainly look for yourself for nutrition and exercise and lifestyle. How does that make you feel when you look for that kind of stuff?
>
> Participant: Most of the time, it makes me feel like I should really do a better job (laughs). But then my habits don't really change. Although, when I do read it, it makes me feel guilty.

Participant 28 (anxiety and depression) explained that she too feels guilty. "I gained fifty pounds... I've just been kind of lazy to lose the weight and to take care of myself." This idea of guilt implied a sense of responsibility; these participants conveyed a feeling that they were responsible for their own health and thus should be seeking health information.

Nine participants explicitly linked this lifestyle and their healthwork to a prevention of illness, stating that their health strategies were sufficiently effective to overcome most (if not all) forthcoming health difficulties. Exercising and eating healthy were referred to as being "proactive" (P31 (generally healthy; vegetarian, hypothyroidism)) or "preventative" (P8 (benign tumour on finger), P19 (generally healthy; rash on chest, backaches), P29 (myopic degeneration)) behaviour. Participant 8's comments were typical: "I have a role to play in my health care, and that's preventative medicine…if I don't [exercise], well, then, I'll probably suffer or I'll have more issues." Two of these participants gave examples of the strategies they felt would be particularly effective in preventing illness. Participant 33 (Post-Traumatic Stress Disorder) declared that healthy food was important: "I believe that food is medicine." Participant 35 (generally healthy; bad experience with tetracycline) spoke of his low risk lifestyle, which he felt contributed to his lack of illness.

> I don't put myself in high-risk behaviour, like play hockey or scuba diving. Jumping out of the plane. My life is just very calm and stable. If you are like this…You are not going to be sick.

Two participants went further in reporting beliefs that a healthy lifestyle would also restore health in the case of illness or in maintaining health during dangerous activities. Participant 13 (generally healthy; past problems with concussions and tropical fever) explained:

> I've been through horrible tropical diseases. Yes. Paralyzed in the jungle for days with a crazy fever…But if you're healthy, if you're a healthy person, the body can heal itself a lot of the time.

Participant 4 (pregnancy) described her belief that a baseline of health would prevent dangerous side effects experienced by children after receiving vaccinations.

> I read several articles about why vaccinations might have an effect or why certain people are more susceptible to the side effects…with that information, I now believe that you can ensure that you're healthy enough, that the vaccinations work as they should.

Two participants reported their belief that these good health behaviours allowed them to avoid not merely illness but what they saw as the emotional difficulties of health information searching. Participant 29 (myopic degeneration), although she herself sought health information, advocated searching wellness information to friends of hers who have experienced negative affective reactions to information regarding illness. "My girlfriend who's really health oriented, the one that freaks out…maybe she shouldn't be looking…she doesn't handle it well…I tell my friends, find out as much as you can preventatively." Participant 19's (generally healthy; rash on chest, backaches) comments also note the link between good health behaviour and an ability to avoid emotionally difficult health information seeking.

> Because I come from the school of thought that prevention is better than cure. So, I look up how to not fall sick so that I don't have to look up how to treat myself. I feel better that way because then I don't have to worry about what to do when I'm sick.

Comments by four participants indicated that their beliefs in health as a personal responsibility could be situational, and that in some cases information seeking was unnecessary. Participant 2 (early onset of deafness (cured), hernia), for example, felt that his hernia was not serious enough to warrant much information searching: "I didn't think it was a serious enough problem. There wasn't recurring pain." Participant 34 (generally healthy; lost tooth when younger, scraped knee) spoke of a minor health problem that she felt was not serious enough to warrant any health information searching.

> I fell and I scraped my knee, but I was able to handle it. I didn't go looking for anything on the website. I felt I could treat this skin abrasion myself. Putting an ice pack, and putting a band-aid on it, and letting it sit for a couple of days.

Participant 13 (generally healthy; past problems with concussions and tropical fever), after playing sports and having had a "few whacks," felt that any subsequent concussion, could be easily overcome. When he experienced what he believed to be another concussion when snowboarding, he brushed it off, rather than looking for information about it.

> I lay there. I was out for some time. And there were 30 people around going oh my God, we heard your head hit the ice from the chairlift. Yeah, it was pretty bad, but it was a concussion...I was with some guys. It was party time at the moment, so we all went back and [laughs] drank some beers.

Two participants spoke of how they could get over some conditions, but for more serious conditions, information would need to be sought. "Would I Google a problem?" asked Participant 35 (generally healthy; bad experience with tetracycline). "Depends on how serious it is." Participant 13 agreed. "I'm not self-destructive. I may be borderline reckless, but not if I think it's something that requires attention."

Some participants thus demonstrated belief in the idea of health as a personal responsibility, one that they maintained, sometimes with effort, by exercising and eating healthily, and at times by researching wellness. This healthwork was motivated in part as a means to avoid illness and other health problems, and, in addition, the emotionally difficult task of health information seeking. There was some evidence to suggest that participants holding this belief were more conscientious about staying healthy than they were about dealing with health difficulties, especially when these problems were deemed "minor."

5.9 Belief that One's Health is in the Hands of Healthcare Professionals or Fate

In contrast to these participants whose comments revealed a belief that they were responsible for their own health, there were eight participants whose comments expressed a belief that their health was in the hands instead of healthcare professionals (usually doctors) or fate. Generally, this belief was associated with less reported information seeking, as participants, believing that they themselves could do little to help the condition, left details of their health to healthcare professionals or fate. For some, but not all participants, this acceptance and consequent lack of agency was a result of having a condition for an extended period of time.

Four participants spoke of "acceptance" (P27 (detached retina (4 times), glaucoma)) of their condition. These participants expressed the belief that their own actions were useless in the face of health conditions, leading to a need for this acceptance. "Nothing I can do to change it," as Participant 27 said of his glaucoma. Participant 16 (bipolar disorder, lithium-related problems with kidneys, osteoporosis), similarly, spoke about a problem with her kidneys that she attributed to prolonged use of lithium, which she felt she needed to treat her bipolar disorder.

> I can't change the lithium aspect…there's nothing I can do; I've just got to accept it …It's just that it happens that the medication that benefits us, also causes these bad side effects…staying well comes with side effects. Anyway, nothing I can do (laughs).

Participant 32 (food intolerances) said of the hypothetical scenario she was presented with, "If I'm close to dying, then there's not much I can do (laughs)." Participant 23 (transient ischemic attack (mini-stroke), hypertension, depression) felt that his conditions were attributable to a lack of care when he was younger, which he could not change. "When you get old, you get old," he said. "And if you don't live well when you're not old, it's there." As a contrast, Participant 15 (arthritis and hip replacement), whose rheumatologist suggested a similar cause for the participant's illnesses, reacted not with acceptance but with anger. "He said, 'You've had an alternative life,' and…'Now you've got to pay.' I felt he was ignoring my pain, why I had come to him."

Acceptance seemed thus to signify that participants felt less self-efficacy and ability to change their health conditions with the result that they reported engaging in less information seeking about these conditions. "I just have to take my drops," said Participant 27 (detached retina (4 times), glaucoma) of his eye condition. "Once in a while I might, if I'm looking at something else and if I hear – see something about glaucoma…I'll give it attention, but generally not." Participant 23 (transient ischemic attack (mini-stroke), hypertension, depression) spoke of stopping information seeking. "I'd been poking at my depression, or having it poked at by other people, for a long time. This is what it is; this is what I got. This is what's got me." For participants 23 and 32 (food intolerances), information seeking was associated with searching for a cure; as they believed their illnesses did not have cures, they did not search. "Given up?" asked Participant 23. "Sure…I think there's a lot of myth in the word 'cure.' For some things there aren't any." Participant 32, too, associated information seeking with finding a cure, something that she did not believe was possible for her condition.

> Interviewer: I was interested in how you did not look for medical information for your food intolerances.
> Participant: How to cure it? I didn't really believe there was a way to cure it. 'Cause I was always told you just don't eat the type of food.

Comments by two participants indicated that this type of acceptance and lack of information seeking for one condition might translate into similar behaviours for other conditions. Participant 23 (transient ischemic attack (mini-stroke), hypertension, depression) indicated that, because he had been afflicted with his chronic condition, depression, for a long period of time, he might seek less information for other such conditions. After receiving a hypothetical scenario about Crohn's disease, this participant said of the condition,

> I figure Medline and even the MedScape that I gave up scrolling through; they talked about…a disease for which there is no cure and not much treatment. It's not debilitating…I'll get on with things…They call them chronic conditions for a reason.

Here "getting on with things" meant not searching for information to change the condition. Similarly, Participant 16 (bipolar disorder, lithium-related problems with kidneys, osteoporosis), already diagnosed with bipolar disorder, spoke of her osteoporosis, for which she did not seek a great deal of information:

> Did I look it up much? I didn't really go to a lot of extent looking it up…I think I've got information but I don't remember really researching about it extensively, actually. It's just something I got—yet another thing (laughs).

For six participants, this acceptance and consequent lack of agency was a result of having a condition for an extended period of time. These participants spoke of a change in their searching; initially they had searched for information, but over time, this searching had ceased. Participant 16 (bipolar disorder, lithium-related problems with kidneys, osteoporosis), in a typical comment, contrasted an initial searching period with her current lack of information seeking. "Definitely," she said, "I looked it up a lot in the beginning. I don't look at it much now, actually, with my medication or my bipolar disorders." As a contrast, Participant 31 (generally healthy; vegetarian, hypothyroidism), whose own thyroid condition had been diagnosed much more recently, was actively engaged in information searching.

> "This is what I'm gonna prescribe to you." And that was it, and I said, "Well, is there anything else I can do, or do you know why I got it?", and she said, "I have no idea"…I was extremely disappointed. So, since then I have gone online to find out how I can better support my thyroid to be healthier.

While self-efficacy or agency seemed to play a major role in the drive to seek or avoid health information, other factors were also involved. Information seeking was mentioned as taking place in one instance unrelated to agency, when inspired by curiosity or "fun" (P16 (bipolar disorder, lithium-related problems with kidneys, osteoporosis)). Eight participants who looked at some information in the interaction session gave as the reason curiosity or interest. During his interaction session, Participant 35 (generally healthy; bad experience with tetracycline) spoke of a general interest in all health material present on the site:

> Interviewer: The information you looked at; you looked at lots; you looked at blogs; you looked at news; you looked at websites.
> Participant: I don't want to miss any interesting thing.

Participants 2 (early onset of deafness (cured), hernia), 4 (pregnancy), 13 (generally healthy; past problems with concussions and tropical fever), 21 (chronic pain in stomach, back), 22 (generally healthy; hypothyroidism), and 34 (generally healthy; lost tooth when younger, scraped knee) also spoke of interest. The comments of Participant 2 are representative: "I'd want to know what the bright side was. I'd be curious and interested." Two other participants spoke of being interested specifically in looking for aspects of a health condition that they could not change, either how the problem could have been prevented (P16 (bipolar disorder, lithium-related problems with kidneys, osteoporosis) or the "cause" (P34 (generally healthy; lost tooth when younger, scraped knee)). Participant 16 declared that she would look for information on how her kidney problem could have been averted, despite the fact that she felt she could do nothing, as she already had this problem:

> I thought, what use could that be? But I still might look it up (laughs). Just for the fun of it (laughs). Just to see what it would say. They would have said maybe regular testing. Interest, fun, interest.

Similarly, Participant 34 (generally healthy; lost tooth when younger) searched for information about the cause. "I'm interested to know what is the major cause of this – just general interest – what causes meningioma on a general level."

One striking example of interest and information seeking came in the comments of Participants 5 (itchy scalp condition), 22 (generally healthy; hypothyroidism), 26 (H pylori bacteria in stomach), 30 (generally healthy; colonoscopy with undiagnosed digestion problems, low iron, discoloured toe), and 34 (generally healthy; lost tooth when younger, scraped knee), who served as exceptions to the typical avoidance of surgical videos. These participants stated their interest in surgeries as a reason to watch. During the interaction session, Participant 26, although she concurred with the previously stated belief among the participants that videos caused disgust, admitted that videos were also intriguing, and her interest caused her to continue watching longer than other participants. Her comments are also representative of many participants. "I find it interesting…I was intrigued by it." Participant 22 expressed the strongest fascination with surgeries, stating that she was

> just really interested. I should really have been a clinician. When my cat was having some surgery, me and the veterinarian were pushing heads 'cause I wanted to see what was doing…I'm just interested; I find it very interesting. I'm just interested.

Here her repetition of the word "interested" emphasizes the strength of this affective reaction for this participant.

5.10 Belief in Healthcare Professionals as Trustworthy

A belief in healthcare professionals as trustworthy also influenced participants' reported amounts of information seeking. This suggested trust was associated with two factors, according to interpretations of participants' comments: a faith in traditional medical knowledge, and a credence that healthcare professionals cared, that they were giving appropriate amounts of attention to participants. Faith in medical knowledge seemed to be associated with reported information seeking, as participants declared that they searched for information that they believed to be associated with the trustworthy medical profession. The credence in caring, on the other hand, was linked to reported information avoidance, as participants testified that they felt no need to usurp the professional's role and thus no need to seek information.

Ten participants exhibited faith in medical knowledge, sometimes citing medical knowledge as being in some way better or more authoritative than other knowledge, for example, their own or that of other laypeople. Three of these participants referred to face-to-face information from healthcare professionals. Participant 24 (cardiac issues (arrhythmia)) described herself as amazed when asked her opinion about whether or not she should go on hormone replacement:

> You go to your doctor and you talk about, 'Well, should I go on estrogen replacement or should I not?', and they go, 'What do you think?', and I go, 'Well, you're the guy that knows what's going on, and you're asking me what I should do'.

Participant 11 (HIV, drug-induced schizophrenia) also lauded healthcare professionals, specifically doctors and their knowledge. "The doctor is the one who knows," he said, clarifying that only a doctor could diagnose the participant's schizophrenia. "It's like somebody tells me, 'are you crazy?' 'Are you a doctor?' 'No, I'm not.' I tell him, 'You cannot diagnose me.'" Here the participant contrasts medical and lay knowledge, determining that from his perspective, medical knowledge is more authoritative. Participant 32 (food intolerances) commented that she would like to solve medical problems by herself but sees value in going to a healthcare professional.

> Sometimes going there, it's a reassurance. 'Cause then you might doubt yourself, and then going there, it might make it better…if I can do it myself then I probably would, but I don't know any medical stuff.

This trust resulted in more reported instances of information seeking, as the remaining seven participants also expressed preference for traditional medical authority in health information material and indicated that they would search these sites for health information, as discussed above. Participant 12 (heat stroke) compared the site he chose with other, less authoritative sites.

> And this, of course, looked official. Yes it did. Because it didn't have any cutesy things like Jenny's Guts Blog. This looked like it had a heading just like your UBC thing has a heading.

Participant 33 (Post-Traumatic Stress Disorder) noted that her preferred information sources had some medical authority: "It's not from a medical site," she said of a TED talk she watched, "but it is a medical researcher. He is now known as one of the world's foremost leading researchers on trauma." During the interaction session, Participants 2 (early onset of deafness (cured), hernia) and 12 both noted with approval that one site was the property of the National Library of Medicine: "Excellent," said Participant 2, clicking on it. Participant 33 said while looking at one site, "the Mayo? That would be good."

Interestingly, while these seven participants cited the "source" (Participant 27 (detached retina (4 times), glaucoma)) or similar signifiers of the authority of health material, only five of them were confident in their ability to judge which sources were superior. Comments from Participant 27 were typical.

> Interviewer: You thought that was very authoritative?
> Participant: Yes, I thought, yes. Because it comes from academics, from respectable institutions in our society. I saw the source, and the sources were Acoustic Neuroma Association, etc.

Participant 27's stress on the academic nature of his chosen health information material is contrasted with that of Participant 9 (generally healthy; gave up sugar) who cited a similar academic provenance for his material but with much less certainty.

> They seemed more academic. [laughs]…I was looking at a variation of PubMed…I didn't know if these were real or fake; I thought maybe they were fake because I noticed a spelling error, right here. So that threw me off a bit.

Participant 7 (generally healthy; cystitis, potential for stroke, IT band issues) spoke of trusting whether material was medically authoritative, but said that this trust could easily be unfounded.

> You just have to trust that what's been put onto this website…actually I can't tell. That's really bad…It's just when you look at websites they can be super professional, but anybody can learn how to do Wordpress…When you sit and think about it, that you actually put your trust and faith into things when you really have no idea.

Four participants contrasted material they believed to be medically authoritative with blogs and news stories of celebrities. Participant 3 (thyroid difficulties, hysterectomy when younger) did not want to see a news story about a celebrity: "I don't want to see…this guy on the news from Pearl Jam…I'm just more directed towards what I feel is highly medical knowledged." Participant 7 (generally healthy; cystitis, potential for stroke, IT band issues) spoke about what she saw as the lack of authority of blogs:

> There are people out there who know nothing. And they write blogs…to me a blog is something that I could go off and write one this afternoon about the things I do during my day.

This participant also spoke disparagingly of a news article detailing the experience of an English journalist: "Five years ago is a long time ago, and I have no idea who Tom Bible is."

Two other participants agreed, both citing disinterest in the stories of patients. "I don't care what somebody else did," said Participant 12 (heat stroke). "I couldn't care less about this guy." Participant, 20, too, was not interested in patient stories. "There is stuff that I choose to ignore," he said. "I don't really know if there's much relevant in Sheryl Crow's self report. I don't really care, and that's hearsay. That's anecdotal."

Three participants gave another reason for trust of medical authority; they spoke of trusting individual healthcare professionals, noting that they felt a personal connection with their family doctors. "I feel she's an ideal doctor," said Participant 15 (arthritis and hip replacement) of the doctor who had treated his arthritis and other conditions.

> I have a personal contact…and I have all my questions ready. If I'm going for an annual check up, I have all of the things that have happened to me through that the year that I'd just like little answers on.

Length of time and familiarity with a healthcare professional were both associated by patients with trust; Participant 12 (heat stroke) and 23 (transient ischemic attack (mini-stroke), hypertension, depression) stressed that their relationships with their doctors were long-term and close due to the amount of time these people had known each other. Participant 23's comment is typical: "I really trust my GP. I've known him for 25 years." As contrasts, two participants reported their dissatisfaction with healthcare professionals, a feeling due not to a lack of skill, but to an absence of this personal connection. Participant 24 (cardiac issues (arrhythmia) commented that she did not like her current doctor: "He's very businesslike…I'm sure he's fine, but I am fussy about my medical people...I'm just not this inert person in a plastic gown." This feeling, implied the participant, led to a lack of trust.

Relationships with individual doctors also related to information seeking. Two participants discussed how their searches for information about conditions were brief, giving as reasons trust in his healthcare professionals. The following comments are illustrations. "I probably spent more than 15 minutes, but not a long time. And some of that is…I really trust my GP" (Participant 23). "I put the faith that the doctors would know what they need…I trust the medicines that I'm taking" (Participant 20 (generally healthy; HIV positive)). Seven participants searched for information to prepare questions for their healthcare professionals; this information searching seemed limited, as it would always be verified with a healthcare professional. As Participant 24 (cardiac issues (arrhythmia)) said, "we're doing this together," a sentiment echoed by other participants (3 (thyroid difficulties, hysterectomy when younger), 4 (pregnancy), 21 (chronic pain in stomach, back), 22 (generally healthy; hypothyroidism), 29 (myopic degeneration), 34 (generally healthy; lost tooth when younger, scraped knee)) who felt that medical treatment was a joint process. Three participants spoke of searching for information in order to ask questions of the ultimate authority, a healthcare professional. Participant 24 spoke of engaging with her doctor: "I like to engage with them…What's the best way of us handling this, and why?...I want to be able to ask questions about what's happening. What's this and that?" Participant 34 spoke of joint work performed by herself and the doctor:

> I think it's both parts – the doctor and yourself. I can work [with the] doctor…Try to find out ways myself. From that, then I can talk with my doctor, with "This is what I found." It's like a two-way situation.

Participant 3 spoke of how she would like a "part" of her treatment:

> I want to have part of the treatment plan, not under my control, but I want to be a part of it [laughs]. I just take it from a point of I'm here for you to tell me what it is and take a step towards what we're going to do about it.

One participant believed information seeking to be not merely something she "want[ed]" (P24, P3) to do, but that it was necessary in order to achieve proper medical care.

> I think you build a better relationship with your doctor that way; I think you get better care if the doctor knows that you are paying attention, and you're not just a talking head or a walking body who doesn't understand the reality. (Participant 33)

5.11 Belief in Healthcare Professionals as Not Trustworthy

Thirteen participants indicated a lack of trust in healthcare professionals or their knowledge. This lack of trust was sometimes due to what participants viewed as a failure of medical knowledge, as two participants commented on the lengthy process of tests and attempts to find a diagnosis, which led to some loss of trust in healthcare professionals. Participant 21 (chronic pain in stomach, back) comments:

> There's no epiphany; this is what you have…and now you can take this and this and now you're going to be fine…Over the course of 20 years, I've seen probably 10 gastro doctors and many tests and x-rays and scopes and they've never seen anything.

Participant 26 (H pylori bacteria in stomach) was in accord. "When I had illnesses that weren't cured right away or maybe the doctor provided treatment that wasn't effective the first time, it did make me trust the doctor a little bit less." Three participants also criticised their treatment plans and diagnoses. Participant 17 (childhood scoliosis) spoke of a time when healthcare professionals had advocated what he felt was an unnecessary treatment, a bolt in his spine:

> When I was younger, doctors wanted to put in that bolt thingy to help straighten my spine. I had to fight tooth and nail for them not to do that. I actually had to get the government on my side to step in. Otherwise they were gonna do it...I did not want that.

Participant 18 (Post-Traumatic Stress Disorder with accompanying anxiety and depression, learning disorder) and 33 (Post-Traumatic Stress Disorder), both with mental illnesses, spoke of their healthcare professionals as "out-dated, old school" (P18), refusing to acknowledge their health conditions. The following comments are illustrative. "Mental health is one of the areas that you don't really talk about. And in family practice it's almost like the extreme…I go, 'I think I'm depressed.' The doctor's 'no you're not'" (Participant 18). "Doctors are not necessarily up to speed in very specific areas," added Participant 33. "There are very many old school people out there too."

Criticisms of diagnoses also occurred in cases where the participant had already self-diagnosed through information seeking. Two participants described occasions where they were angry with a healthcare professional for this reason. Participant 2 (early onset of deafness (cured), hernia) described his annoyance with his family doctor upon receiving the diagnosis of his hernia: "it was irritating. Because I had already known for a long time what the problem was. And that I was okay and that I would get better." Participant 18 (Post-Traumatic Stress Disorder with accompanying anxiety and depression, learning disorder) described her diagnosis of Post-Traumatic Stress Disorder as a confirmation of her own self-diagnosis, for which she had to struggle:

> I went from self-informing, self-diagnose and I took it to the doctor. And then to the point where I think I'm PTSD, because I have all the symptoms of this, and they're sceptical and well, okay, if you say so I'll refer you to a psychiatrist.

Six participants pointed to the suspect nature of the motives of healthcare professionals, commenting on how these professionals, usually doctors, were motivated by finances rather than a desire to see people healthy. Participants 2 (early onset of deafness (cured), hernia) and 17 (childhood scoliosis) talked of healthcare professionals, here doctors, who advocated treatments for financial gain. In a typical example, Participant 2 criticized the treatments offered for his hypothetical condition of acoustic neuroma:

> Doctors do this all the time. What are your options? And do nothing is never one of them. Just something where they can bill you for services or a pharmaceutical company can profit from the procedure or whatever it is.

Participant 17, too, spoke of doctors:

> Doctors don't always give you the right information…There's actually plants and foods that can cure pretty much everything, but they won't tell you that. They'd rather give you pills because that's how they make money.

Participant 23 (transient ischemic attack (mini-stroke), hypertension, depression) talked of doctors' reluctance to advocate treatments given by other healthcare professionals such as nurses.

> They've continuously fought, and continue to fight, nurse practitioners, which would mean a fee for service health professional that costs less than docs…They have turf; I get that. Doesn't make them bad. Just makes them human.

This dearth of trust in healthcare professionals functioned as a rationale for seeking health information, for six participants. Two participants spoke of how healthcare professionals merely gave a diagnosis, rather than discussing how participants, as complete individuals, could integrate the condition into their lives. Participant 23 (transient ischemic attack (mini-stroke), hypertension, depression) spoke of his goal in information seeking: "I need to know how I'm going to live with this…What I'm going to have to do on a day-to-day basis, year by year to live with it. Participant 18 (Post-Traumatic Stress Disorder with accompanying anxiety and depression, learning disorder) described her doctor's limited diagnosis of her learning disability and discussed how this diagnosis led her to find other information resources. "It's like okay, now I have the diagnosis, what do I do… It was later that I found the school that specialized in the learning disability…versus here's the label; have fun." Participant 21 (chronic pain in stomach, back) and 26 (H pylori bacteria in stomach) stressed that their searching was due to a failure of the part of healthcare professionals to diagnose and treat health difficulties effectively. Participant 21 declared:

> I've been told "I don't know what's wrong."...So, over many many many years, I've learned that I really need to stay on top of things and take responsibility for my own health and read about it.

Participant 26, too, points to a lack of treatment as stimulation searching sessions: "Some of the treatments that I've gotten from the doctor, it didn't work immediately; that's why that spurred me to find information from other sources too." Negative assumptions about doctors were also motivation for searching: Participant 17 (childhood scoliosis) announced: "I like to find where the doctors aren't telling people. Because I like to tell the doctor to smarten up." Participant 33 (Post-Traumatic Stress Disorder) pointed to her assumptions about problems in the medical system: "You cannot lie down and roll over and play dead just because you've got a condition…it helps everybody – yourself, your own doctor, the entire system – if you can educate yourself." Here the passivity of roll[ing] over and play[ing] dead" equates in the participant's mind with not information seeking.

Four participants who expressed a lack of trust for healthcare professionals often searched for information outside traditional medicine. Participants 1 (goitre) and 2 (early onset of deafness (cured), hernia) preferred alternative medicine. Participant 2's comments are typical: "I would probably look for holistic or alternative medicine. I would search on the keyword, and then I would first start with esoteric or alternative meaning." Participant 18 (Post-Traumatic Stress Disorder with accompanying anxiety and depression, learning disorder) searched for information for community resources:

> if I've a lung tumour or cancer, if I know there's a lung association locally, then I'll be like, okay, I'm done this. If I really want legit scientific or medical treatment, I'll just call the agency or the support group.

Participant 33 (Post-Traumatic Stress Disorder) reported a preference for websites and TED talks from researchers and trauma specialists to assist her in dealing with her PTSD.

> Bigthink.com, TED, Brain Pickings Weekly, The Edge…Some Bessel Vanderkolk, a five minute video, did me a world of good versus going to the doctor who gives me a very strong sleeping pill. I needed that, but I'm not getting the information from him that I am online, which is putting pieces of the puzzle together for me.

Seven participants were interested in hearing from other patients, rather than searching for traditionally authoritative medical information. Participant 17 (childhood scoliosis) described his method of discovering patients' viewpoints: "Go sit in the waiting room and talk to the other patients. Then you can find out if the doctor's a pill pusher, if they ask questions or just automatically assume to cure it this way." Often, as discussed above, these participants looked at the materials rejected by others as representing patients' viewpoints: blogs with personal stories and news articles depicting patients' and celebrities with illnesses. Participant 13 (generally healthy; past problems with concussions and tropical fever) wanted to look at blogs, explaining, "It's the people's view. It empowers the patients; the physicians, sometimes they have too much power. So by reading a lot of these blogs, I piece together the picture." Participant 18 (Post-Traumatic Stress Disorder with accompanying anxiety and depression, learning disorder) showed a preference for news stories about celebrities. "Sheryl Crow, oh, wow, someone public actually went and spoke about it. So it makes it more realistic." Participants 27 (detached retina (4 times), glaucoma), 28 (anxiety and depression) and 32 (food intolerances) searched for information on discussion forums. Participant 28's comments are typical here: "Other people have it too, so we're like a group; we can share all our thoughts, and then, we can just share our tips." For participant 4 (pregnancy), this searching for patient information was only performed in select situations:

> if it was something different—general—say weight loss--I'd be more interested in other peoples stories (laughs). Because…you can follow similar guidelines for your own weight loss journey or pregnancy.

For three participants, this lack of trust regarding healthcare professionals and traditional medical information served as a rationale for not seeking information or even treatment. Participant 32 (food intolerances) commented: "Sometimes I feel like what they say is not really useful…I felt like I just wasted my time." Participant 13 (generally healthy; past problems with concussions and tropical fever) agreed, speaking of a concussion he believed he had:

> It was pretty bad, but it was a concussion…I just figured what are they going to do? Tell me to rest? So I just rested. That's what I imagined; I don't think they can really do much for a concussion; I don't know if there's treatment.

Participant 9 (generally healthy; gave up sugar) was also in accord. "I don't think health practitioners are the go-to authorities anymore. Just because they have the authority doesn't mean they have the right answer."

5.12 Belief in Information Seeking as a Societal Responsibility

Evidence from the interviews suggested that participants' perceptions of the social value of health information seeking played a role in their seeking and avoidance behaviour. Some comments indicated views by participants of health information seeking as a societal responsibility, noting their skills at performing this task and indicating the problems that arrive when people do not search. Other comments pointed to the understanding of patients that health information seeking could cause difficulties with the medical system and with people's emotions. Both of these viewpoints seemed to influence reported information seeking behaviour.

Inherent in the comments of twelve participants was the belief that health information seeking has social value. Two participants indicated that they do not blindly follow the dictates of the doctor but perform their own searches. Participant 20's (generally healthy; HIV positive) comments here are typical: "I'm gonna take control of my own health; I'm going to do my own research, and not just swallow pills that people tell me to swallow…keeping myself informed is a healthy way to be that will lead to a better health outcome." Participant 3 (thyroid difficulties; hysterectomy when younger) likened healthcare to a consumer environment with a buyer beware mentality:

> It's just like going to a used car salesman; if you don't know…the market price of the vehicle you're going to be purchasing, you can be blindsided… health care these days …you're not just relying on the doctor. I think you have to have your own information to make the choices you have to make.

One participant elaborated that information seeking was necessary in the current medical system. Participant 33 (Post-Traumatic Stress Disorder) commented: "I think we have to be our own advocates...Because you cannot count on getting the help that you need in the medical system."

This belief appeared to be linked to a sense of pride, a sense that these participants were in a better situation than others who did not practise this behaviour. Participant 13's (generally healthy; past problems with concussions and tropical fever) comments were representative:

> It's more of a preventative lifestyle that if you're healthy; you're active; you eat right; you have a positive mental attitude that I believe, maybe naively so, gives you an edge on people who don't eat right, don't exercise, smoke, drink excessively, abuse their body, and run to the doctor when they have any issue.

Comments revealed that, for three participants, this belief seemed to be associated with confidence in health information seeking skills, particularly as compared with others. Participant 33 (Post-Traumatic Stress Disorder) spoke of the reaction of healthcare professionals to her searching:

> They're all quite…surprised at what I knew and what I came in with. Versus I suspect they're seeing a lot of people who are not even remotely at our capacity to research and digest and understand.

Participant 9 (generally healthy; gave up sugar), as well, spoke of being an outlier, declaring, "Most people would probably weigh more closely what the healthcare professional would say." Participant 20 (generally healthy; HIV positive), too, reported being "a different thinker…very self-reliant." Participant 20 and 33 also described various skills that they felt led to better health information seeking on the Internet: critical reading (P20) and scanning (P33). Participant 20 reported that he possessed

> an ability to look for consistency across websites, across information sources; it gives me an option to be thorough and explore things…to look at abstract, complex multi-factorial contributors…this gives me an option to look at the whole picture.

Participant 33 also reported having skills:

> I'm very comfortable and very happy with how quickly I can research…It makes a lot of difference. If you are a snail moving through the web, you're screwed. If you are a cheetah, then you're in much better shape.

Three participants raised concerns about people who did not search for information, either online or from a healthcare professional. Participant 32 (food intolerances) spoke of not seeking information or treatment:

> I feel that's not facing reality. If your thing is severe, and you wait just because you didn't want to see it, what if when you go later on, they'll be like, "You're probably in stage two, and then you could have been a stage one, but you didn't come here."

Participant 5 (itchy scalp condition) spoke of her grandmother, who refused treatment when she had elephantitis, to the point of not allowing ambulance attendants to bring her to the hospital, a refusal to which the participant attributes her grandmother's early demise: "she ended up dying really young, 60 or 61, because she wouldn't doctor." Participant 21 spoke of the avoidance of health information and treatment by men.

> Men are in denial about illness because illness is a feminine; it's not a masculine thing...that's why there's actually a high rate of men who are actually diagnosed with something and they never seek treatment early enough and that's why they die from it.

5.13 Information Seeking as Not a Societal Responsibility

Comments by eleven participants showed that in some ways, information seeking was not a societal responsibility. Six participants expressed their opinion that information seeking could be problematic, resulting in personal problems. Participant 29 (myopic degeneration) spoke of the emotional danger:

> Participant: [If] you look at the operation – and you're gonna be a basket case before the operation, that's really not smart.
> Interviewer: So it should be done…
> Participant: Judiciously. Depending who you are and how you handle information. (P29)

Participants 3 (thyroid difficulties; hysterectomy when younger), 7 (generally healthy; cystitis, potential for stroke, IT band issues) and 20 (generally healthy; HIV positive) worried that others would think they would be viewed as making big deals of nothing. Participant 7's comments were typical: "I just don't want to be a drama queen about it, really." Participant 20 agreed: "I'm not a catastrophic thinker whatsoever." Participant 8 (benign tumour on finger), referring to the health concern he discussed, a benign tumour on his hand that resulted in a broken finger, said:

> It just seemed a stupid incident…insignificant. You have a broken bone; they want a big story that something exciting happened to you; you fell off a cliff…I couldn't provide anything.

Comments made by five participants also touched on problems with information seeking in a societal context. Participant 4 (pregnancy) commented on people who follow the wrong sources to gain information for their health: "people are listening to other people as a guide, who don't necessarily have any sort of formal education." Participant 13 (generally healthy; past problems with concussions and tropical fever) described health care difficulties: "I think a lot of people are so quick to run… Think of the billions of dollars of health care costs that are spent on things that are completely unnecessary." Participant 33 (Post-Traumatic Stress Disorder) agreed:

> I'm thinking of people who are jumping from doctor to doctor or trying to extend the timeframes…and coming back, repeatedly, very quickly, just because they've learned something new…that's what I'm thinking about in terms of abusing the system.

5.14 Profile of Information Avoiders

In this section, I describe two study participants who most fit the profile of information avoiders. Here I draw upon the stories, comments, and demographic information of participants 7 (generally healthy; cystitis, potential for stroke, IT band issues) and 11 (HIV, drug-induced schizophrenia) as a means of illustrating information avoidance patterns. Participant 7 was a woman in her early thirties who perceived her health as being very good and the same as last year. She had a Need for Cognition (NfC) score of -4, a low Monitoring score of 37, and a high Blunting score of 52. Her positive and negative affect scores were both low, at 10.

Participant 7 reported having no chronic conditions, but she did speak of her information behaviour with regards to three health problems: cystitis, iliotibial band strain from running, and a potential for stroke that she believed could be genetic. She described how she avoided information for this last issue, avoidance that took the form of not seeking information online or going to a doctor for tests. "When I think about it now I should go to the doctor… I've just mentally worried about it and left it…I know that I have issues. It's like burying my head in the sand, essentially." For this participant, information avoidance could also be linked with negative affect, as she spoke of worry and fear causing avoidance: "I've just mentally *worried*" (italics mine). This participant saw genetic potential for stroke as a serious condition, one that has killed members of her family. She described the death of her aunt with whom she was close. "She sat up to go get some water, put the glass back down, and that was it. She started screaming in pain…I don't even know if she made it to the hospital." The participant, when asked, was unaware of any solution. "I just assume…you'd have blood thinners…but it sounds vile, doesn't it? I have an arts degree so let's be honest. I'm not a doctor, so I'm just using my imagination; it's all just guesswork."

The participant saw her avoidance of information and treatment as a pattern that ran through her family, in particular her grandfather, who also may have suffered from the same condition. She commented:

> My granddad was horrendous for that…I think that's why he ended up dying. …I think…he knew there was stuff wrong. But the only time he'd ever go to the doctor's was when…people would force him to go… My granddad was a huge worrier.

Instead of going to the doctor or seeking information, her grandfather would take the drug paracetemol, everyday, by the boxful: "I think it prevents worry," explained the participant. The participant had her own strategy for worry prevention. She explained: "I know I have issues…I use here or being here [in Canada], as an excuse to bury my head."

The participant's cystitis elicited similar information behaviour. When faced with unpleasant and embarrassing symptoms, this participant searched online for possible diagnoses. This searching resulted in extreme negative affect, as the participant's eye was drawn to the diagnosis "bladder cancer." She explained: "I Googled it, and one of the things that came up was bladder cancer. [I] literally melted down…I'm sure the word cystitis was in there somewhere, but my brain automatically goes to cancer." Another comment further linked her negative affect with information searching:

> I get myself worked up and stressed out because the more things I read about, the more upset I get about it, the more I start worrying about it, and that's when I go off into a oh my God it's drastic.

In this case, the participant's information searching ceased, and she remained in a terrified state until her boyfriend came home and insisted she go to the doctor. "I couldn't tell anyone else beforehand, and I told him, like, what I had found. And he was why haven't you been to the doctor?…I hoped it would go away." Here the negative affect felt by the participant prevented her from seeking further information or treatment until assisted by another person.

For the third condition referenced by the participant, iliotibial (IT) band strain from running, the participant searched a great deal, asking friends with similar problems and browsing a Facebook runner's forum. She also sought multiple forms of treatment: "I felt like I needed to do something to make it go away. I've been to the physios, all the usual whatevers." For this problem, information searching did not seem to cause the paralyzing fear of bladder cancer or stroke potential; the participant described her exhaustive search for a remedy: "For this particular thing, I'd be open to anything." Here she spoke of the negative affect not running caused: "When I'm not active; I'm not running, running specifically, craziness. Bodies under the patio craziness. Oh my God it drives me nuts. I get irritable." However, for this problem, this negative affect served to drive the participant's search for information, rather than causing avoidance. She commented:

> I have tried some weird stuff. Whatever fixes me…For example my friend, she has IT band issues; she's going to this guy; he uses big iron bars that have curves and bends in them in certain places…I was thinking oh wow, is this a thing? So I've Googled it, and looked into it…it cost $65-$100.

Here it was finances, rather than fear, that instigated the participant's hesitation.

Participant 11 was another participant who reported practising some information avoidance. This participant, who was a Spanish-speaking man of 45 with a high school education, perceived his health to be very good and about the same as last year. He achieved a high NfC score (11), a high Monitoring score of 51, and a middle Blunting score of 49. After looking at health information, he obtained a high positive affect score of 21 and a middle negative affect score of 16. During the interaction session, he looked at a total of 3 items of information for a total time of 11 minutes 29 seconds.

This participant discussed two chronic health problems, an HIV infection and schizophrenia caused by substance abuse. For both health difficulties, the participant reported tending to rely on other people for information, whether friends or healthcare professionals. He described his typical information behaviour:

> I will ask to some people first…I will ask the doctor…but most of the time I have always people guiding me to information. And I don't read anything so most of the time people looking and saying look, read this. And then I read it. And that's how it be.

In the case of HIV, this information behaviour seemed to have allowed the participant to concentrate on the negative affect brought upon by the diagnosis. He noted: "I was angry at the beginning…Am I going to look like these people?...If I'm going to look like that, then I don't want to look like that." The participant described the context of his diagnosis, in which fear was rampant in his community:

> It was very shocking for everybody. But they came out to talk. And everything was very scared [*sic*], no? I didn't know whether I was supposed to drink wine from their glasses or not? I didn't know anything and I was very scared, and I didn't want them to get infected, no?

This extreme negative affect caused some further limits to the participant's information searching. He remarked about online searching: "Sometimes on the computer, this disease…sometimes it scares me to see… Sometimes I just don't want to go in some things. I'm just in denial. In denial about some things." This caution regarding information searching also related to his questioning of the doctor: “Sometimes I ask about this medication or that medication. And things like that. But not too much, no.”

One cause of the participant’s information behaviour appeared to be a strong respect for medical authority. He stated his preference for information from his healthcare professional: “the doctor is the one who knows. If the doctor tells me, there is something wrong with you, I do pay attention.” Here the participant seemed to feel as if his health was the doctor’s responsibility. He did state that he himself would have to become more informed in the following quote: “I know I should do more. It’s one of the goals that I’m trying to bring to myself, to get more involved with my health, to get more informative.” However, his directives to the doctor were much more forceful. In the following example, the participant demanded attention from his doctor. With regards to a recent weight gain, this participant declared: “You tell me I look very skinny; okay, perfect, you are my doctor. But if in three months… if you don’t look [*sic*] a change; you don’t see a change then I’ll get upset and I’ll say I want you to look at it.”

When faced with his schizophrenia, the participant continued his policy of relying on healthcare professionals. As above, the participant emphasized that his doctor should help, as illustrated by the following quote, which repeated the phrase “do something.”: “So do something. I say you do something. So these are my voices, you do something…So do something. He say, what you want me to do? I say, I don’t know. I hear voices. Do something.” In this case, this respect for a healthcare professional appeared to have been the driving force, as the participant’s schizophrenia caused less negative affect than his HIV. He commented: “I have schizophrenia, yeah? I have the psychosis. Me better than to get scared, I just go to the doctor.” This lack of negative affect may have been caused by the more simple solution to the schizophrenia: “Is it because of the drugs? And I say okay, perfect. Done.”

5.15 Conclusion

Participants described methods of information avoidance, which were grouped into two main approaches: self-regulation, especially with respect to time spent searching and avoidance of certain types of content, and delegation, either to family members or to healthcare professionals. Delegation was usually the result of fear or the need to reduce anxiety in the person with the health condition but was also sometimes due to this person's lack of skill or knowledge. Sets of beliefs held by participants were identified as factors that contribute to information avoidance and seeking patterns. One set of beliefs was focused on health, responsibility, and a sense of personal agency or self-efficacy relating to health. Comments revealed that participants could feel responsibility for their own health and be confident in their own ability to change their health conditions, while others felt less responsibility and confidence. Another set of beliefs related to the trustworthiness of healthcare professionals, the health system and traditional medicine, which varied considerably among the study participants. A final set of beliefs related to the societal value or importance of health information seeking perceived by patients, which again, varied within this group. These various beliefs were expressed by participants in their stories of health information seeking and avoidance and seemed to play a role in shaping both those behaviours and participants' accounts of those behaviours, but not always in consistent ways.

6 Discussion

This chapter will discuss the results presented in the two previous chapters. I will begin with a summary of the results, and then move to a discussion, commencing with the view of information avoidance as informed by this research. Next, I will move to discussing the individual findings, in particular the responses to the research questions regarding the mechanisms of information avoidance and the factors that influence this phenomenon. I will then move to the implications of this research for theory, method, and practice.

6.1 Summary of Results

Information avoidance is a challenging topic to study. First of several reasons is that avoidance can be, and often is, construed as non-behaviour: something that cannot be observed, an absence of seeking. It is problematic to study what people are not doing as opposed to actual activities, a fact reflected by this research, in which participants were questioned about their health information seeking in order to reveal instances of avoidance. This fact raised the question of the extent to which not seeking is equivalent to avoidance stemming from intention. A further challenge is that overt information avoidance runs counter to current social norms regarding health information seeking, in which this seeking is viewed as a positive and desirable behaviour. Thus, people have an incentive to over-report seeking and to conceal or minimize instances of avoidance as inappropriate or shameful, even to deny to themselves that they engage in these behaviours.

Results reflect these issues. Few participants admitted practising information avoidance in either a hypothetical or simulated context. This fact that participants failed to mention information avoidance was particularly striking in the Affect and Avoidance study (Study 1), which asked if people would search for information in the context of a scenario that invited them to imagine themselves in an unpleasant or life-threatening health situation. In this study, a large majority of participants claimed they would search for the maximum amount of information possible, and very few indicated that they would avoid information. By contrast, analysis of data from the Interview and Interaction study (Study 2), in which participants were given the opportunity to interact with health information in real time and were interviewed as to their interactions and past health information behaviour, found more evidence of information avoidance, although few participants characterized their behaviour as such. This difference was likely due in part to the methods of data collection and the more realistic nature of the second study. It may have been amplified further by the different recruitment strategies used; in the Affect and Avoidance study, participants were recruited using a crowdsourcing software, Amazon Mechanical Turk, while in the Interview and Interaction study, recruitment took place by means of convenience sampling, both word of mouth, and virtual and print recruitment notices. The samples themselves differed; Affect and Avoidance study participants reported being on average younger than the Interview and Interaction participants. This age difference may be an indication that Affect and Avoidance study participants were also healthier, as researchers have suggested that age can lead to more health concerns (Ahluwalia, Gross, Chaudhry, Ning, Leo-Summers, Van Ness & Fried, 2012). The convenience sample may have led to self-selection in the Interview and Interaction study for participants who wished to discuss this particular health behaviour, as participants in this study reported searching more frequently for health information. The highest percentage of Affect and Avoidance participants searched a few times per month (40%, *n*=80), as compared with the highest percentage of Interview and Interaction participants, who searched daily (38%, *n*=13). Additionally, while the Affect and Avoidance study participants may have had health concerns, the format of the Interview and Interaction study may have led participants to recall and think about these concerns in more depth, leading to more grounded and experience-based responses.

Despite this disparity, similarities did exist between the two studies. Questions and instruments between the two studies were similar, and findings from the Affect and Avoidance study such as responses to the optional comment on the likelihood of information seeking echoed findings from the Interview and Interaction study. Thus although it is certainly conceivable that the samples diverged in ways that may have affected information seeking and avoidance behaviours, comparing the two samples is a feasible strategy and can lead to discoveries about how information avoidance is viewed.

In the Interview and Interaction study, the information avoidance uncovered was mostly selective filtering of information rather than a complete refusal to engage with information. Here results demonstrated that participants employed various strategies to restrict and filter their health information seeking and thus exposure to information, rather than utilizing a broad brushstroke approach to capture all possible information as suggested by responses in the Affect and Avoidance study. Analysis of these Interview and Interaction study data found participants, as well as the friends and relatives these participants spoke about, used two main filtering strategies: self-regulation and delegation. In self-regulation, individuals themselves perform filtering of information related to their health problems; in delegation, this filtering is conducted by a delegate, whether family, a friend or a healthcare professional.

Both studies identified results indicating factors that influenced health information behaviour, either stimulating or hindering information seeking. Several beliefs emerged regarding participants' health, health care, and health information seeking, including beliefs as to the responsibility for their own health and activities participants believed they should be performing. Situational affect, including fear, disgust and disinterest, were identified as factors influencing health information behaviour. Disgust and disinterest were associated with the filtering of information, and fear was linked to filtering and to its opposite, the expressed intent to seek the maximum amount of information possible. Participants' attitudes to information sources were another influence on health information behaviour. For example, some sources were viewed as untrustworthy or capable of invoking negative affective reactions; such reactions may prompt participants to filter.

Further sections in this chapter will discuss these concepts in more detail, beginning with information avoidance as a whole, and continuing to the mechanisms and influencing factors found by this research.

6.2 Information Avoidance

Information avoidance is commonly portrayed by researchers in accordance with Sweeny and colleagues (2010) as "any behaviour intended to prevent or delay the acquisition of available but potentially unwanted information'' (p. 341). This portrayal has tended to focus on methods of avoidance that consist of the opposite of seeking, of a complete refusal to engage with information such as declining to ask questions and neglecting to make appointments (Miller, 1980; Barbour et al., 2012). However, in this research, filtering, a strategic and selective approach to avoiding information, emerged as the most common method. Participants who spoke of filtering reported engaging with some information but not all, a partial rather than complete information avoidance. On this basis, I have amended the definition of information avoidance to "any behaviour intended to prevent or delay the partial or complete acquisition of available but potentially unwanted information."

This research therefore indicates that information avoidance exists on a continuum, in which individuals employ a range of behaviours that regulate seeking, and allow for the avoidance of varying amounts of information. At either end of the continuum, there are complete behaviours, complete avoidance and complete seeking: attempts to maximize and minimize access and exposure to the maximum and minimum amounts of information available. In the middle, there are situations where people are avoiding to some degree, but letting in some information (delegation is a good example of how people accomplish this), and situations where they are mostly seeking, but limiting and managing their access and exposure to information (the good example here is self-regulation).

Another contribution of this research relates to the motivations for information avoidance. The definition stated above does not include a rationale for information avoidance; indeed, Miller (1980) conceptualized information avoidance as an innate tendency, a function of personality rather than of situational factors. However, more recent work often points to situational affect, particularly fear as the essential ingredient for avoidance (Howell & Shepperd, 2013). In this research, the situational factors tested showed more of an association with information avoidance than the personality traits assessed, Need for Cognition and Monitoring and Blunting coping, that the research also examined. There is also, though, the question of what situational factors influence information avoidance. Lambert and colleagues (Lambert, Loiselle & Macdonald, 2009) call for information avoidance to be distinguished from "information disinterest" (p. 26). This disinterest, they explain, is dissimilar from true information avoidance in that it is characterized by a lack of fear and a presence of disinterest or a disinclination to search. Information disinterest was suggested in this research where participants who expressed disinterest in some health information material reported not consulting that material.

Both information disinterest and information avoidance, though, can be prompted by information that in some way invokes threat. Researchers of information avoidance note that some form of physical threat—an upcoming surgery, a dangerous diagnosis—is often present about which people avoid learning (Howell & Shepperd, 2013). Threat can also be present in information disinterest. This disinterest can be related to cognitive dissonance, a theory which posits that people's viewpoints take time and effort to establish; thus people can be unwilling to engage with information that may disagree with and thus threaten these viewpoints (Festinger, 1957, 1961). Due to the presence of threat in both information disinterest and avoidance, I have decided to include information disinterest under the umbrella of information avoidance. This inclusion reflects the notion that a conscious or subconscious desire to avoid information for many different reasons may be expressed in the form of disinterest. On this basis, I propose a second amendment to the definition so that it now reads: "any behaviour intended to prevent or delay the partial or complete acquisition of available but potentially unwanted information for reasons including fear and disinterest."

6.3 Mechanisms of Health Information Avoidance

The first research question concerns the nature of health information avoidance and asks what the mechanisms are that make up the tangible expression of this concept. This research identified two such mechanisms: self-regulation and delegation, both ways of filtering information to reduce exposure to unwanted information. Much of the identification and detailing of the mechanisms stemmed from the results of the Interview and Interaction study, in which participants interacted with health information and described their situational and personal health information behaviour in an interview.

6.3.1 Self-regulation

Study participants reported limiting their acquisition of information through self-regulation. Regarding this mechanism, participants told of filtering out information that which they believed to be overly negative such as videos of surgeries or explanations of what would occur in a surgical operation, or overly detailed such as complex journal articles or websites containing medical jargon. These instances of self-regulation can be understood through the theory of Selective Exposure. In this theory, related to cognitive dissonance, people avoid information in situations where such information may generate some form of negative affect, whether disagreement or fear. Selective Exposure is frequently referenced in studies of responses to preventative health material designed to warn about risky health behaviours (Knobloch-Westerwick, Johnson & Westerwick, 2013).

Some participants reported self-regulation by means of setting time limits on their search and refusing to exceed these limits for fear of going “crazy” (P23). These time limits could be considered a way of preventing information overload (Toffler, 1970). In this information reaction, people can become overwhelmed or exhausted by information searching. Information overload is particularly prevalent when information is present in large amounts and when these large amounts are highly scattered rather than concentrated (Bawden & Robinson, 2009). Both of these conditions are present in the current health situation, in which vast amounts of information are now present on the Internet (Zhang, Broussard, Ke & Gong, 2014), and where people have reported searching for topics ranging from directions to medical facilities to details of surgeries (Bhavnani & Peck, 2010). The similarity of the results to Selective Exposure and information overload indicates that many people avoid information in situations where they anticipate feeling negative affect.

6.3.2 Delegation

Delegation is another mechanism identified by this research. While it may be suggested that delegation, especially delegation to healthcare professionals, could be viewed as an information seeking mechanism similar to traditional roles of health information seeking (Henwood, Harris & Spoel, 2011), comments by participants indicate that delegation is used as an information avoidance mechanism. Comments by participants note that delegation was performed when a need for information was present but that they themselves or their friends or relatives chose to delegate the searching required to fill that need to another. Participants or friends/relatives could then choose to receive none or only a filtered part of the looked-for information. The emphasis here was not on seeking but on avoidance of certain types of information, e.g., frightening medical procedures. Participant 7, for example, spoke of her desire to place her trust in healthcare professionals rather than discover details about surgery, declaring "ignorance is bliss."

Although delegation as avoidance was the primary aim of participants, some participants may have chosen delegation as a means of letting in some information. Research indicates that choice of health information source can be related to views of authority, whether personal, i.e., family and friends (Wathen & Harris, 2007) or medical (Johnson, 1997). These authorities may be selected as enablers of information avoidance for similar reasons. Information behaviour researchers note that people prefer to receive information from their friends and family (Wathen & Harris, 2007). This preference is based on ease of access and a social bond that aids in information acquisition; those who know and care about you are also those who know what information you do not want but also what information you do want. By allowing or asking a family member or friend to search on their behalf, delegators in this research could ensure that the proper content of information was delivered and avoided. Individuals tending towards medically authoritative sources for information may also be reliant on a social bond, this time to provide emotional rather than informational support, as it may be reassuring to consult healthcare professionals rather than friends and family. Such consultation may also allow people to relax into traditional and more passive patient roles, facilitating some information avoidance but also allowing some, perhaps necessary, information to filter through.

6.3.3 Filtering Mechanisms

The findings of this research, the mechanisms of self-regulation and delegation, assist in the understanding of how people avoid information overall. In this way these findings complement other studies that focused on individual behaviours such as controlling conversations or not asking questions (Miller, 1980; Barbour et al., 2012) and serve also to show a greater range of information avoidance behaviours. One reason for this range may be the changes in technology and social norms regarding health information seeking. Health information seeking is now more widespread and is considered a normative and desirable behaviour, particularly in the context of health difficulties (Wyatt, Harris & Wathen, 2010). Thus it may be that the participants who chose to complete either of the two studies were unwilling or unable to admit to complete avoidance, a respondent bias. However, it may also be that partial avoidance is increasingly common because information is so prevalent through so many channels, that situations previously resulting in complete avoidance now lead to partial avoidance, such as these mechanisms of self-regulation and delegation.

6.4 Influencing Factors Associated with Health Information Avoidance

The second research question considered the extent to which three factors, personality, affect, and information source, prompted information avoidance. Quantitative data gathered in both studies using various scales and metrics showed little impact of these factors, particularly in the Affect and Avoidance study (Study 1) likely due in part to the very low levels of information avoidance reported. The interviews conducted in the Interview and Interaction study (Study 2) proved more useful in revealing the nuanced connections between these factors and information avoidance.

6.4.1 Personality

Personality traits initially believed to have a strong impact on information avoidance and seeking behaviours, such as Need for Cognition (NfC) and Monitoring and Blunting orientation, were not shown to be associated with information avoidance. One explanation for this lack of association may be the changing nature of health information seeking since these scales were initially developed. These scales may not be appropriate in the context of new technologies and their impact on seeking behaviours. For example, neither scale makes reference to the Internet or to portable technologies such as smart phones that have altered health information seeking (Barbarin, Klasnja & Veinot, 2016). An opportunity exists to redesign these scales to account for such changes. Research shows that traits such as NfC can be linked to education and intellectual inquiry (Putte et al., 2012). Yet health information seeking particularly in this research appears less about this intellectual curiosity and more about the pragmatic task of maintaining health (Wyatt, Harris & Wathen, 2010). As such, the health information seeking behaviours reported in this research appeared to be associated more in participants' minds with the task of searching for health information about a particular condition. Participants may have been acting primarily out of the belief that they were responsible for their own health information searching, rather than out of an intellectual desire to learn about the world around them.

Health motivation and health perception were personality traits that did emerge as influential, and can be connected to information seeking as personal responsibility for one's health. Health motivation, a strong personal interest in health subjects and in taking care of one's health, surfaced in the interviews through the accounts of participants such as P21, P22, and P29, who noted their great interest in health and correspondingly high levels of information seeking. By contrast, other participants expressed lower levels of health motivation, often commenting on their need to "accept" (P16) health difficulties rather than attempt to change their health situations. An important consideration is the central role health information seeking has in healthcare. Patients perform the duty of health information seeking as a part of being involved in their own health (Wyatt, Harris & Wathen, 2010). This notion of health information seeking responsibility was accepted at varying levels by participants, with some reporting seeking health information, some reporting instead performing the lesser emotional task of wellness seeking, and still others adhering to a more traditional allocation of health responsibility in which healthcare professionals or fate are responsible for health.

Health perception also emerged as an influence on participants' reported health information behaviour. Prior research has established that people with positive perceptions of their own health, often described as an optimistic bias, tend to search less for health information than those with negative perceptions, as they believe themselves less likely to fall victim to illnesses (Shepperd, Klein, Waters & Weinstein, 2013). Such was the case in this research as Interview and Interaction study participants often stated their confidence in a protective "baseline" (P4) of health. These participants noted that, because they were already healthy, they had less chance of becoming ill and a greater chance of defeating any health difficulties they encountered. Thus these participants had less need to search for health information (P13, P20 for example).

6.4.2 Affect

Of the situational affect examined in this research, particular emotions were notable in their influence: fear, disgust, and disinterest. Fear shaped participants' health information behaviour in contradictory ways; although some participants cited fear as a reason for their reported avoidance behaviours (P7, P11), other participants, particularly in the Affect and Avoidance study, seemed to indicate that fear was an impetus to seek information, saying that, for example, the more serious the problem, the greater likelihood they would search for health information. Many researchers comment on the central role of fear in information avoidance (Howell & Shepperd, 2013, 2017), but others posit that serious and fear-inducing health conditions can act as stimuli for health information seeking (Persoskie, Ferrer & Klein, 2014). This dual effect recalls the theory of uncertainty management, in which researchers attribute information seeking and avoidance to differing reactions to uncertainty. When people fear bad news and thus prefer uncertainty to certainty, they avoid information; on the other hand, when people fear they will imagine worse scenarios than the truth, the preference is for certainty over uncertainty and information is sought. In this research, participants who report avoiding information also report that their uncertainty regarding their health is to be preferred (P7, P20). As the stimulating influence of fear is seen mainly in the Affect and Avoidance study in response to hypothetical scenarios, it may be that those participants miscalculated their reactions to uncertainty.

The influence of disgust was more straightforward. Participants in the Interview and Interaction study who reported feelings of disgust also reported avoiding that health information that evoked those feelings. The avoided health information was often videos of surgeries, which participants referred to as “gross” (P26), “gor[y]” (P33), “yucky” (P13). Reynolds, McCambridge, Bissett and Consedine (2014) point out that few studies have looked at disgust as an arbiter of information avoidance, but that this emotion, often stemming from penetration of the physical envelope, can be linked to anticipated avoidance of health stimuli. This connection suggests that images and videos of graphic events may be avoided in the same way as physical objects like needles (Reynolds, Consedine & McCambridge, 2014; Reynolds, Lin, Zhou & Consedine, 2015). However, not all participants avoided videos of surgery. Curtis, Barra and Aunger (2011) suggest that disgust is a learned reaction and can be overcome with habituation (see also Reynolds, Consedine & McCambridge, 2014; Reynolds, Lin, Zhou & Consedine, 2015). Participants who did look at videos often gave as a reason a prolonged “interest” in either surgeries (P26) or health (P22), suggesting that this affective reaction might function as a sort of conditioning, inuring these participants to health information that would normally prompt disgust and avoidance.

Disinterest was another negative affective reaction that was often mentioned in context with information avoidance. The opposite reaction, interest, was also present as an association with information seeking. Note that interest and disinterest are distinguished here from high and low health motivation. Participants exhibiting the latter exhibited a general disinclination that prevented them from looking for most or all health information, whereas disinterested participants reported feeling that emotion in response to a particular item of health information. Disinterest was reported in two notable cases: when participants were faced with complex medical information, and when they were faced with further information regarding a chronic condition they had had for a prolonged period of time. The appraisal theory of interest suggests that interest comprises two elements, novelty and a still comprehensible complexity that allows users to be challenged but not overwhelmed (Silvia, 2005; van der Sluis, van den Broek, Glassey, van Dijk & de Jong, 2014).

The reaction of several participants to medical jargon—"I trip over drug names" (P23)—suggests that the material was not at the proper level of complexity. The absence of novelty may also go some way to explain the disinterest of chronically ill participants, some of whom indicated they were or had been extremely familiar with the health information regarding their condition. It may be that either they had simply had enough and felt this topic held no more new information for them or believed that their condition would persist and that no novel information would appear regarding changes. This supposition may indicate another way in which health information seeking in this study was not influenced by Need for Cognition (NfC); participants with chronic conditions expressed disinterest in information seeking regardless of NfC scores.

6.4.3 Information Source

The information source was also a factor in participants' information avoidance, as evidenced primarily by interview data and participants' comments regarding choices made in the interaction sessions in the Interview and Interaction study. With reference to the theory of Selective Exposure (Festinger, 1957, 1961), I identified information avoidance when participants selected one source or one type of source instead of another, citing problems with the latter source as a reason for this choice. Avoidance of videos to limit exposure to graphic content is one example of such tactics, but more commonly, participants avoided certain types of sources on the basis of authorship and authority, with some seeking more traditional medical authorities, such as journal articles and medical websites, and others avoiding those in favour of alternative medical information. Participants who preferred non-traditional sources explained this avoidance by noting that representatives of traditional medical authority such as doctors were in some way flawed, either because they had suspect motives or because the treatments these doctors had proposed were unsuccessful or unsatisfactory. Substituted material was of two types, health information participants deemed "alternative" (P4), and information participants connected with the viewpoints of patients such as blogs and videos of patients' stories (P13, P17).

The avoidance of this health information material is related to self-regulation, in which participants avoided negative or complex information. These assumptions regarding genres and authority also show a link between distrust of the information source and information avoidance. Participants who reported judging sources as untrustworthy also reported avoiding these sources. Here trust may here be associated to different definitions of medical authority. Other studies indicate that this last can be defined in other ways than it has traditionally been, the traditional definition of authority being a legitimate sanctioning of knowledge or skill (Foucault, 1980). Researchers note that, in health, authority is increasingly being interpreted in ways other than legal sanctioning (Wilcox, 2010; Huber, Knottnerus, Green, van der Horst, Jadad, Kromhout, Smit et al., 2011). Some participants revealed that, in certain situations, dwindling trust in traditional medical authorities led them to believe in other authorities, patients or alternative health practitioners. This redefining of authority may have caused participants to alter selection preferences, to avoid traditional medically authoritative information in favour of information representative of other definitions of authority.

6.5 Theoretical Implications

This research and the expanded notion of information avoidance afforded by this work can contribute both to the redesign of instruments used to measure information avoidance and to the redesign and elaboration of theoretical models of information behaviour. In this section, I will examine the instruments used, and I will also discuss the implications for two theoretical models, both of which focus on the decisions to seek or not to seek information: Johnson's (1997) Comprehensive Model of Information Seeking (CMIS), and Wilson's (1999) General Model of Information Seeking Behaviour.

As stated in section 6.4.1, results of this research, in particular the difference between quantitative and qualitative findings, point to possible difficulties with the measures utilized. Although the Need for Cognition and Monitoring and Blunting scales are commonly used to indicate motivations for information seeking, the difference between the quantitative results, e.g., the comparison between Blunting scores and interaction session measures, were notably dissimilar than the qualitative results, e.g., comments by participants in that study. Thus the Monitoring and Blunting and Need for Cognition scores were not supported by participants' descriptions of their own health information behaviour or the attitudes regarding health information seeking and avoidance expressed in the interviews. Thus the scales did not aid in indicating how much participants would search, a flaw due certainly in part to the failure of these scales to encompass the complexity of the health information sphere. As aforesaid, one clear example is the omission of the Internet as a health information source, which also points to the need to update these scales to reflect the current reality of information seeking. Another example is the failure of the Monitoring and Blunting scale to mention the full range of health information. Statements such as "I will get more information at other medical centers first" seem inclusive but fail to mention directly information sources such as alternative health practitioners, sources that, as indicated by participants' comments, were clearly consulted at certain times. This fact points to the need for further testing of these scales, to determine the extent to which they are measuring a consistent human trait or a particular state brought about by circumstances.

These difficulties with the scales may also indicate that personality is less a factor in information avoidance than factors that stem from the situation. Information avoidance behaviours varied greatly from situation to situation, depending both on information sources and emergent affect not taken into consideration by these scales such as disgust stemming from, as one example, visualization of surgeries. Thus the health information behaviours identified by this research seem more nuanced than these personality measures would suggest. Instruments such as the survey used in this research that include these scales should be retested and revalidated to ensure greater reliability and validity.

The scenarios employed in this research to present situations in which information might be sought or avoided also warrant re-examination. Although the scenarios in this research were based on those employed by previous researchers, the scenarios varied in meaningful ways, notably in their presentation of different numbers of decision-making options (Evans et al., 2014). For example, the Affect and Avoidance "acoustic neuroma strong negative" scenario treatment sentence reads, "Treatment options are observation, surgical removal, or radiation, " while the "acoustic neuroma weak negative" scenario treatment sentence is, "If you do need treatment, surgery and radiation are options." This variability in decision choices was included in order to vary controllability and treatability, associated with health information seeking and avoidance, as well as to maintain verisimilitude, as the scenarios were intended to resemble real situations as closely as possible (Dawson, Savitsky & Dunning, 2006; Evans et al., 2014). However, the decision choice variability is noteworthy in that the resultant complexity of the decision task facing study participants may have influenced information seeking and avoidance patterns, rather than perceptions of controllability and treatability; i.e., some of the difficulties with the strong and weak negative divisions in the Affect and Avoidance study may have been due to the differences in treatment options (Bystrom & Hansen, 1995; Kryworuchko et al., 2012; Feenstra et al., 2014). Consistency in decision options should be examined in future scenarios in order to measure whether the number of decision options alters information seeking and avoidance.

This research also suggests amendments to models of information behaviour. Johnson's (1997) CMIS identifies factors that come into play when people are deciding whether or not to seek information but does not mention information avoidance as a behaviour in itself. The CMIS details the decisions people make as binary; people can choose to seek or not to seek information, an explanation that implies information avoidance is the opposite of information seeking. Yet information avoidance has been revealed by this research to be located on a range or continuum of information behaviours. While some information avoidance and some information seeking is absolute, participants were more commonly employing strategies such as filtering or delegation to limit, manage or narrow their information acquisition.

Factors cited as reasons for information seeking decisions by the CMIS are also brought into question by this research. These factors include demographics, experience, personal relevance or salience, and beliefs. For the last factor, Johnson (1997) lists beliefs that appear in this research such as a credence in the efficacy of good health behaviours and the efficacy of treatment, both beliefs that, if held strongly, could allow people to make the decision not to seek information. Similar beliefs with similar consequences were also held by participants in this research, as participants' faith in the effectiveness of a "preventative" (P19) level of health or their trust in healthcare professionals indicates. Yet here, too, the list of beliefs is not as inclusive as this research demonstrates. One belief present in this research that is not mentioned by Johnson (1997) is the beliefs participants had about the health information seeking as a social responsibility, which may be related to ideas from the consumer health movement, in which access to health information is said to grant much-needed power to patients. The CMIS, created in 1997, does not take into consideration these beliefs found here to be a factor influencing the seeking decisions of participants. These omissions—the belief or lack of belief in health information seeking as a social responsibility and the addition of information avoidance as part of the range of information behaviour—suggest that the CMIS could be expanded to represent health information seeking more fully.

. The range of health information interaction shown in this research may also be employed to elaborate upon and suggest redesign of Wilson's (1999) Model of General Information Seeking Behaviour. Wilson (1999) explains that between people's recognition of an information need and the seeking of information to fill this need stand several activating mechanisms and intervening variables. The choice to seek and the manner of seeking vary in this model, such that people may not seek, may seek passively, may search actively and may perform an ongoing search. However, these behaviours do not include information avoidance mechanisms. Though Wilson (1999) defines the information behaviour depicted in this model as the "totality of human behaviour in relation to sources and channels of information, including both active and passive information seeking and information use" (p. 249), he omits strategies such as filtering that permit the partial avoidance of information. Rectifying this omission is essential to render this model more clearly representative of the "totality" of information behaviour.

6.6 Implications for Practice

This study of information avoidance was conducted in the domain of information science; however, the subject of the information behaviour studied is health, and thus there are practical implications for professionals who are employed in libraries and other information-intensive environments including healthcare settings. One note here is that information professionals and others who work in information-intensive environments should be aware of information avoidance and the common motivations and methods of avoiding information. Previous research indicates that such professionals may not be mindful of such behaviour (Case & Johnson, 2012; Johnson, 2014). Professionals should be aware of information avoidance and its ties to various factors including personality, affect, and information source, as people with whom these professionals associate could exhibit this behaviour. Professionals should display sensitivity and tact while dealing with people practising this behaviour either in its absolute or partial forms as these people may be embarrassed or attempt to hide the fact that they avoid health information.

Another important implication of this research is that there may be a stigma associated with information avoidance that may cause misleading claims and assumptions about health information seeking. Study participants in the Affect and Avoidance study (Study 1) made claims that they would search a great deal; however, in the Interview and Interaction study, when given the opportunity to browse health material, participants often chose not to do so for the maximum amount of time or to scan all the information. In the Affect and Avoidance study, only one participant admitted that s/he would avoid information entirely. However, the Interview and Interaction study (Study 2) revealed that participants employed various information avoidance and filtering strategies. Even in this smaller sample, two participants admitted to a great deal of avoidance. Thus the assumptions of some participants about amounts of searching were not matched by the amounts of searching that other participants demonstrated. This disparity may have been due to the differing recruitment strategies employed by these two studies, which may have caused a corresponding and, here, important difference in samples. Despite this possibility, the fact that the Affect and Avoidance study asked questions about participants' assumptions about their information seeking while the Interview and Interaction study presented participants with the opportunity to browse information in real time, this difference in findings may indicate a disconnection between participants' intentions and behaviours and demonstrates that the position of seeking warrants further consideration by practitioners.

Another implication arises from comments of participants in the Interview and Interaction study regarding the societal value of health information seeking. Certain participants revealed their belief that health information seeking was an important societal responsibility, comparing themselves favourably with others who did not search or whose searches were less effective (P3, P32, P33) and commenting on the benefits to searching in the current healthcare system (P33). Yet many participants, upon reflection, commented on limitations in their searching strategies, pointing to the fact that they did not know which sources were medically authoritative (P7, P9). These comments recall Competency Theory, which notes that people engaged in a new area tend to overestimate their abilities; as they have no understanding of what the area entails, they have no means to judge ability, a situation called the "dual curse" (Kruger & Dunning, 1999, p. 1121). Studies have shown that competency theory, also known by the flattering-to-researchers name of the Dunning-Kruger effect, translates to the information literacy sphere where people often overestimate their skills and abilities in searching for information regarding many topics (Gross & Latham, 2007, 2009, 2011, 2013). Comments by Interview and Interaction study participants reveals that this application may also be present in some health information behaviour, a problematic conclusion for those who may rely in part on an understanding of people's abilities in this area.

6.7 Conclusion

The information avoidance mechanisms, as well as the factors that influence the use of these mechanisms, add to the understanding of information avoidance and information behaviour. In self-regulation, study participants reported limiting and filtering the information for which they searched when that information was deemed negative or detailed. Delegation was present when information searching was allocated to another who could also be nominated to filter the information received. These mechanisms, both of which point to a filtering of information, indicate a partial avoidance of information that expands the notion of information avoidance as simply not-seeking.

Personality, affect, and information source were all implicated as motivations for information avoidance. Personality traits, operationalized here as Need for Cognition and Monitoring and Blunting orientation, had much less of an effect than anticipated on participants' health information behaviour. Two other personality traits, health motivation and health perception, did emerge as influential from the analysis of results from the Information and Interaction study. Health motivation, a strong interest in health and health maintenance, was noted as some participants displayed this trait, while others, less likely to search, felt instead that they should "accept" (P16) ill health. Health perception and often the accompanying optimistic bias was also present in this research as some participants felt that their good health made them in some way immune to either illness or any strong side effects of illness.

Thus three forms of affect were an influence on participants' health information behaviour: fear, disgust, and disinterest. Fear generally functioned as a cause of information avoidance, an effect much seen in literature about this topic and perhaps stemming from situations in which uncertainty was a desirable rather than undesirable affective condition. Participants also avoided information that provoked disgust, often videos of surgeries, while participants who evaluated medical information as too complex or lacking in novelty avoided this information as well. The latter form of affect, disinterest, was significant, as some researchers note that information disinterest is separate from information avoidance. However, this research found that information disinterest and information avoidance both function as a means of avoiding threat.

Information avoidance of sources was determined to have occurred when participants who cited problems with one source, usually those sources associated with traditional medical authority, expressed preferences for other sources in lieu. This choice of sources may have taken place as participants may hold definitions of medical authority that differ from those in traditional medicine.

This research also suggests that measures, in particular Need for Cognition and Monitoring and Blunting, previously employed to indicate motivations for information seeking may not be suitable in this context. The general usefulness of instruments that contain these scales should be assessed. Scenarios, as well, vary in the number of decision options they present, which may have affected findings. Consistency in decision options should be further examined.

This research suggests the redesign of Johnson's (1997) Comprehensive Model of Information Seeking (CMIS) and Wilson's (1999) General Model of Information Seeking. With regards to Johnson's (1997) CMIS, factors that contribute to people's avoidance are also elaborated upon, with beliefs influencing information avoidance expanded to include those surrounding health information seeking and responsibility. Both the CMIS and Wilson's (1999) model, which provides an overview of information seeking processes including passive attention and ongoing searching, are lacking mention of information avoidance. Without this behaviour, neither model presents the full range of information interaction.

Implications for practice include a greater understanding of the notion of health information seeking and responsibility, which may be responsible for participants' wrongful belief that they would search for the maximum amount of information possible when faced with health difficulties. This last idea is worthy of more attention from practitioners, who may be faced with people who believe fully that information searches will be more extensive. This belief in health information seeking may also be responsible for an assumption that people search better than they actually do, a finding that recalls competency theory that posits people encountering a new area do not have the knowledge to gauge their capacity.

7 Conclusion

The following chapter concludes this dissertation. I will begin by giving an overview of the research conducted, and a summary of both its implications and the contributions it has made. I will then look at directions for future research.

7.1 Overview

Through this research, I sought to understand information avoidance, the mechanisms by which people avoid information and the extent to which personality, affect, and information source factors influence avoidance behaviours. A greater comprehension of these elements is essential. Information is considered in general extremely beneficial; it follows that seeking information is viewed as a natural drive that all possess (Case et al., 2005). In the field of health, the lens through which I explored information avoidance, information is painted as a vital component of being healthy, with health information seeking increasingly depicted as important for good health. Information avoidance, due at least in part to these views of information and information seeking, is often ill defined as a negation of behaviour, a not-seeking.

This research revealed that people employ filtering mechanisms, delegation and self-regulation, to partially avoid health information. Thus information avoidance as depicted here can be found on a continuum, contrary to the current image of avoidance as a simple negation of information seeking, as a not-seeking. One reason for this continuum might be the current view of health information seeking as a desirable behaviour, which may have encouraged participants to search more than previous studies in which participants in other situations may have been more likely to simply avoid. However, it may also be that this continuum of information avoidance indicates that this reaction to information should be included within the range of people's information behaviour, instead of being placed outside of this range as a simple negative mirror of seeking. This more comprehensive view of information avoidance could be used to amplify such macro-models of information behaviour as those of Johnson (1997) and Wilson (1999) that purport to show information behaviour on a larger scale and allow for a fuller, better understanding of how people interact with information.

This research also makes an important contribution to views of health information seeking. It has previously been noted that health information seeking is currently in a position of desirability, a behaviour that people should engage in if they are more properly to care for their health and existing as a base for many health initiatives. This research makes evident that this attitude can obscure the reality of how people interact with health information even to those people who are interacting themselves.

This research also sheds light on the motivations for information avoidance, finding that while personality and information source factors do influence information avoidance, situational factors such as affect seemed to be yet more influential for these participants and in response to these scenarios. Here, these situational affective factors that sway information behaviour in this study are fear, disgust, and disinterest. These particular factors are indicative of a threat to people, whether to their viewpoint or their physicality.

7.2 Limitations

This research was limited in several ways. As mentioned in section 3.5.6, I am a former patient who had emergency surgery for an acoustic neuroma in 2003, for which concern I sought only minimal information. I am also a librarian who encountered a negative bias against information avoidance, an information behaviour that I myself engaged in. These perspectives influenced my choice of dissertation topic, and also affected the qualitative analysis, as this analysis is interpretive and reliant on the individual researcher. Such experiences led to my identification of behaviours as information avoidance; additionally, it gave me a more neutral and sometimes positive view of information avoidance, contrary to that expressed by some other researchers (Johnson, 2014). I also approached information avoidance with an information science lens, rather than looking at this phenomenon as a health researcher would; for example, I took a broad approach to health information, including screening and diagnoses under this umbrella. Although this approach allowed me to look at information avoidance from a more comprehensive standpoint, I was unable to examine more situation-based differences that may have affected avoidance of particular information in particular contexts.

In this research, I have concentrated consistently on the seeking of health information by patients on their own behalf. Admittedly, some research does not treat searching for oneself and searching for others differently (see Sweeny & Miller, 2012; Miller, 1980 for examples). However, the separate role of the caregiver in assisting people who are in crisis with information seeking and other activities has been the subject of some study (Barbarin, Klasnja & Veinot, 2016; Veinot, Kim & Meadowbrooke, 2011; Hepworth, 2004). Health decisions are also not made in a vacuum, with many patients weighing factors such as the perceived opinion of the healthcare professional administering treatment before making a health decision (Aronson, 2013; Kryworuchko et al., 2012; Nouvet et al., 2016). Social exclusion may also be a factor in health information avoidance (Howell & Shepperd, 2017). More focused work is needed to enable a better understanding of information avoidance within these different contexts and situations.

Another, related, limitation is that I concentrated on information avoidance as a general phenomenon, rather than looking at specific demographic differences. Such demographics have been linked to variations in health information seeking. In particular, researchers have noted that older people have more health concerns and thus can search for more health information (Ahluwalia et al., 2012). Still other studies show that concerns of older people tend to be more complex and thus people, intimidated by the resulting and daunting task, may be reluctant to search (Agree, King, Castro, Wiley & Borzekowski, 2015). Similar paradoxes are visible in research regarding gender and its influence on health information seeking (Warner & Procaccino, 2007; Manierre, 2015; Lund-Nielsen et al., 2011). Women have been labelled the "gatekeepers" of health information (Warner & Procaccino, 2007, p. 787); often being the primary caregivers, they tend to seek out health information as part of that care (see also Manierre, 2015). Despite this fact, research also shows that caregiving for others can be such an onerous task that it may lead to women neglecting their own health (Lund-Nielsen et al., 2011). In this research, little evidence of either gender or age as an influencing factor was found: in the Affect and Avoidance study, Spearman's tests were performed between Age and Information Seeking, and Gender and Information Seeking. There were no significant results found. Thus, relationships between demographic characteristics and health were deemed outside the scope of the research. However, while not a focus of this research, there is a need for further investigation of information avoidance that considers the role of gender and age.

Recruitment tools included an online labour market, Amazon's Mechanical Turk (AMT). Online labour markets in general and AMT are currently commonly used in social science and other research (Zhu & Carterette, 2010), and AMT in particular has been much lauded for its ability to link up "requestors" who need a large number of people to complete a Human Intelligence Task (HIT) with "workers" who are willing to do so (Paolacci, Chandler, & Ipeirotis, 2010; Rand, 2011). However, critics point out that the online and impersonal format of the survey may allow for participants to waver in their attention (Paolacci & Chandler, 2014). In addition, this method of recruitment was different from the method used in the Interview and Interaction study, which resulted in dissimilar samples. I added an attention-seeking question regarding the nature of the disease; however, it is impossible to know if participants maintained a similar level of attention throughout the survey, a problem not present in the Interview and Interaction study, in which the interviewer was physically present.

Another issue present in this research is the use of hypothetical scenarios to simulate situations in which health information seeking and avoidance can occur. The use of hypothetical scenarios has been criticized as people may respond differently to hypothetical scenarios than they do to real situations. This limitation of using hypothetical scenarios was mitigated in the Interview and Interaction study, as the interviews covered both the assigned scenarios and participants' health experiences, often allowing the scenarios to function as starting points for discussions about health (Evans et al., 2014). Participants in the Interview and Interaction study responded to general questions about health information seeking in a manner that indicated they considered the hypothetical disease assigned as well as their own real health. A concern with the use of such scenarios is that they have the potential to lead to real distress on the part of participants. Hypothetical scenarios have been used extensively in studies of information avoidance (Melnyk & Shepperd, 2012; Dawson, Savitsky & Dunning, 2006) with no ill effects reported; however, steps were taken in the second study to ensure that the study took place in a quiet and private space, and that interviews were flexible enough to allow participants to address or not address their emotional responses to the scenarios. No signs of emotional distress were observed in reaction to the scenarios; however, the scenarios may have had unseen effects, with reference both to participants' responses and to their comfort and mental health. This is an important and persistence issue in health information research, given the need to study human behaviour in response to stressful health conditions.

7.3 Future Work

It is notable in this research, constituting studies of information avoidance, its mechanisms and influencing factors, that despite the focus on this challenging topic, evidence of information avoidance was found. It seems clear that the concentrations on information seeking shown in information behaviour and health care have their limits and that further work on information avoidance is needed in both disciplines. One question that remains is the extent to which these results on health information avoidance can be translated into the avoidance of other subjects. It is certain that information is avoided on many occasions and yet thus far those who study this subject have by and large concentrated on the avoidance of health information. Miller's (1980) seminal Monitoring and Blunting scale suggested that Monitoring and Blunting behaviours were found in a variety of stressful situations in which the spectre of economic loss was present as well as personal danger; later studies point to societal and romantic rejection as another circumstance (Sweeny & Miller, 2012). Yet few researchers have attempted to examine stressful situations at a higher level, focusing on all such occurrences that may result in information avoidance. This research, which itself addressed information avoidance at one such macro-level, that of the avoidance of all health information, suggests that other scenario-driven studies might approach the topic of information avoidance at another higher level, in order to garner a clearer and more universal picture of this behaviour.

Gaps are additionally present in the study of health information avoidance. One of the pressing questions in this research is the extent to which the individual health care systems influences the likelihood and effect of health information avoidance. Much of the literature including Miller's (1980) seminal study was American, as were participants in the Affect and Avoidance study, and thus based in a private health care system. Problems with private systems are suggested by the comment from one participant in the Affect and Avoidance study: "I would be too scared to look for information. Since I don't have insurance, I'd be stuck with some very expensive bills for the next year at least." However, Veinot (2008) noted that public health care systems have difficulties as well. In her study of governmental health websites from Canada and the United Kingdom, she found that health information seeking can be as much a burden as an empowerment, a task people must complete to be "good citizens" (p. 30), a fact also denoted in part by the concept of "healthwork" (Mykhalovskiy & McCoy, 2002) used in this research. Other shortcomings in the Canadian system that may contribute to health information avoidance are long wait times and a shortage of treatment options in some areas (Standing Committee on Health, 2016).

7.4 Summary

This research demonstrates that information avoidance is present in quantities and in circumstances largely unsuspected by much research and many who advocate the benefits of information seeking. It is to be hoped that these researchers, advocates, and those whose work relies on the assumption that people will search for health information will benefit from a closer examination of this behaviour including the information filtering and influencing factors found by this research. Such attention would aid others in better understanding how people interact with all information and that of health, thus allowing for the fact that people can and do avoid.

Bibliography

Adams, K., Greiner, A.C. & Corrigan, J.M. (Eds). (2004). *Report of a summit. The 1st annual crossing the quality chasm summit — A focus on communities.* Washington, DC: National Academies Press*.*

Adams, S. (2010). Sourcing the crowd for health experiences: Letting the people speak or obliging voice through choice? In R. M. Harris, C. N. Wathen, & S. Wyatt (Eds.), *Configuring health consumers* (pp. 104–129). New York: Palgrave Macmillan.

Agree, E. M., King, A. C., Castro, C. M., Wiley, A., & Borzekowski, D. L. G. (2015). "it's got to be on this page": Age and cognitive style in a study of online health information seeking. *Journal of Medical Internet Research, 17*(3), e79.

Ahluwalia, S. C., Gross, C. P., Chaudhry, S. I., Ning, Y. M., Leo-Summers, L., Van Ness, P. H., & Fried, T. R. (2012). Impact of comorbidity on mortality among older persons with advanced heart failure. *Journal of General Internal Medicine, 27*(5), 513-519. doi:10.1007/s11606-011-1930-3

Amazon.com, Inc. or its Affiliates. (2016). Amazon Mechanical Turk. Retrieved November 10, 2016, from www.mturk.com/mturk/welcome

Aronson, L. (2013). “Good” patients and “difficult” patients--Rethinking our definitions. *New England Journal of Medicine*, 796–797. http://doi.org/10.1056/NEJMp130357

Association for College and Research Libraries. (2000). *Information Literacy Competency Standards for Higher Education*. Chicago.

Association for College and Research Libraries. (2016) Framework for information literacy for higher education. http://www.ala.org/acrl/standards/ilframework

Auerbach, C. F., & Silverstein, L. B. (2003). *Qualitative data: An introduction to coding and analysis*. New York, NY, USA: New York University Press (NYU Press).

Babrow, A. S. (1992). Communication and problematic integration: Understanding diverging probability and value, ambiguity, ambivalence, and impossibility. *Communication Theory*, *2*(2), 95–130.

Bakardjieva, M. (2010). Impatient on the net: Exploring the genres of Internet use for health. In R. M. Harris, C. N. Wathen, & S. Wyatt (Eds.), *Configuring health consumers* (pp. 65–82). New York: Palgrave Macmillan.

Baker, L. M. (1997). Preference for physicians as information providers by women with multiple sclerosis: A potential cause for communication problems? *Journal of Documentation*, *53*, 251–262.

Baker, L. M. (1996). A study of the nature of information needed by women with multiple sclerosis. *Library and Information Science Research*, *18*(1), 67–81.

Bandura, A. (1977). *Social learning theory*. Englewood Cliffs, NJ: Prentice Hall.

Barbarin, A. M., Klasnja, P., & Veinot, T. C. E. (2016). Good or bad, ups and downs, and getting better: Use of personal health data for temporal reflection in chronic illness. *International Journal of Medical Informatics*, *94*, 237–245. http://doi.org/10.1016/j.ijmedinf.2016.06.011

Barbour, J. B., Rintamaki, L. S., Ramsey, J. A., & Brashers, D. E. (2012). Avoiding health information. *Journal of Health Communication*, *17*(2), 212–229. http://doi.org/10.1080/10810730.2011.585691

Bawden, D., & Robinson, L. (2015). "Waiting for carnot": Information and complexity. *Journal of the Association for Information Science and Technology*, *66*(11), 2177–2168. http://doi.org/10.1002/asi.23535

Bawden, D., & Robinson, L. (2009). The dark side of information: Overload, anxiety, and other paradoxes and pathologies. *Journal of Information Science*, *35*(2), 180–191. http://doi.org/1-.1177/0165551508095781

Bawden, D., & Robinson, L. (2011). Individual differences in information-related behaviour: What do we know about information styles? (pp. 127–158). Emerald Group Publishing Limited. http://doi.org/10.1108/S1876-0562(2011)002011a009

Beck, C. S., Aubuchon, S. M., McKenna, T. P., Ruhl, S., & Simmons, N. (2014). Blurring personal health and public priorities: An analysis of celebrity health narratives in the public sphere. *Health Communication*, *29*(3), 244–256. http://doi.org/10.1080/1040236.2012/741668

Bhavnani, S. K., & Peck, F. A. (2010). Scatter matters: Regularities and implications for the scatter of healthcare information on the web. *Journal of the American Society for Information Science and Technology, 61*(4), 659-n/a. doi:10.1002/asi.21217

Bjarnadottir, R. I., Millery, M., Fleck, E., & Bakken, S. (2016). Correlates of online health information-seeking behaviors in a low-income Hispanic community. *Informatics for Health & Social Care*, *41*(4), 341–349. http://doi.org/10.3109/17538157.2015.1064429

Blechner, A. J. (2015). Improving usability of legal research databases for print disabilities. *Legal Reference Services Quarterly*, *34*(2), 138. http://doi.org/10.1080/0270319X.2015.1048647

Bosk, C. L. (1979). *Forgive and remember: Managing medical failure*. Chicago: University of Chicago Press.

Brashers, D. E. (2001). Communication and uncertainty management. *Journal of Communication*, *51*(3), 477–497. http://doi.org/10.1093/joc/51.2.477

Brashers, D. E., Goldsmith, D. J., & Hsieh, E. (2002). Information seeking and avoiding in health contexts. *Human Communication Research*, *28*(2), 258–272.

British Columbia. Ministry of Health, & British Columbia Government EBook Collection. (2011). *Self-management support: A health care intervention*. Victoria, B.C.: Ministry of Health.

Buist, M. (2011). Instead of writing policy and procedure, we in the NHS should learn to listen. *Guardian*.

Bystrom, K., & Hansen, P. (1995). Task complexity affects information seeking and use. *Information Processing & Management 31*(2), 191-213.

Cacioppo, J. T., & Petty, R. E. (1982). The Need for Cognition. *Journal of Personality and Social Psychology*, *42*, 116–131.

Cacioppo, J. T., Petty, R. E., Feinstein, J. A., & Jarvis, W. B. G. (1996). Dispositional differences in cognitive motivation: The life and times of individuals varying in Need for Cognition. *Psychological Bulletin*, *119*(2), 197–253. http://doi.org/10.1037//0033-2909.119.2.197

Campbell, C., Scott, K., Skovdal, M., Madanhire, C., Nyamukapa, C., & Gregson, S. (2015). A good patient? How notions of "a good patient" affect patient-nurse relationships and ART adherence in Zimbabwe. *BMC Infectious Diseases*, *15*(404). http://doi.org/10.1186/s12879-015-1139-x

Canada Health Infoway: Digital health in Canada. (2016). Retrieved on November 16, 2016 from https://www.infoway-inforoute.ca/en/

Case, D. O. (2012). *Looking for information: A survey of research on information seeking, needs and behavior* (3rd Ed.). Bingley, UK: Emerald Group Publishing Limited.

Case, D. O., Andrews, J. E., Johnson, J. D., & Allard, S. L. (2005). Avoiding versus seeking: The relationship of information seeking to avoidance, Blunting, coping, dissonance, and related concepts. *Journal of the Medical LIbrary Association*, *93*(3), 353–362.

Catellier, J. R. A., & Yang, Z. J. (2012). Trust and affect: How do they impact risk information seeking in a health context? *Journal of Risk Research*, *15*(8), 897–911. http://doi.org/10.1080/13669877/2012/686048

Chang, G., & Caneday, L. (2011). Web-based GIS in tourism information search: Perceptions, tasks and trip attributes. *Tourism Management*, *32*(6), 1435–1437. http://doi.org/10.1016/j.tourman.2011.01.006

Chatman, E. A. (1991). Life in a small world: Applicability of gratification theory to information-seeking behavior. *Journal Fo the American Society for Information Science and Technology*, *42*(6), 438–449.

Chatman, E. A. (1996). The impoverished life-world of outsiders. *Journal of the American Society for Information Science and Technology*, *47*(3), 193–206.

Chatman, E. A. (1999). A theory of life in the round. *Journal of the American Society for Information Science and Technology*, *50*(3), 201–217.

Creswell, J. W., & Plano Clark, V. L. (2007). *Designing and conducting mixed methods research*. Thousand Oaks, California: Sage Publications, Inc.

Crutzen, R., Cyr, D., Larios, H., Ruiter, R. A. C., & de Vries, N. K. (2013). Social presence and use of Internet-delivered interventions. *PloS ONE*, *8*(2), e57067. http://doi.org/10.1371/journal.pone.0057067

Curtis, V., Barra, M. d., & Aunger, R. (2011). Disgust as an adaptive system for disease avoidance behaviour. *Philosophical Transactions: Biological Sciences*, *366*(1563), 389–401. http://doi.org/10.1098/rstb.2010.0117

Dawson, E., Savitsky, K., & Dunning, D. (2006). "Don't tell me; I don't want to know": Understanding people's reluctance to obtain medical diagnostic information. *Journal of Applied Psychology*, *26*(3), 751–768.

Dunning, D. (2011). The Dunning-Kruger effect: On being ignorant of one's own ignorance. *Advances in Experimental Psychology*, *44*, 247–296. http://doi.org/10.1016/B978-0-12-385533-0.00005-6

Dutta-Bergman, M. J. (2004). Primary sources of health information: Comparisons in the domain of health attitudes, health cognitions, and health behaviors. *Health Communication*, *16*(3), 273–288. http://doi.org/10.1207/S15327027HC1603_1

Dutta-Bergman, M. J. (2005). Theory and practice in health communication campaigns. *Health Communication*, *18*(2), 103–122. http://doi.org/10.1207/s15327027hc1802_1

Dwyer, L. A., Shepperd, J. A., & Stock, M. L. (2015). Predicting avoidance of skin damage feedback among college students. *Annals of Behavioral Medicine*, *49*(5), 685–695. http://doi.org/10.1008s12160-=015-9703-6

Eheman, C. R., Berkowitz, Z., Lee, J., Mohile, S., Purnell, J., Marie Rodriguez, E., & Morrow, G. (2009). Information-seeking styles among cancer patients before and after treatment by demographics and use of information sources. *Journal of Health Communication*, *14*(5), 487–502. http://doi.org/10.1080/10810730903032945

Eisenberg, M. B., Lowe, C. A., & Spitzer, K. L. (2008). *Information literacy: Essential skills for the information age* (2nd Ed.). Westport, Connecticut: Libraries Unlimited, Inc.

Ek, S., & Heinstrom, J. (2011). Monitoring or avoiding health information -- the relation to inner inclination and health status. *Health Information & Libraries Journal*, *28*(3), 200–209. http://doi.org/10.1111/j.1471-1842.2011.00947.x

Emerson, R. M., Fretz, R. I., & Shaw, L. L. (1995). *Writing ethnographic field notes*. Chicago: University of Chicago Press.

Erdelez, S. (2004). Investigation of information encountering in the controlled research environment. *Information Processing & Management*, *40*(6), 1013–1025. http://doi.org/10.1016/jpm.2004.02.002

Erdelez, S. (1999). Information encountering: It's more than just bumping into information. *Bulletin of the Association for Information Science and Technology*, *25*(3), 26–29. http://doi.org/10.1002/bult.118

Evans, S. C., Roberts, M. C., Keeley, J. W., Blossom, J. B., Amaro, C. M., Garcia, A. M., Stough, C. O., Canter, K. S., Robles, R., & Reed, G. M. (2014). Vignette methodologies for studying clinicians' decision making: Validity, utility, and application in ICD-11 field studies. *International Journal of Clinical and Health Psychology 15*, 160-170.

Feenstra, B., Boland, L., Lawson, M. L., Hamilton, D., Kryworuchko, J., Leblanc, M., & Stacey, D. (2014). Interventions to support children's engagement in health-related decisions: A systematic review. *BMC Pediatrics 14*, 104-109.

Ferguson, R. (2013). Health literacy. *Journal of Community Hospital Internal Medicine Perspectives*, *3*(2). http://doi.org/10.3402/jchimp.v3i2.21217

Festinger, L. (1957). *A theory of cognitive dissonance*. Stanford, CA: Stanford University Press.

Festinger, L. (1961). The psychological effects of insufficient rewards. *American Psychologist*, *16*(1), 1–11. http://doi.org/10.1037/h0045112

Fisher, K. E., Erdelez, S., & McKechnie, L. (E. F.) . (2005). Preface. In K. E. Fisher, S. Erdelez, & L. (E. F.) McKechnie (Eds.), *Theories of information behaviour* (pp. xix–xxii). Medford, New Jersey.

Flight, I. H., Wilson, C. J., Zajac, I. T., Hart, E., & McGillivray, J. A. (2012). Decision support and the effectiveness of web-based delivery and information tailoring for bowel cancer screening: An exploratory screening. *JMIR Research Protocols*, *1*(2), e12. http://doi.org/10.2196/resprot.2135

Folkman, S. (2010). Stress, coping, and hope. *Psycho-Oncology*, *19*(9), 901–908. http://doi.org/10.1002/pon.1836

Folkman, S., & Lazarus, R. (1984). *Stress, appraisal and coping*. New York: Springer Publishing Company, Inc.

Foucault, M. (1980). *Power/Knowledge: Selected interviews and other writings 1972-1977*. New York: Pantheon Books.

Freund, L. (2008). *Exploiting task-document relations in support of information retrieval in the workplace (Doctoral dissertation)*. University of Toronto.

Freund, L. (2013). A cross-domain analysis of task and genre effects on perceptions of usefulness. *Information Processing & Management*, *49*(5), 1108–1121.

Freund, L., & Berzowska, J. (2010). The goldilocks effect: Task-centred assessments of e-government information. *Proceedings of the American Society for Information Science and Technology*, *47*(1), 1–10. http://doi.org/10.1002/meet.14504701261

Fulton, C. (2009). The pleasure principle: The power of positive affect in information seeking. *Aslib Proceedings*, *61*(3), 245–261. http://doi.org/10.1108/00012530910959808

Greene, J. C. (2006). Toward a methodology of mixed methods social inquiry. *Research in the Schools*, *13*(1), 93–98.

Greene, J. C. (2008). Is mixed methods social inquiry a distinctive methodology? *Journal of Mixed Methods Research*, *2*, 7–22.

Greene, J. C., Caracelli, V. J., & Graham, W. F. (1989). Toward a conceptual framework for mixed method evaluation designs. *Educational Evaluation and Policy Analysis*, *11*, 255–274.

Gretzel, U. (2007). Introduction to the special issue on travel information search. *Information Technology & Tourism*, *9*(3), 147–148. http://doi.org/10.3727.109805077782166999

Gross, M., & Latham, D. (2009). Undergraduate perceptions of information literacy: Defining, attaining, and self-assessing skills. *College & Research Libraries*, *70*(4), 336–350. http://doi.org/10.5860/crl.70.4.336

Gross, M., & Latham, D. (2013). Addressing below proficient information literacy skills: Evaluating the efficacy of an evidence-based educational intervention. *Library and Information Science Research*, *35*(3), 181–190. http://doi.org/10.1016/j.lisr.2013.03.001

Gross, M., & Latham, D. (2007). Attaining information literacy: An investigation of the relationship between skills level, self-estimates of skill and library anxiety. *Library and Information Science Research*, *29*(3), 332–353. http://doi.org/10.1016/j.lisr.2007.04.012

Gross, M., & Latham, D. (2011). Experiences with and perceptions of information: A phenomenographic study of first year college students. *College & Research Libraries*, *81*(2), 161–185. http://doi.org/10.1086/658867

Hays, R. D., & Morales, L. S. (2001). The RAND-36 measure of health-related quality of life. *Annals of Medicine*, *33*(5), 350–357. http://doi.org/10.3109/07853890109002089

Heinstrom, J. (2003). Five personality dimensions and their influence on information behaviour. *Information Research*, *9*(1), 165.

Heinstrom, J., Sormunen, E., & Kaunisto-Laine, S. (2014). Spanning information behaviour across the stages of a learning task. *Journal of Documentation*, *70*(6), 1076–1097. http://doi.org/10.1108/JD-02-2014-0041

Henwood, F., Harris, R. M., & Spoel, P. (2011). Informing health? Negotiating the logics of choice and care in everyday practices of "healthy living." *Social Science and Medicine*, *71*(12), 2026–2032. http://doi.org/10.1016/j.socscimed.2011.04.007

Hepworth, M. (2004). A framework for understanding user requirements for an information service: Defining the needs of informal carers. *Journal of the American Society for Information Science and Technology*, *55*(8), 695–708. http://doi.org/10.1002/asi.20015

Hernandez, L. M., & Pleasant, A. F. (2013). *Health literacy: Improving health, health systems, and health policy around the world workshop summary*. Washington, D. C.: National Academies Press.

Hertwig, R., & Engel, C. (2016). Homo ignorans: Deliberately choosing not to know. *Perspectives on Psychological Science*, *11*(3), 359–373.

Holstein, J. A., & Gubrium, J. F. (1995). *The active interview*. Thousand Oaks, California: Sage Publications, Inc.

Hosier, A. (2016). Creating learning outcomes from threshold concepts for information literacy instruction. *College & Undergraduate Libraries,*1-13. doi:10.1080/10691316.2017.1246396

Howell, J. L., Crosier, B. S., & Shepperd, J. A. (2014). Does lacking threat-management resources increase information avoidance? A multi-sample, multi-method investigation. *Journal of Research in Personality*, *50*, 192–109. http://doi.org/10.1016/j.jrp.2014.03.003

Howell, J. L., Ratliff, K. A., & Shepperd, J. A. (2016). Automatic attitudes and health information avoidance. *Health Psychology: Official Journal of the Division of Health Psychology, American Psychological Association*, *35*(8), 816–823. http://doi.org/10.1037/hea0000330

Howell, J. L., & Shepperd, J. A. (2012). Reducing information avoidance through affirmation. *Psychological Science*, *23*(2), 141–145.

Howell, J. L., & Shepperd, J. A. (2013). Behavioral obligation and information avoidance. *Annals of Behavioral Medicine*, *45*(2), 258–263. http://doi.org/10.1007/s121160-012-9451-9

Howell, J. L., & Shepperd, J. A. (2017). Social exclusion, self-affirmation, and health information avoidance. *Journal of Experimental Social Psychology*, *68*, 21–26. http://doi.org/10.1016/j.jesp.2016.05.005

Howell, J. L., & Shepperd, J. A. (2016). Establishing an information avoidance scale. *Psychological Assessment*, *Advance on*. http://doi.org/10.1037/pas0000315

Howell, J. L., Shepperd, J. A., & Logan, H. L. (2013). Barriers to oral cancer screening: A focus group study of rural black American adults. *Psycho-Oncology*, *22*(6), 1306–1311. http://doi.org/10.1002/pon.3137

Howell, J. L., Sweeny, K., & Shepperd, J. A. (2014). Psychological distance and the discrepancy between recommendations and actions. *Basic and Applied Social Psychology*, *36*(6), 502–514. http://doi.org/10.1080/01973533.2014.958229

Huber, M., Knottnerus, J. A., Green, L., van der Horst, A., Jadad, A. J., Kromhout, D., … Schnabel, P. (2011). How should we define health? *The BMJ*, *28*, 343. http://doi.org/10.1136/bmj.d4163

Hunt, J. M., Stevens, K. M., Chatterjee, A., & Kernan, J. B. (1994). Socially desirable responses in the measurement of Need for Cognition. *Advances in Consumer Research*, *21*, 543.

Hyman, H. H., & Sheatsley, P. B. (1947). Some reasons why information campaigns fail. *Public Opinion Quarterly*, *11*(3), 412–423.

James, L., & Nahl, D. (2014). A metatheory integrating social, biological and technological factors in information behavior research. *Webology*, *11*(1), a116.

Johnson, J. D. (1997). *Cancer-related information seeking*. New York: Hampton Press.

Johnson, J. D. (2013). *Dosage: A guiding principle for health communicators*. Lanham: Rowman & Littlefield Pub.

Johnson, J. D. (2014). Health-related information seeking: Is it worth it? *Information Processing & Management*, *50*(5), 708–717. http://doi.org/10.1016/j.ipm.2014.06.001

Johnson, J. D., & Case, D. O. (2012). *Health information seeking*. New York: Peter Lang.

Johnson, R. B., & Onwuegbuzie, A. J. (2004). Mixed methods research: A research paradigm whose time has come. *Educational Researcher*, *33*(7), 14–26.

Johnson, R. B., Onwuegbuzie, A. J., & Turner, L. A. (2007). Toward a definition of mixed methods research. *Journal of Mixed Methods Research*, *1*(2), 112–133. http://doi.org/10.1177/1558689806298224

Julien, H., & Williamson, K. (2010). Discourse and practice in information literacy and information seeking: Gaps and opportunities. *Information Research*, *15*(1).

Kelly, D. (2009). Methods for evaluating interactive retrieval systems with users. http://doi.org/10.1561/1500000012

Knobloch-Westerwick, S., Johnson, B. K., & Westerwick, A. (2013). To your health: Self-regulation of health behaviour through Selective Exposure to online health messages. *Journal of Communication*, *63*(5), 807–829. http://doi.org/10.1111/jcom.12055

Kryworuchko, J., Hill, E., Murray, M. A., Stacey, D., & Fergusson, D. A. (2012). Systematic review: Effectiveness of interventions intended to improve the quality; of end-of-life decision making in the Intensive Care Unit. *Worldviews on Evidence-based Nursing 4*(1), 1-16. Doi: 10.1111/j.1741-6787.2012.00247.x

Kruger, J., & Dunning, D. (1999). Unskilled and unaware of it: How difficulties in recognizing one's own incompetence lead to inflated self-assessments. *Journal of Personality and Social Psychology*, *77*, 1121–1134.

Kuhlthau, C. C. (1993). A principle of uncertainty for information seeking. *Journal of Documentation*, *49*(4), 339–355.

Kuhlthau, C. C. (2004). *Seeking meaning: A process approach to library and information services* (2nd Ed.). Westport, Connecticut: Libraries Unlimited, Inc.

Lambert, S. D., & Loiselle, C. G. (2007). Health-information seeking behavior. *Qualitative Health Research*, *17*(8), 1006–1014. http://doi.org/10.1177/1049732307305199

Lambert, S. D., Loiselle, C. G., & Macdonald, M. E. (2009). An in-depth exploration of information-seeking behavior among individuals with cancer: Part 2 Understanding patterns of information disinterest and avoidance. *Cancer Nursing*, *32*(1), 26–36.

Lawn, S., McMillan, J., & Pulvirenti, M. (2011). Chronic condition self-management: Expectations of responsibility. *Patient Education and Counseling, 84*(2), e5-e8. doi:10.1016/j.pec.2010.07.008

Lazar, J., & Briggs, I. (2015). Improving services for patrons with print disabilities at public libraries. *The Library Quarterly: Information, Community, Policy*, *85*(2), 172–184. http://doi.org/10.1086/680155

Lee, S. Y., & Hawkins, R. P. (2016). Worry as an uncertainty-associated emotion: Exploring the role of worry in health information seeking. *Health Communication*, *31*(8), 926. http://doi.org/10.1080/10410236.2015.1018701

Lialiou, P., & Mantas, J. (2015). Health professionals' use of computer databases to utilize research for practice: A pilot study. *Studies in Health Technology and Informatics*, *213*, 291.

LimeSurvey Project Team / Carsten Schmitz (2015). / LimeSurvey: An Open Source survey tool /LimeSurvey Project Hamburg, Germany. URL http://www.limesurvey.org

Lindberg, M. (2012). Monitoring and Blunting in fluid restriction consultation. *Hemodialysis International*, *16*(2), 282–285. http://doi.org/10.1111/j.1542-4768.2011.00641.x

Lloyd, A. (2014). Following the red thread of information research: Recovering local knowledge through interview to the double. *Library and Information Science Research*, *36*(2). http://doi.org/10.1016/j.lisr.2013.10.006

Lloyd, A. (2012). Information literacy as a socially enacted practice. *Journal of Documentation*, *68*(6), 772–783. http://doi.org/10.1108/00220411277037

Lloyd, A. (2005). Information literacy: Different contexts, different concepts, different truths? *Journal of Librarianship and Information Science*, *37*(2), 82–88.

Lloyd, A. (2010). *Information literacy landscapes: Information literacy in Education, Workplace, and Everyday Contexts*. Oxford: Chandos.

Lopatovska, I. (2014). Toward a model of emotions and mood in the online information search process. *Journal of the American Society for Information Science and Technology*, *65*(9), 1775–1793. http://doi.org/10.1002/asi.23078

Lu, H.-Y., Andrews, J. E., & Hou, H.-Y. (2009). Optimistic bias, information seeking and intention to undergo prostate cancer screening: A Taiwan study on male adults. *Journal of Medical Health*, *6*(3), 183–190.

Lu, H., Dzwo, T., Hou, H., & Andrews, J. E. (2011). Factors influencing information-seeking intentions and support for restrictions. *British Food Journal*, *113*(11), 1439–1452. http://doi.org/10.1108/00070701111180030

Lund-Nielsen, B., Midtgaard, J., Rørth, M., Gottrup, F., & Adamsen, L. (2011). An avalanche of ignoring: A qualitative study of health care avoidance in women with malignant breast cancer wounds. Cancer Nursing, 34, 277–285.

Lustria, M. L. A. (2007). Can interactivity make a difference? effects of interactivity on the comprehension of and attitudes toward online health content. *Journal of the American Society for Information Science and Technology, 58*(6), 766-776. doi:10.1002/asi.20557

MacGregor, J. C. D., & Wathen, C. N. (2014). "My health is not a job": A qualitative exploration of personal health management and imperatives of the "new public health." *BMC Public Health*, *14*(1), 726. http://doi.org/10.1186/1471-2458-14-726

Manierre, M. J. (2015) Gaps in knowledge: Tracking and explaining gender differences in health information seeking. *Social Science & Medicine* 128, 151-158. http://dx.doi.org/10.1016/j.socscimed.2015.01.028

Maslow, A. (1963). The need to know and the fear of knowing. *Journal of General Psychology*, *68*, 111–125.

Maxwell, A. J. (2011). *A realist approach to qualitative research*. Thousand Oaks, California: Sage Publications, Inc.

McCay-Peet, L., Lalmas, M., & Navalpakkam, V. (2012). On saliency, affect and focused attention. In *Proceedings of SIGCHI Conference on Human Factors in Computing Systems (CHI '12), Austin, TX* (pp. 541–550). New York: ACM.

McCloud, R. F., Jung, M., Gray, S. W., & Viswanath, K. (2013). Class, race, and ethnicity and information avoidance among cancer survivors. *British Journal of Cancer*, *108*(10), 1949–1956. http://doi.org/10.1038/bjc.2013.182

McKenzie, P. (2010). Informing relationships: Small talk, informing and relationship building in midwife-woman interaction. *Information Research, 15*(1)

McKenzie, P. J. (2004). Positioning theory and the negotiation of information needs in a clinical midwifery setting. *Journal of the American Society for Information Science and Technology*, *55*(8), 685–694. http://doi.org/10.1002/asi.20002

McKenzie, P. J. (2003). A model of information practices in accounts of everyday-life information seeking. *Journal of Documentation, 59*(1), 19-40. doi:10.1108/00220410310457993

McKenzie, P. J. (2001). *Negotiating authoritative knowledge: Information practices across a life transition*. The University of Western Ontario, London.

Melnyk, D., & Shepperd, J. A. (2012). Avoiding risk information about breast cancer. *Annual Behavioural Medicine*, *44*, 216–224. http://doi.org/10.1007/s12160-012-9382-5

Mentis, H. M. (2007). Memory of frustrating experiences. In D. Nahl & D. Bilal (Eds.), *Information and emotion* (pp. 197–210). Medford, New Jersey: Information Today, Inc.

Mentis, H., & Rosson, M. B. (2009). It's like a circus in here!: Affect and information sharing in an emergency department. In *Paper presented at the CHI '09 Extended Abstracts on human factors in computing systems* (pp. 4423–4428). http://doi.org/10.1145/1520677

Miles, M. B., & Huberman, A. M. (1984). *Qualitative data analysis: A sourcebook of new methods*. Thousand Oaks, California: Sage Publications, Inc.

Miles, M. B., Huberman, A. M., & Saldana, J. (2014). *Qualitative data analysis: A methods sourcebook* (3rd Ed.). Beverly Hills: Sage Publications, Inc.

Miller, S. M. (1995). Monitoring versus Blunting styles of coping with cancer influence the information patients want and need about their disease. *Cancer*, *76*, 167–177.

Miller, S. M. (2014). Monitoring style of coping with cancer related threats: A review of the literature. *Journal of Behavioral Medicine*, *37*(5), 931–954. http://doi.org/10.1007/s10865-014-9553-x

Miller, S. M. (1980). When is a little information a dangerous thing? Coping with stressful events by Monitoring versus Blunting. In S. Levine & H. Ursing (Eds.), *Coping and health* (pp. 145–169). New York: Plenum.

Miller, S. M. (1987). Monitoring and Blunting: Validation of a questionnaire to assess styles of information seeking under threat. *Journal of Personality and Social Psychology*, *52*(2), 345–353.

Mills, J. (1965). Avoidance of dissonant information. *Journal of Personality and Social Psychology*, *2*(4), 589–593.

Moorman, C., & Matulich, E. (1993). A model of consumers' preventative health behaviors: The role of health motivation and health ability. *Journal of Consumer Research*, *20*(3), 208–228. http://doi.org/10.1086/209344

Muramatsu, J., & Pratt, W. (2001). Transparent queries: Investigating users' mental models of search engines. In *SIGIR '01*. New Orleans, L.A.

Muris, P., Van Zuuren, F. J., De Jong, P. J., De Beurs, E., & Hanewald, G. (1994). Monitoring and blunting coping styles: The miller behavioural style scale and its correlates, and the development of an alternative questionnaire. *Personality and Individual Differences, 17*(1), 9-19. doi:10.1016/0191-8869(94)90257-7

Mykhalovskiy, E., & McCoy, L. (2002). Troubling ruling discourses of health: Using institutional ethnography in community-based research. *Critical Public Health*, *12*(1), 17–37. http://doi.org/10.1080/09581590110113286

Nabi, R. L., & Thomas, J. (2013). The effects of reality-based television programming on diet and exercise motivation and self-efficacy in young adults. *Health Communication*, *28*(7), 699.

Nahl, D. (2005). Affective load. In K. E. Fisher, S. Erdelez, & L. E. F. McKechnie (Eds.), *Theories of information behaviour* (pp. 39–43). Medford, New Jersey: Information Today, Inc.

Nazari, M., & Webber, S. (2012). Loss of faith in the origins of information literacy in e-environments. *Journal of Librarianship and Information Science*, *44*(2), 97–107. http://doi.org/10.1177/0961000611436095

Neuberger, L. (2016). Self-reports of information seeking: Is social desirability in play? *Atlantic Journal of Communication*, *24*(4), 242. http://doi.org/10.1080/15456870.2016.12.08661

Neuberger, L., & Silk, K. J. (2016). Uncertainty and information seeking patterns: A test of competing hypotheses in the context of health care reform. *Health Communication*, *31*(7), 892–902. http://doi.org/10.1080/10410236.2015.1012633

Nielsen, J., & Shapiro, S. (2009). Coping with fear through suppression and avoidance of threatening information. *Journal of Experimental Social Psychology*, *15*(3), 258–274. http://doi.org/10.1037/a001718

Nijhof, N., Hoeven, T., Claartji, L., & de Jong, M. D. T. (2008). Determinants of the use of a diabetes risk-screening test. *Journal of Community Health*, *33*(5), 313–317. http://doi.org/10.1007/s10900-008-9099-3

Nouvet, Strachan, P. H., Kryworuchko, J., Downar, J., You, J. J. (2016). Waiting for the body to fail: Limits to end-of-life communication in Canadian hospitals. *Mortality 21*(4), 340-356. doi: 10.1080/13576275.2016.1140133

NVivo Qualitative Data Analysis Software; QSR International Pty Ltd. Version 10, 2014.

Odyemi, R. O., Ayegboyin, M., & Salami, K. K. (2016). Perceptions of Ebola virus disease in Nigeria: Understanding the influence of imagination on health orientation. *International Journal of Nursing Practice*, *22*(3), 291–299. http://doi.org/10.1111/ijn.12425

OECD. (2016). *Health at a glance*.

Oh, Y. S., & Cho, Y. (2015). Examining the relationships between resources and online health information seeking among patients with chronic diseases and healthy people. *Social Work in Health Care*, *54*(2), 83. http://doi.org/10.1080/00981389.2014.987940

Onwuegbuzie, A. J., Johnson, R. B., & Collins, K. M. (2009). Call for mixed analysis: A philsophical framework for combining qualitative and quantitative approaches. *Journal of Multiple Research Approaches*, *3*(2), 114–136. http://doi.org/10.5172/mra.3.2.114

Paolacci, G., & Chandler, J. (2014). Inside the Turk: Understanding Mechanical Turk as a participant pool. *Current Directions in Psychological Science: A Journal of the American Psychological Society*, *23*(3), 184–188. http://doi.org/10.1177/0963721414531598

Paolacci, G., Chandler, J., & Ipeirotis, P. G. (2010). Running experiments on Amazon Mechanical Turk. *Judgment and Decision Making*, *5*(5), 411–419.

Paolacci, G., Chandler, J., & Ipeirotis, P. G. (2014). Inside the Turk: Understanding Mechanical Turk as a participant pool. *Current Directions in Psychological Science: A Journal of the American Psychological Society*, *23*(3), 184.

Persoskie, A., Ferrer, R. A., & Klein, W. M. P. (2014). Association of cancer worry and perceived risk with doctor avoidance: An analysis of information avoidance in a nationally representative US sample. *Journal of Behavioral Medicinee*, *37*, 977–987. http://doi.org/10.1007.s10865-013-9537-2

Peterson, R. A. (2000). Rating scales. In *Constructing effective questionnaires* (pp. 61–83). Thousand Oaks, California: Sage Publications, Inc. http://doi.org/10.4135/9781483349022

Phares, E. J. (1991). *Introduction to personality* (3rd ed.). New York: Harper Collins.

Polit, D. F. (2010) *Statistics and data analysis for nursing research* (2nd ed.). Boston: Pearson.

Powers, A. D., & Oltmanns, T. F. (2013). Personality pathology as a risk factor for negative health perception. *Journal of Personality Disorders*, *27*(3), 359–370.

Prochaska, J. O. & DiClemente, C. C. (1983) Stages and processes of self-change of smoking: Toward an integrative model of change. *Journal of Consulting & Clinical Psychology, 51,* 390-395.

Prochaska, J. O., DiClimente, C. C. & Norcross, J. C. (1992) In search of how people change: Applications to addictive behaviors. *Addictive Psychologist, 47,* 1102-1114.

Rand, D. G. (2011). The promise of Mechanical Turk: How online labor markets can help theorists run behavioral experiments. *Journal of Theoretical Biology*, *299*, 172–179. http://doi.org/10,1016/j.jtbi.2011.03.004

Reynolds, L. M., Consedine, N. S., & McCambridge, S. A. (2014). Mindfulness and disgust in colorectal cancer scenarios: Non-judging and non-reacting components predict avoidance when it makes sense. *Mindfulness*, *5*(4), 442–452. http://doi.org/10.1007/s12671-013-0200-3

Reynolds, L. M., Lin, Y. S., Zhou, E., & Consedine, N. S. (2015). Does a brief state mindfulness induction moderate disgust-driven social avoidance and decision-making? An experimental investigation. *Journal of Behavioral Medicine*, *38*(1), 98–109. http://doi.org/10.1007/s10865-014-9582-5

Reynolds, L. M., McCambridge, S. A., Bissett, I. P., & Consedine, N. S. (2014). Trait and state disgust: An experimental investigation of disgust and avoidance in colorectal cancer decision scenarios. *Health Psychology: Official Journal of the Division of Health Psychology, American Psychological Association*, *33*(12), 1495–1506. http://doi.org/10l.1037/hea0000023

Sairanen, A., & Savolainen, R. (2010). Avoiding health information in the context of uncertainty management. *Information Research*, *15*(4).

Salvador, d. B., Arquero, J. L., & Romero-Frías, E. (2015). Personal learning environments acceptance model: The role of need for cognition, e-learning satisfaction and students' perceptions. *Journal of Educational Technology & Society, 18*(3), 129-141. Retrieved from http://ezproxy.library.ubc.ca/login?url=http://search.proquest.com.ezproxy.library.ubc.ca/docview/1707773429?accountid=14656

Sandelowski, M. (2010) What's in a name? Qualitative description revisited. *Research in Nursing & Health 33*, 77-84.

Sandelowski, M. (2000) Whatever happened to qualitative description? *Research in Nursing & Health 23*, 334-340.

Sandelowski, M. (1993). Rigor or rigor mortis: The problem of rigor in qualitative research revisited. *ANS. Advances in Nursing Science, 16*(2), 1.

Savolainen, R. (2014). Emotions as motivators for information seeking: A conceptual analysis. *Library and Information Science Research*, *36*(1), 59. http://doi.org/10.1016/j.lis.2013.10.004

Savolainen, R. (2015). Cognitive barriers to information seeking: A conceptual analysis. *Journal of Information Science*, *41*(5), 613. http://doi.org/10.1177/0165551515587850

Savolainen, R. (2012). Expectancy-value beliefs and information needs as motivators for task-based information seeking. *Journal of Documentation*, *68*(4), 492–511. http://doi.org/10.1108.00220411211239075

Savolainen, R. (2009). Small world and information grounds as contexts of information seeking and sharing. *Library and Information Science Research*, *31*(1), 38–45. http://doi.org/10.1016/j.lisr.2008.10.007

Sears, D., & Freedman, J. (1967). Selective Exposure to information: A critical review. *Public Opinion Quarterly*, *31*(2), 194–213.

Serafini, K., Malin-Mayor, B., Nich, C., Hunkele, K., & Carroll, K. M. (2016). Psychometric properties of the positive and negative affect schedule (PANAS) in a heterogeneous sample of substance users. *The American Journal of Drug and Alcohol Abuse, 42*(2), 203-212. doi:10.3109/00952990.2015.1133632

Shepperd, J. A., Emanuel, A. S., Howell, J. L., & Logan, H. L. (2015). Predicting scheduling and attending for an oral cancer examination. *Annals of Behavioral Medicine*, *49*(6), 828–838. http://doi.org/10.1007/s12160-015-9717-0

Shepperd, J. A., Klein, W. M. P., Waters, E. A., & Weinstein, N. D. (2013). Taking stock of unrealistic optimism. *Perspectives on Psychological Science*, *8*(4), 395–411.

Shepperd, J. A., Pogge, G., & Howell, J. L. (2016). Assessing the consequences of unrealistic optimism: Challenges and recommendations. *Consciousness and Cognition*. http://doi.org/10.1016/j.concog.2016.07.004

Shneyderman, Y., Rutten, L. J. F., Arheart, K. L., Byrne, M. M., Kornfeld, J., & Schwartz, S. J. (2016). Health information seeking and cancer screening adherence rates. *Journal of Cancer Education*, *31*(1), 75–83. http://doi.org/10.1007/s13187-015-0791-6

Silvia, P. J. (2005). What is interesting? Exploring the appraisal structure of interest. *Emotion*, *5*(1), 89–102. http://doi.org/10.1037/1528-3542.5.1.89

Smith, C. A., Dobbins, C. J., & Wallston, K. A. (1991). The mediational role of perceived competence in psychological adjustment to rheumatoid arthritis. *Journal of Applied Social Psychology*, *21*(15), 1218.

Smith, M. S., Wallston, K. A., & Smith, C. A. (1995). The development and validation of the perceived health competence scale. *Health Education Research*, *10*(1), 51–64. http://doi.org/10.1093/her/10.1.51

Soederberg Miller, L. M., & Bell, R. A. (2012). Online health information seeking: The influence of age, information trustworthiness and search challenges. *Journal of Aging and Health*, *24*(3), 525–541. http://doi.org/10.1177/0898264311428167

Standing committee on Health. (November 2016, 42nd Parliament, 1st session). "Interim report and recommendations on the opioid crisis in Canada." Ottawa, Canada: House of Commons, Canada.

Sweeny, K., Melnyk, D., Miller, W., & Shepperd, J. A. (2010). Information avoidance: Who, what, when and why. *Review of General Psychology*, *14*(4), 340–353. http://doi.org/10.1037/a0021288

Sweeny, K., & Miller, W. (2012). Predictors of information avoidance: When does ignorance seem most blissful? *Self and Identity*, *11*(2), 185–201. http://doi.org/10.1080/15298868.2010.520902

Sweeny, K., Shepperd, J. A., & Howell, J. L. (2012). Do as I say (not as I do): Inconsistency between behavior and values. *Basic and Applied Social Psychology*, *34*(2), 128. http://doi.org/10.1080/01973533.2012.655998

Thompson, E. R. (2007). Development and validation of an internationally reliable short-form of the positive and negative affect schedule (PANAS). *Journal of Cross-Cultural Psychology, 38*(2), 227-242. doi:10.1177/0022022106297301

Toffler, A. (1970). *Future shock*. New York: Random House.

Toms, E. G., O'Brien, H. L. O., Kopak, R., & Freund, L. (2005). Searching for relevance in the relevance of search. In *Context: Nature, impact, and role: COLIS 5: Proceedings of the Fifth International Conference Library and Information Sciences (Glasgow, UIK, June 5-8)* (pp. 59–78). Glasgow, UK.

Townsend, L., Hofer, A. R., Hanick, S. L., & Brunetti, K. (2016). Identifying threshold concepts for information literacy: A Delphi study. *Communications in Information Literacy, 10*(1), 23.

van den Broek, E. L., Glassey, R. J., van der Sluis, F., de Jong, F. M. G., & van Dijk, E. M. A. G. (2014). When complexity becomes interesting. *Journal of the American Society for Information Science and Technology*, *65*(7), 1478.

van Zuuren, F. J., de Groot, K. I., Mulder, N. L., & Muris, P. (1996). Coping with medical threat: An evaluation of the Threatening Medical Situations Inventory (TMSI). *Personality and Individual Differences*, *21*(1), 21–31. http://doi.org/10.1016/0191-8869(96)00029-3

van Zuuren, F., & Muris, P. (1993). Coping under experimental threat: Observable and cognitive correlates of dispositional Monitoring and Blunting. *European Journal of Personality*, 7245–7253.

Veinot, T. C. E. (2010). Power to the patient? A critical examination of patient empowerment discourses. In R. M. Harris, C. N. Wathen, & S. Wyatt (Eds.), *Configuring health consumers* (pp. 30–41). New York: Palgrave Macmillan.

Veinot, T. C. E., Kim, Y.-M., & Meadowbrooke, C. C. (2011). Health information behavior in families: Supportive or irritating. *Proceedings of the American Society for Information Science and Technology*, *48*(1), 1–10.

Wakefield, C. E., Homewood, J., Mahmut, M., Taylor, A., & Meiser, B. (2007). Usefulness of the Threatening Medical Situations Inventory in individuals considering genetic testing for cancer risk. *Patient Education and Counselling*, *69*(1), 29–38. http://doi.org/10.1016/j.pec.2007.07.001

Wallston, K. A., Maides, S., & Wallston, B. S. (1976). Health-related information seeking as a function of health-related locus of control and health value. *Journal of Research in Personality*, *10*, 215–222.

Ward, P. R., Coffey, C., & Meyer, S. (2015). Trust, choice and obligation: A qualitative study of enablers of colorectal cancer screening in south Australia. *Sociology of Health & Illness*, *37*(7), 988–1006. http://doi.org/10.1111/1467-9566.12280

Warner, D., & Procaccino, J. D. (2007). Women seeking health information: Distinguishing the web user. *Journal of Health Communication, 12*(8), 787-814. doi:10.1080/10810730701672090

Wathen, C. N., & Harris, R. M. (2007). "I try to take care of it myself": How rural women search for health information. *Qualitative Health Research*, *17*(5), 639–651. http://doi.org/10,1177/1049732307301236

Wathen, C. N., Wyatt, S., & Harris, R. M. (2008). Mediating health information: The go-betweens in a changing socio-technical landscape. In S. Wyatt, R. M. Harris, & C. N. Wathen (Eds.), *Go-Betweens: Health, Technology, and Info(r)mediation*. New York: Palgrave Macmillan.

Watson, D., Clark, L. A., & Tellegren, A. (1988). Development and validation of brief measures of positive and negative affect: The PANAS scales. *Journal of Personality and Social Psychology*, *54*(6), 1063–1070.

Weinstein, N. D. (1980). Unrealistic optimism about future life events. *Journal of Personality and Social Psychology*, *39*(5), 806–820. http://doi.org/10.1037/0022-3514.39.5.806

Weinstein, N. D. (1982). Unrealistic optimism about susceptibility to health problems. *Journal of Behavioral Medicine*, *5*(4), 441–460.

Weng, Y., Kuo, K. N., Yang, C., Lo, H., Shih, Y., & Chiu, Y. (2013). Information-searching behaviors of main and allied health professionals: A nation-wide survey in Taiwan. *Journal of Evaluation in Clinical Practice*, *19*(5), 902–908. http://doi.org/10.1111/j.1365-2753.2012.01871.x

Westerwick, A., Johnson, B. K., & Knobloch-Westerwick, S. (2016). Change your ways: Fostering health attitudes toward change through Selective Exposure to online health messages. *Health Communication*, 1–11. http://doi.org/10.1080/10410236.2016.1160319

Wilcox, S. (2010). Lay knowledge: The missing middle of the expertise debates. In R. M. Harris, C. N. Wathen, & S. Wyatt (Eds.), *Configuring health consumers* (pp. 41–64). New York: Palgrave Macmillan.

Williams-Piehota, P., Latimer, A. E., Katulak, N. A., Cox, A., Silvera, S. A. N., Mowad, L., & Salovey, P. (2009). Tailoring messages to individual differences in monitoring-Blunting styles to increase fruit and vegetable intake. *Journal of Nutrition Education and Behavior*, *41*(6), 398–406. http://doi.org/10.1016/jneb.2008.06.006

Wilson, T. D. (2000). Human information behavior. *Informing Science*, *3*(2), 49–55.

Wilson, T. D. (1999). Models of information behaviour research. *Journal of Documentation*, *55*(3), 249–270. http://doi.org/10.1108/EUM0000000007145

Wilson, T. D. (1994). Information needs and uses: Fifty years of progress? In B. C. Vickery (Ed.), *Fifty years of information progress: A Journal of Documentation review* (pp. 15–51). London: Aslib.

Wilson, T. D. (2010). Fifty years of information behaviour research. *Bulletin*, *36*(3), 27–34.

Wilson, T. D. (1997). Information behaviour: An interdisciplinary perspective. *Information Processing & Management*, *33*(4), 551–572.

Wright, N. (n.d.). Keep it jargon-free. Retrieved November 10, 2016, from www.plainlanguage.gov/howto/wordsuggestions/jargonfree.ctm

Wyatt, S., Harris, R. M., & Wathen, C. N. (2010). Health(y) citizenship: Technology, work, and narratives of responsibility. In S. Wyatt, R. M. Harris, & C. N. Wathen (Eds.), *Configuring health consumers*. New York: Palgrave Macmillan.

Yates, J., & Orlikowski, W. J. (1992). Genres of organizational communication: A structurational approach to studying communication and media. *The Academy of Management Review*, *17*(2), 299–326. http://doi.org/10.5465/AMR.1992.4279545

Yli-Uotila, T., Rantanen, A., & Suominen, T. (2013). Motives of cancer patients for using the Internet to seek social support. *European Journal of Cancer Care*, *22*(2), 261–271. http://doi.org/10.1111/ecc.12025

York, V. K., Brannon, L. A., & Miller, M. M. (2012). Increasing the efectiveness of messages promoting responsible undergraduate drinking: Tailoring to personality and matching to context. *Health Communication*, *27*(3), 302–309. http://doi.org/10.1080/10410236.2011.585450

Young, S. O., & Youngmin, C. (2015). Examining the relationships between resources and online health information seeking among patients with chronic diseases and healthy people. *Social Work in Health Care*, *54*(2), 83–100. http://doi.org/10.1080/00981389.2014.987940

Zhang, Y., Broussard, R., Ke, W., & Gong, X. (2014). Evaluation of a scatter/gather interface for supporting distinct health information search tasks. *Journal of the American Society for Information Science and Technology*, *65*(5), 1028–1041. http://doi.org/10.1002/asi.23011

Zurkowski, P. G. (1974). *The information service environment relationships and priorities*. Washington, D. C. National Commission on Libraries and Information Science.

Appendices

Appendix A: Questionnaire for Affect and Avoidance Study*

*Please note that this questionnaire has been reformatted from its online version for improved readability.

Participant demographics

The following questions ask you to give some basic information about your age, gender, and education level.

1. Gender

Please indicate your gender. Choose one of the following answers.

Male
Female
Other
No answer

2. Age

Please indicate your age group. Choose one of the following answers.

19-29
30-39
40-49
50-59
60-69
70+
No answer

3. Level of education

Please indicate your highest level of education. Choose one of the following answers.

Less than high school
High school
College diploma
Undergraduate degree
Master's degree
Doctorate degree
Other ____

No answer

Health demographics

The following questions ask you to give some basic information about your health.

4. General health

Please rate your general health. Choose one of the following answers.

Poor
Fair
Good
Very good
Excellent
No answer

5. General health comparison to last year

Please rate your general health as compared to last year at this time. Choose one of the following answers.

Much worse than one year ago
Somewhat worse than one year ago
About the same
Somewhat better than one year ago
Much better than one year ago
No answer

Knowledge of disease

The following question will test your knowledge of a disease.

6. Please indicate which of the answers best fits the question.

What is the definition of a disease?

a. An abnormal and debilitating condition of a part, organ, or system of an organism resulting from various causes
b. A condition leading to death or incapacitation
c. The relative incidence of conditions within a community
d. A condition in which felines experience discomfort

Information demographics Part I

The following question asks about your use of online information of various subjects. Choose from the answers below.

5. Please indicate how frequently you use the Internet to find information related to the following subjects.

   Health and wellness
   Research and studies
   Government information and services
   Personal interests and entertainment
   News and current events

Questions were rated on a 7-point Likert scale: Never, A few times per year, Monthly, A few times per month, Daily, A few times per day, No answer

Information demographics Part II

The following question will ask about how much you like to think. Please choose from the following answers.

7. The following scale asks you to rate the extent to which you agree with each of 18 statements about the satisfaction you gain from thinking. Sample statements include "I find satisfaction in deliberating hard and for long hours," "The notion of thinking abstractly is appealing to me," and "Thinking is not my idea of fun".

I prefer complex to simple problems.
I like to have the responsibility of handling a situation that requires a lot of thinking.
Thinking is not my idea of fun.
I would rather do something that requires little thought than something that is sure to challenge my thinking abilities.
I try to anticipate and avoid situations where there is a likely chance I will have to think in depth about something.
I find satisfaction in deliberating hard and for long hours.
I only think as hard as I have to.
I prefer to think about small daily projects to long term ones.
I like tasks that require little thought once I've learned them.
The idea of relying on thought to make my way to the top appeals to me.
I really enjoy a task that involves coming up with new solutions to problems.
Learning new ways to think doesn't excite me very much.

I prefer my life to be filled with puzzles I must solve.
The notion of thinking abstractly is appealing to me.
I would prefer a task that is intellectual, difficult, and important to one that is somewhat important but does not require much thought.
I feel relief rather than satisfaction after completing a task that requires a lot of mental effort.
It's enough for me that something gets the job done; I don't care how or why it works.
I usually end up deliberating about issues even when they do not affect me personally.

Questions were rated on a 5 point Likert scale: Extremely uncharacteristic of me, Somewhat uncharacteristic of me, Uncertain, Somewhat characteristic of me, Extremely characteristic of me, No answer

Emotional state

The following question will ask you questions about your current emotional state.
8. This question asks you how you feel right now. Please look at the emotion words and rate the extent to which this word applies to you in this moment.

Interested
Distressed
Excited
Upset
Strong
Guilty
Scared
Hostile
Enthusiastic
Proud
Irritable
Alert
Ashamed
Inspired
Nervous
Determined
Attentive
Jittery
Active
Afraid

Questions were rated on a 5 point Likert scale: Very slightly or not at all, A little, Moderately, Quite a bit, Extremely, No answer

Health condition knowledge

The following questions will test your knowledge of a health condition.

9. Have you heard of the condition _______________________?

acoustic neuroma, Bell's palsy, Crohn's disease, lupus, meningioma

____

10. What do you think of when you hear the words _______________________?

acoustic neuroma, Bell's palsy, Crohn's disease, lupus, meningioma

____

Health condition

The following question asks you to read a scenario involving a health condition.

11. Please read the scenario and answer the question below.

Your doctor tells you that you have an acoustic neuroma, a noncancerous tumour located in your ear and close to your brain. It has a number of side effects, the most common being hearing loss in the tumour ear; others include facial paralysis, loss of brain function, and even death. The tumour grows at a rate of 1.5mm/yr. Treatment options are observation, surgical removal or radiation.

Please indicate whether you have read the scenario.

Yes
No
No answer

Post-scenario emotional state

The following question will ask you about your current emotional state, after having looked at the information.

12. This question asks you how you feel after having looked at the scenario. Please look at the emotion words and rate the extent to which this word applies to you in this moment.

Interested
Distressed
Excited
Upset
Strong
Guilty
Scared
Hostile
Enthusiastic
Proud
Irritable
Alert
Ashamed
Inspired
Nervous
Determined
Attentive
Jittery
Active
Afraid

Questions were rated on a 5 point Likert scale: Very slightly or not at all, A little, Moderately, Quite a bit, Extremely, No answer

Likelihood of looking for information

The following questions will ask you how likely you are to look for information about the condition described in your scenario.

13. Please indicate how likely you would be to look for information regarding the condition from your scenario.

1 I would avoid information about this disease
2 I would not avoid information, but would not actively look for it
3 I would look for a small amount of information
4 I would look for a moderate amount of information
5 I would look for a great deal of information
6 I would look for as much information as I could find
No answer

14. Please comment.

____

____

Appendix B: Questionnaire for Interview and Interaction Study*

*Please note that this questionnaire has been reformatted from its online version for better readability.

Participant profile

The following questions ask you to give some basic information about your age, gender, and education level.

1. Gender

Please indicate your gender. Choose one of the following answers.

Male
Female
Other
No answer

2. Age

Please indicate your age group. Choose one of the following answers.

19-29
30-39
40-49
50-59
60-69
70+
No answer

3. Level of education

Please indicate your highest level of education. Choose one of the following answers.

Less than high school
High school
College diploma
Undergraduate degree
Master's degree
Doctorate degree
Other
No answer

Health profile

The following questions ask you to give some basic information about your health.

4. General health

Please rate your general health. Choose one of the following answers.

Poor
Fair
Good
Very good
Excellent
No answer

5. General health comparison to last year

Please rate your general health as compared to last year at this time. Choose one of the following answers.

Much worse than one year ago
Somewhat worse than one year ago
About the same
Somewhat better than one year ago
Much better than one year ago
No answer

Information profile—Part I

7. Please indicate how frequently you use the Internet to find information related to the following subjects.

Health and wellness
Research and studies
Government information and services
Personal interests and entertainment
News and current events

Questions were rated on a 7-point Likert scale: Never, A few times per year, Monthly, A few times per month, Daily, A few times per day, No answer

Information profile Part II

7. The following question will ask about how much you like to think. Please choose from the following answers.
The following scale asks you to rate the extent to which you agree with each of 18 statements about the satisfaction you gain from thinking. Sample statements include "I find satisfaction in deliberating hard and for long hours," "The notion of thinking abstractly is appealing to me," and "Thinking is not my idea of fun".

I prefer complex to simple problems.
I like to have the responsibility of handling a situation that requires a lot of thinking.
Thinking is not my idea of fun.
I would rather do something that requires little thought than something that is sure to challenge my thinking abilities.
I try to anticipate and avoid situations where there is a likely chance I will have to think in depth about something.
I find satisfaction in deliberating hard and for long hours.
I only think as hard as I have to.
I prefer to think about small daily projects to long term ones.
I like tasks that require little thought once I've learned them.
The idea of relying on thought to make my way to the top appeals to me.
I really enjoy a task that involves coming up with new solutions to problems.
Learning new ways to think doesn't excite me very much.
I prefer my life to be filled with puzzles I must solve.
The notion of thinking abstractly is appealing to me.
I would prefer a task that is intellectual, difficult, and important to one that is somewhat important but does not require much thought.
I feel relief rather than satisfaction after completing a task that requires a lot of mental effort.
It's enough for me that something gets the job done; I don't care how or why it works.
I usually end up deliberating about issues even when they do not affect me personally.

Questions were rated on a 5 point Likert scale: Extremely uncharacteristic of me, Somewhat uncharacteristic of me, Uncertain, Somewhat characteristic of me, Extremely characteristic of me, No answer

Information profile—Part III

8. The following question contains situations you may have found yourself in or you can imagine yourself in. Each situation is followed by several statements detailing thoughts, concerns, and action tendencies people may have in such a situation. Please try to imagine that you are in the situation described. Choose from the following answers to indicate for each statement to what degree it is applicable to you.

1. Imagine you have suffered from headaches and dizziness for some time already. You visit your doctor. He or she tells you things don't look good and refer you to a specialist for a rather trying medical exam.

I plan to ask the specialist as many questions as possible.
I think things will turn out to be all right.
I will get more information at other medical centers first.
For the time being, I try not to think of unpleasant outcomes.
I plan to start reading about headaches and dizziness.
I am not going to worry; such an examination is not as bad as suffering from headaches all the time.

2. Imagine you work hard and you are overweight. Your doctor has told you several times already that this is unwise. During a visit he or she observes hypertension.

I look on the apparatus too to ensure he or she is not mistaken.
I take things rather easy.
I decide to live on normally.
I ask my doctor extensively about the risks and consequences involved.
I tell myself, "Some ailments are worse than this one."
I plan to start reading a lot about hypertension.

3. Imagine you have heart complaints. Your specialist advises an operation. He tells you that you will have to wait four months for it and that it is not certain whether the operation will be effective.

I take the line that, in my case, the operation will be effective.
I decide to delve deeply into all that is known about heart surgery.
I decide to undertake as many pleasant and useful activities as possible for the next few months.

I am going to find out whether there is a chance that the operation will make things worse.
I decide to contact other patients with the same medical problem for information.
I tell myself, "Things will turn out all right."

4. Imagine that you visit your doctor with problems of the bowel that don't appear severe. He or she diagnoses acute appendicitis and tells you that you have to have an operation in the hospital as soon as possible.

I tell him or her I want to know precisely what they are going to do with me.
I decide to relax in the face of what is happening.
I ask and think about what can go wrong.
I take things easy.
I tell myself, "Things will turn out all right."
I immediately try to call somebody who will inform about this operation.

Questions were rated on a 5 point Likert scale: Not at all applicable to me, Not very much applicable to me, A tiny bit applicable to me, Rather applicable to me, Strongly applicable to me, No answer

Section Heading

Thank you for completing the first part of the survey. You will now be presented with a health scenario. Next you will have one more page to complete of the survey before progressing to the MedBrowser.

Post-information emotional state

9. This question asks you how you feel after having looked at the information. Please look at the emotion words and rate the extent to which this word applies to you in this moment.

Interested
Distressed
Excited
Upset
Strong
Irritable
Alert
Ashamed
Inspired
Nervous

Guilty
Scared
Hostile
Enthusiastic
Proud
Determined
Attentive
Jittery
Active
Afraid

Questions were rated on a 5 point Likert scale: Very slightly or not at all, A little, Moderately, Quite a bit, Extremely, No answer

Appendix C: Recruitment form for Interview and Interaction study

iSchool@UBC
SCHOOL OF LIBRARY, ARCHIVAL & INFORMATION STUDIES
a place of mind
THE UNIVERSITY OF BRITISH COLUMBIA

HELP US LEARN MORE ABOUT DR. GOOGLE

PARTICIPANTS NEEDED FOR HEALTH INFORMATION SEARCHING

We are looking for volunteers to take part in a study of health information searching.

You would be asked to: fill out demographic and other brief questionnaires
read text about health conditions
choose from a variety of health-related documents
participate in a brief interview about your choices

Your participation would involve 1 session.
Each session will be about 90 minutes long.

In appreciation for your time, you will receive
$20 cash or a Starbucks gift certificate.

For more information about this study, or to volunteer for this study, please contact:
Colleen Addison
School of Library, Archives and Information Studies
Email: [withheld for privacy]

This study has been reviewed by, and received ethics clearance by the Behavioural Research Ethics Board, UBC. Colleen Addison is working under the supervision of Dr. Luanne Freund.

Appendix D: Consent form for Interview and Interaction study

Hello and welcome to the study! Please read the following consent form carefully.

Consent form

Study Title: Interactions with online health information

Researcher and Title: Colleen Addison, MA, MLIS, PhD Candidate

[withheld for privacy]

[withheld for privacy]

Who is conducting this study?

Principal Investigator: Colleen Addison, MA, MLIS, PhD Candidate

Department and Institution: School of Library, Archives, and Information Science, University of British Columbia (UBC)

Contact email: [withheld for privacy]

Contact phone: [withheld for privacy]

Researcher's supervisor: Dr. Luanne Freund

Supervisor email: [withheld for privacy]

Supervisor phone: [withheld for privacy]

Colleen Addison works under the supervision of Dr. Luanne Freund. This research will serve as part of Ms. Addison's dissertation.

Why should you take part in this study?

I am doing this study to learn more about how patients interact with health information. I am inviting people like you from the general public to measure your reactions to health information documents, including videos, personal stories, and fact sheets. Your participation will help me discover how the reactions of patients to information are different or similar to healthy people.

How is the study done?

If you say 'yes,' here is how I will do the study:

At the beginning of the study I will ask you to fill out questionnaires about how you feel today and how you look for information. Next I will give you a task to read and complete, using documents that I will give you. Last, I will ask you about your reactions to the task and to the documents. The study will take about 90 minutes.

Do I have to participate in the study?

Participation in the study is voluntary. You may withdraw from this study at any time. You may also refuse to answer any of the questions if you so wish.

Will I be recorded?

Your answers to questions will be recorded and later written down for analysis.

How will the study be reported?

The results of this study will be reported in a graduate dissertation and may also be published in journal articles and books.

Is there any way being in this study could be bad for me?

You may experience some emotional discomfort in reading about health problems. Please let me know if you have any concerns.

What are the benefits of participating?

You may learn more about your reactions to health information.

Where is the survey data being kept?

Survey data is kept on a secure server in Canada.

Will my name be made public?

All the information you give me is kept confidential. No names will be attached to the information.

Will I be paid for my time?

You will receive an honorarium of $20 for participating.

Who can I contact if I have questions about the study?

If you have any questions or concerns about what you will do in the study, please contact me, Colleen Addison, at [withheld for privacy] or at [withheld for privacy].

Who can I contact if I have complaints or concerns about this study?

If you have any concerns or complains about your rights as a research participant and/or your experiences while participating in this study, contact the Research Participant Complaint Line in the UBC Office of Research Ethics at 604-822-8598 or if long distance email RSIL@ors.ubc.ca or call toll free 1-877-822-8598.

Participant Consent and Signature Page

Taking part in this study is entirely up to you. You have the right to refuse to participate in this study. If you decide to take part, you may choose to pull out of the study at any time without giving a reason and without any negative impact on you.

Your signature on the line below indicates that you have received a copy of this consent form for your records.

Sign: ____________________________ Date: ___________________________

Your signature on the line below indicates that you consent to participate in this study.

Sign: ____________________________ Date: ___________________________

Appendix E: Website material included in the MedBrowser for the Interview and Interaction study

Website material	**Explanation for choice**
Acoustic neuroma	
Blogs	
DAN: Diagnosis Acoustic Neuroma	Personal story, no medical jargon
Patients with acoustic neuromas benefit from physicians' experience and collaboration	Blog from association
Tumor: My journey with an acoustic neuroma: Treatment options	Personal story, no medical jargon
Tumor: My journey with an acoustic neuroma: Vestibular schwannoma/Acoustic neuroma	Personal story, no medical jargon
Journal articles	
Quality of life following Vestibular schwannoma surgery	Medical jargon
Vestibular schwannomas in the modern era	Medical jargon
News	
Study launched to discover origins of Acoustic neuromas	Informative, no medical jargon
Stunning news of a tumor serendipitously discovered	Personal story, no medical jargon
Tionne "T-Boz" Watkins fighting to stay alive	Celebrity, no medical jargon
Videos	
2.5 cm Acoustic neuroma post-op 10 days	Non-text format, personal story, no medical jargon, uncertain outcome
Acoustic neuroma association: What is an acoustic neuroma?	Non-text format, informative, no medical jargon
Acoustic neuroma: Healing path 2013	Non-text format, personal story, no medical jargon, certain outcome

Website material	**Explanation for choice**
Videos (cont'd)	
Operation of Acoustic neuroma (schwannoma): with a translabyrinthine approach	Non-text format, graphic, medical jargon
Webpages	
eMedicineHealth: Definition of an acoustic neuroma	Informative, no medical jargon
MedlinePlus: Acoustic neuroma	Informative, no medical jargon
MedScape: Acoustic neuroma	Informative, no medical jargon
Patient.co.uk: Acoustic neuromas	Informative, no medical jargon
Wikipedia: Vestibular schwannoma	Informative, no medical jargon
Bell's palsy	
Blogs	
Bell's palsy? Seriously? The inconsistent ramblings of a half-wit with a half-face	Personal story, uncertain outcome
Frozen: A Bell's palsy Diary: Day 3: Full paralysis	Personal story, uncertain outcome
Frozen: A Bell's palsy Diary: Day 52: One year on	Personal story, certain outcome
Journal articles	
Question from practice: Bell's palsy treatment and recovery	Medical jargon
Physical therapy: Bell's palsy	Medical jargon
News	
Drug combo helps Bell's palsy patient recover	
I couldn't smile at my newborn babies and felt my face scared them	Personal story
Steroids help unfreeze Bell's palsy	
Upside down: George Clooney says smile	Celebrity

Website material	**Explanation for choice**
Videos	
Bell’s palsy--Day 21--Erin’s story	Non-text format, personal story, uncertain outcome
Bell’s palsy recovery: How to tape your eye shut at night	Non-text format, presence of person
Botox treatment for Bell’s palsy	Non-text format, graphic
Surgical options for Bell’s palsy	Non-text format, presence of person
Transmastoid facial nerve decompression	Non-text format, graphic
Webpages	
eMedicineHealth: Definition of Bell’s palsy	Informative, no medical jargon
MedlinePlus: Bell’s palsy	Informative, no medical jargon
MedScape: Bells palsy	Informative, no medical jargon
Patient.co.uk: Facial nerve palsy	Informative, no medical jargon
Wikipedia: Bell’s palsy	Informative, no medical jargon
Crohn’s disease	Informative, no medical jargon
Blogs	
The bright side of Crohn’s	
Jenny’s guts blog	Personal story, uncertain outcome
Life, lemons, and lemonade: 5 reasons having an ileostomy is awesome	Personal story, certain outcome
Life, lemons, and lemonade: When fear and anxiety…	Personal story, uncertain outcome
We are all in this together	Blog from association
Journal articles	
Colonic adenocarcinoma revealing Crohn’s disease: a case report	Medical jargon
New Crohn’s disease treatment may result from “bodyguard protein” discovery	Medical jargon
News	
Pearl Jam guitarist shares his personal struggle with Crohn’s disease	Celebrity

Website material	**Explanation for choice**
News (cont'd)	
Woman, 23, wakes from surgery to discover she has an ileostomy bag…	Personal story
Videos	
I cured my Crohn's disease through simple dietary changes	Non-text format, personal story, certain outcome
Laparoscopic assisted ileocolic resection for Crohn's disease with psoas abscess	Non-text format, graphic
Minimally invasive surgery for Crohn's disease at the Mount Sinai hospital	Non-text format, graphic
Update and TIPS for living with an ileostomy	Non-text format, certain outcome
What is Crohn's disease?	Non-text format, video from association
Webpages	
eMedicineHealth: Definition of Crohn's disease	Informative, no medical jargon
MedlinePlus: Crohn's disease	Informative, no medical jargon
MedScape: Crohn's disease	Informative, no medical jargon
Patient.co.uk: Crohn's disease	Informative, no medical jargon
Wikipedia: Crohn's disease	Informative, no medical jargon
Meningioma	
Blogs	
3rd tumor-versary	Personal story, certain outcome
My benign meningioma	Personal story, uncertain outcome
My seizure, finding the meningioma, and my brain tumor surgery (part I)	Personal story, uncertain outcome
Journal articles	
Interparenchymal papillary meningioma of brainstem	Medical jargon
Primary extra-cranial meningioma in the right submandibular region of an 18 year old woman	Medical jargon

Website material	**Explanation for choice**
News	
Brain storm: Five years ago Tom Bible was diagnosed	Personal story, certain outcome
Meningioma: A tumor on the edge of the brain	Informative
Sheryl Crow's brain tumor: What is a meningioma?	Celebrity
Videos	
24 hours post-op for de-bulking of my meningioma	Non-text format, uncertain outcome
Brain surgery removal of a metastatic tumor high power surgical microscope	Non-text format, graphic
Leonard Cerullo, MD, discusses meningiomas	Non-text format, presence of person
Meningioma: 10 days after surgery	Non-text format, uncertain outcome
Microsurgical resection of giant intraventricular meningioma	Non-text format, graphic
Webpages	
eMedicineHealth: Definition of meningiomas	Informative, no medical jargon
MedlinePlus: Brain tumor—primary—adults	Informative, no medical jargon
MedScape: Optic nerve sheath meningioma	Informative, no medical jargon
Patient.co.uk: Meningiomas	Informative, no medical jargon
Wikipedia: Meningioma	Informative, no medical jargon

Appendix F: Interview and Interaction study interview questions

Thank you for completing the first online portion of this study. Now I'd like to ask you a few questions about the information you just looked at. I will be audio recording this interview.

What did you think of the documents you looked at? Why did you choose these documents?

Prompts:

- What features affected why you looked at it?
- What was it about this document that first caught your attention?

If the situation you read about was a real life situation, to what extent would the documents you looked at help you deal emotionally? For example, would they make the situation seem much worse, a little worse, a little better, or much better?

Prompts:

- Were there any features of the documents that made you feel better or worse? The inclusion of information from other patients with the same condition, for example? Or the inclusion of information from doctors or other healthcare professionals?
- Were there any particular formats you liked over others? Why do you think you felt this way?

If the situation you read about was a real life situation, how much time would you spend reading online about this disease? For example, would you spent a lot more time, about the same amount of time, or a lot less time?

Prompts:

- Would you like more information or less?
- Were there any formats you liked more than others? Why do you think you felt this way?

Now I would like to ask you some questions about the project in general. What this project aims to discover is the way in which people interact with online health information. For example, if you get a mole on your arm and you want to check online to see if this is dangerous. You might see a scary picture or read a scary article and panic and think it's something very dangerous. What this project aims to find out is what it is about the information you see online that makes you panic. And additionally, what makes some people panic and turn off their computer and some people panic and keep looking forever and ever.

I am interested in hearing about any times you have been concerned about your health. If you are comfortable talking about it, can you describe what happened?
How did you feel emotionally when faced with this problem?
How did you go about searching for information with regards to these problems? If you did not search for information, what caused you not to do this?
For example, did you search online, did you talk to healthcare professionals, did you read books, or talk to friends?
(If they did search for information) How did searching for information make you feel? For example did finding out more about the issue make you feel more or less comfortable or in control of the situation?
(if they did not search for information) How did not searching for information make you feel? Was there any activity you did instead?
Can you think of any other instances that we haven't touched on in which you yourself have avoided information? Is this something you do or you have seen in friends or family members?

Appendix G: Code rationale for interview data in Interview and Interaction study

1. Affect Refers to affective reactions experienced by participants or acquaintances of participants

Code no.	Code	Definition	Example
A	Anticipated affect	Refers to affect that is not yet felt, but is anticipated as a result of looking at some information source	Do you think, for searching for regular information, it depends on how you feel? …R Yeah, I think so… But it could be either being upset or ..maybe being upset and wanting to make myself feel more upset if I was depressed or something. (P8)

1A. Negative affect Refers to negative affective reactions experienced by participants or acquaintances

Code no.	Code	Definition	Example
A	Disinterest	Refers to 'disinterest' as an affective reaction experienced by participants or acquaintances	I wasn't super interested. I'm not really interested. (P13)
B	Dislike of viewing surgery	Refers to participants' dislike of/avoidance of videos depicting surgical operations Also refers to participants' who did NOT dislike videos.	And I definitely wouldn't watch anything on Mt Sinai. They got pictures of operations. And I'd throw up. (P12)

Code no.	Code	Definition	Example
C	Distrust	Refers to 'distrust' as an affective reaction experienced by participants or acquaintances	That one, as soon as it starts talking about physicians and collaboration, it feeds my distrust of doctors. (P2)
D	Doubt	Refers to 'doubt' as an affective reaction experienced by participants or acquaintances	I didn't really believe there was a way to cure it. (P32)
E	Fear	Refers to 'fear' as an affective reaction experienced by participants or acquaintances	I do hear about people; they're afraid of knowing what they have. (P34)
E	Guilt	Refers to 'guilt' as an affective reaction experienced by participants or acquaintances, usually in relation to wellness/health information	Then I feel more guilty, and then maybe a day or a week, I try the whatever is a better choice, but then it fades off. (P25)
F	Information overload	Refers to 'information overload' as an affective reaction experienced by participants or acquaintances	I think sensory and information overload: you just get overwhelmed by the information. (P13)
G	Lack of control	Refers to 'lack of control' as an affective reaction experienced by participants or acquaintances	I felt like I had no control. When you have no control, the little bits of you have start[ed] to fade after a while. (P17)

Code no.	Code	Definition	Example
H	Worry	Refers to ‘worry’ as an affective reaction experienced by participants or acquaintances	Physically, I’m not worried about somebody cutting my skull open. (P13)

1B. Positive affect	Refers to positive affective reactions experienced by participants or acquaintances

Code no.	Code	Definition	Example
A	Control	Refers to ‘control’ as an affective reaction experienced by participants or acquaintances	I think it would make you feel better. Because you have more information. And you have more knowledge. And knowledge is power. (P21)
B	Hope	Refers to ‘hope’ as an affective reaction experienced by participants or acquaintances	I if you looked at The New Crohn’s Disease, would that make you feel better? R Well, of course. Nothing is hopeless. We must hope for everything. (P12)
C	Interest	Refers to ‘interest’ as an affective reaction experienced by participants or acquaintances	I’d want to know what the bright side was. I’d be curious and interested. (P12)
D	Reassurance	Refers to ‘reassurance’ as an affective reaction experienced by participants or acquaintances	I think with the emotion, the knowledge gives me a sense of I wouldn’t say calm but just more informed so I’m not freaking out for no reason. (P18)

Code no.	Code	Definition	Example
E	Relief	Refers to 'relief' as an affective reaction experienced by participants or acquaintances	I was really glad to have a diagnosis because I really wasn't feeling well, …and you get kind of weird symptoms; my skin was really dry. (P22)
F	Sympathy	Refers to 'sympathy' as an affective reaction experienced by participants or acquaintances	What did you think of the document that you looked at – The Frozen Bells Palsy Diary, Day Three. R I felt very sorry for the person. Yes, because nobody should have to go through that. (P17)
G	Trust	Refers to 'trust' as an affective reaction experienced by participants or acquaintances	I go to Wikipedia quite a lot. I think I've even subscribed to them. And I trust most of what they have to say. (P2)

2. Content Refers to the content of the information sought by participants

Code no.	Code	Definition	Example
A	Cause	Refers to the cause of the condition	Once I'd figured out what the cause was, if there is a cause. Once you figure out the cause, then what's the effect? (P12)
B	Definition	Refers to the definition of the condition	I'm looking for the description of a meningioma, in general. Definition. (P34)
C	Diagnosis	Refers to the diagnosis of the condition, often self-diagnosis by the participant or a check of the diagnosis from the healthcare professional of the condition	I went from self-informing, self-diagnose and I took it to the doctor; I go I think I'm depressed. (P18)

Code no.	Code	Definition	Example
D	History	Refers to the history of the condition	Because I don't really know very much about it. I read definitions, and then frequency in the population, and even a little bit about the history. (P22)
E	Life information	Refers to life information of the condition: how is a patient's life now? What can I expect in my life if I have this condition?	What I was really interested in, which was how is your life now? Physically. (P13)
F	Prevention	Refers to prevention of the condition	Are you going to look for how it could have been avoided? R I might do that (laughs). (P16)
G	Prognosis	Refers to the prognosis of the condition	What kinds of things would you like to know on a daily basis? R How the symptom will progress. (P34)
H	Severity	Refers to the severity of the condition	I might look into what it is about – that's why I clicked the visual thing and see how severe it is. (P32)
I	Symptoms	Refers to symptoms of the condition	What do you think about the blogs? R It would be interesting to knowing what – 'cause people really keep the diaries of their other symptoms, and what they've experienced. (P34)
J	Treatment	Refers to treatment of the condition	Because I want to know about treatment; I don't want to know about somebody else's problem. (P12)

3. Coping Refers to coping strategies on the part of participants

3A. Managing emotions Refers to strategies on the part of participants for managing emotions

Code no.	Code	Definition	Example
A	Avoidance of regret	Refers to avoidance of regret of past (medical) experiences	It's an event that I've moved past; not that I'm going to celebrate every year (laughs).(P4)
B	Self-regulation	Refers to curtailing of information seeking	Because by the time you read so much medical stuff, sometimes you get freaked out because you have all this conspiracy theories that everything will keep getting worse so sometimes, the less you read about the fine prints, the better. (P19)
Subcode A	Preference for easy information	Refers to searching only or predominantly for 'easy' information	So I will go to this drug combo health. I will go into those ones. They're easy. (P11)

3B. Planning and preparation Refers to strategies for searching for solutions to problems

Code no.	Code	Definition	Example
A	Planning and preparation	Refers to searching (extensively) for the purposes of 'planning'	'Cause I really need a good breadth of information. Basically, what's out there. Basically, you know, trying to find useful ways to help me cope with this condition. (P34)

4. Holistic Refers to 'holistic' or alternative medicine, anything not considered traditional or allopathic medicine

Code no.	Code	Definition	Example
A	Types of holistic information	Refers to any mention of specific alternative medicine, in an effort to determine what participants thought of as alternative medicine	What do you mean by Eastern? P: There's herbal. (P13)
B	Ambivalent about use of holistic	Refers to participants' use of alternative medicine—that they would 'maybe' use this medicine	For holistic information? I generally have heard some good things about that, but…it wouldn't be my number one that I would pick. (P34)
C	Negative about use of holistic	Refers to participants' use of alternative medicine—that they would 'not' use this medicine	A lot of people that I've interviewed have said they looked for holistic information, like acupuncture and all that kind of stuff. Did you do that? P: No, I did not do that. (P11)
D	Holistic as a whole body experience	Refers to one reason that participants would use alternative medicine: that it would provide a 'whole body experience.'	I'd want to treat myself as not a part. This is your brain; we're gonna cut it open and take off this piece, and you're gonna be better. I want a whole body experience. (P4)
E	Positive about use of holistic	Refers to participants' use of alternative medicine—that they would 'definitely ' or 'probably' use this medicine	I would search on the keyword, and then I would first start with esoteric or alternative meaning. (P2)

Code no.	Code	Definition	Example
5	**Information avoidance**	Refers to instances of information avoidance on the part of participants or their friends/relatives	So what I'm trying to do is look at how people Google and then get frightened and then stop looking altogether. So first, have you ever had that experience or do you know anyone who does that? P: He's an acquaintance, not a close friend. (P23)

Code no.	Code	Definition	Example
6	**Information seeking**	Refers to instances of information seeking on the part of participants or their friends/relatives	You mentioned you're HIV positive – do you look for information about that? R Initially, I did. Of course, initially I did. I wanted to know. (P20)

Code no.	Code	Definition	Example
7	**Medical horror stories**	Refers to medical experiences which participants describe as difficult or traumatic	I have scoliosis. When I was younger, doctors wanted to put in that bolt thingy to help straighten my spine. (P17)

8 **Medical problem** Refers to specific medical problems that participants had experienced or thought they had experienced

Code no.	Code	Definition	Example
A	Medical students' problem	Refers to medical problems that participants diagnosed themselves with as a result of information seeking.	I talked to my boyfriend about it, and he was like, 'Well, it doesn't make sense to get worked up about this until you see a doctor about it,' but I did, and it was nothing (laughs). (P28)
B	Severity-impact	Refers to instances when participants describe how severe or impactful their medical problem was	Have I ever had anything really wrong with me? No. The paralysis in the jungle was pretty scary, but I didn't go. (P13)
C	Specific conditions	Refers to instances when participants describe which conditions they had	I get diagnosed with my HIV. (P11)
D	Stigma	Refers to instances when participants describe experiences regarding their medical condition where societal stigma was demonstrated	There's a stigma. Who can you tell? How would they react? Will they reject you? (P16)
E	Uniqueness	Refers to instances where participants describe how unique or different than others their medical problem was	I did do some research but I couldn't find anything. Well, you know, snapping noise in gut while doing yoga. Not too many people experience that, so there wasn't much on that. It was a hard search. (P2)

9 **Search behaviour** Refers to instances where participants describe aspects of their search behaviour

Code no.	Code	Definition	Example
A	Order	Refers to instances where participants describe the order in which they searched for information	I'd figured out what the cause was, if there is a cause. Once you figure out the cause, then what's the effect? And then, how do I fix it? Where's my pill? Where's my scrip? (P12)
B	Process	Refers to instances where participants described the process by which they searched for information	But supplemented with far more reading after the initial bloggy stuff; I'd delve more deeply. To news articles, and journals and more scientific and objective information. (P13)
Subcode A	Pearl growing	Refers to instances where participants described pearl growing techniques, where they learned a little at a time from each piece of information they looked at	When I was reading it, they were talking about the eye. So that's why maybe it was my immediate, how to tape your eye. (P11)
Subcode B	Satisficing	Refers to instances where participants described sufficing, where they searched to the point where they had enough	That's the way I looked at what I did, and then that's why I would have walked away at the point at which I did, and said, 'Let's do it!' (laughs). (P20)
C	Time	Refers to instances where participants described how much time they searched for	I would spend up to forever. (P12)

10 Selection Refers to instances where participants mention reasons that may influence choice of searching for or avoiding information

10A Features of information Refers to features of information that participants cited as reasons for choosing/not choosing

Code no.	Code	Definition	Example
A	Anticipated good or bad affective reaction	Refers to affective reactions that participants anticipated having as a result of looking at information	The videos? I don't want to see photography of someone's troubled anus. (P23)
B	Authority	Refers to the authority of the information	And this, of course, looked official. Yes it did. Because it didn't have any cutesy things like this. (P12)
C	Confirmation bias	Refers to information that may/may not confirm with already cited beliefs	Because when I go search for online, I'm already primed of what I want to see so I just go online to validate what I want to see. (laughs) (P25)
D	Convenience	Refers to information that is easy to hand, convenient	You don't like the Internet very much? P: I use it all the time. Just picking up the phone is very easy. (P35)
E	Currency	Refers to information that is current	So that's usually why I like the news; it's current. (P18)
F	Design features	Refers to design features of information, particularly of websites, i.e., layout	It's just the layout of the page. Anything like this here, looks like it's got ads. Some of them have pictures on them. (P12)

Code no.	Code	Definition	Example
G	Direct experience	Refers to features of information that indicated that the originator had direct experience with the medical condition being described	I probably wouldn't ask any except if they have the medical background. A doctor, or they have somebody close to them that have experienced the disease before. (P18)
H	Ease of use	Refers to how easy information is to use	while I'm visual; I learn visually; I learn a lot faster visually if it's words than pictures. (P27)
I	Entertaining	Refers to information that has entertainment value, is fun to read	I look upon the videos as entertainment value. (P15)
J	Interest	Refers to information that is interesting	And this one, I don't know, I was very interested for me to, because I'm very narcissist. (P11)
K	Level of detail	Refers to information that is either detailed or not detailed	So often they're into jargon, and medical. I have a doctor that I talk honestly, but I talk in pure layman's terms. (P15)
L	Origin	Refers to information that has a specific place of origin	Because the Internet only tells you so much, so like oo, Washington, you can go to this place for this, but the reality is that I'm still in Vancouver. (P18)
M	Personal relevance and similarity	Refers to information that is about some person/persons that are similar/dissimilar to the participant	if I was in the situation where I was afflicted by it for a certain length of time, I would probably feel more connected to that person and would want to know more. (P21)
N	Popularity	Refers to information that is in some way 'popular'	I find the Internet is full of Internet celebrities…self made experts. There's just a few people who I'll go and look at their blogs or their sites. (P4)

Code no.	Code	Definition	Example
O	Positive information	Refers to information that generates positive affect	Why did you click on this document? You said you found it interesting. R Because I like looking on the bright side and being positive. (P12)
P	Presence of celebrity	Refers to information that contains mention of a celebrity	I know the name Pearl Jam, but I don't really know the actual musicians so, I just thought, oh, this looks interesting – the celebrity. Just always interested in celebrity things (laughs). Out of interest. (P16)
Q	Sensational	Refers to information that generates a sensational response	Where did you hear about these side effects? R News, those sensational stories. Researching it specifically online for side effects of certain types of medication. Anecdotal stories – again, that's all on the Internet too in forums (laughs). (P28)

10B Genre Refers to features of information related to the genre of the information, which can be the reason for selection/avoidance

Code no.	Code	Definition	Example
A	Blogs	Refers to specific mention of blogs	Because when I look at these blogs, I think it's very interesting to see people's personal journeys. (P13)

Code no.	Code	Definition	Example
Subcode a	Authority	Refers to mention of authority in connection with blogs	And it might steer, in some ways it might lead my appraisal of what the various treatments for the condition, which routes I might like to go vis-à-vis the different treatments, based on the blogger's experience. (P13)
Subcode b	Lack of authority	Refers to mention of lack of authority in connection with blogs	It's more of a person's information, what they put on their blog, their ideas and opinions, so I don't really see it as an informational resource (P34)
Subcode c	Positive experience	Refers to mention of a positive experience in connection with looking at blogs	So, you looked at Life, Lemons and Lemonade 'cause you said you wanted something positive. R Just something that looked fun. (P16)

Code no.	Code	Definition	Example
B	Community board	Refers to mention of community boards	As opposed to just finding some sort of community board or blog where this is what they think and it's just an opinion…also drastic sides clashing. (P4)

Code no.	Code	Definition	Example
C	Discussion forums	Refers to mention of discussion forums	A lot of times, when I'm searching for information about medical conditions or illnesses, a lot of times I go to discussion forums. I find they're good, because some of those discussion forums seem like good resources for medical conditions. (P26)

Code no.	Code	Definition	Example
D	Journal articles	Refers to mention of journal articles	So you also looked at the journal article, Physical Therapy, Bells Palsy. R I thought they might have another angle to it. (P15)
Subcode a	Appropriateness of level	Refers to mention of appropriate or inappropriate levels of detail in connection with journal articles	What about… the journals? R …I talk about shit as shit. (P15)
Subcode b	Authority	Refers to mention of authority in connection with journal articles	So you also looked at this journal article, this Vestibular Schwannoma in the modern era? P: I thought it would offer a statistical finding, a big population, what their methodology for the remedy was. An outcome, …a bell curve. (P20)
Subcode c	Bias	Refers to mention of bias in connection with journal articles	I don't doubt the research, but I also know that research can be directed by pharmaceuticals. (P20)
Subcode d	Interest or lack thereof	Refers to mention of interest or lack thereof in connection with reading/otherwise consulting journal articles	I have a degree so I know you kind of have to depend on journal articles for a paper and stuff. I don't usually go for those when it comes to medical disease because it's too dry [laughs]. (P18)

Code no.	Code	Definition	Example
E	News	Refers to mention of news articles	News? I find news cursory. The little seven second blur – it might not be – but my perception of news is that it's not as in depth. (P24)

Code no.	Code	Definition	Example
Subcode a	Authority	Refers to mention of authority in connection with news articles	I was turned off when I hear the names of celebrities or like this other one, ‘couldn’t smile at my newborn baby’ ‘cause it just seemed like it was more tabloidish almost. (P6)
Subcode b	Bias	Refers to mention of bias in connection with news articles	For news, of course it’s already influenced by the media so I don’t trust them either. (P25)
Subcode c	Positive experience	Refers to the positive experience of reading/otherwise interacting with news articles	It helps to feel I’m not alone in something, and to get a sense that other people deal with this too. (P28)
Code no.	Code	Definition	Example
F	Videos	Refers to mention of videos	So that’s why I chose that video. I guess my approach is kind of high scatter, low penetration at the beginning. (P13)
Subcode a	Authority	Refers to authority in connection with videos	Looking at the source, but this was not done in a illegal clinic. Probably was done in a clinic that’s approved or licensed by the government. (P27)
Subcode b	Brevity and clarity	Refers to the mention of brevity and clarity in connection with videos	I liked that one (laughs). More of coming back to that simplified explanation like she had, the picture and the words, tying things together. More concise. (P16)
Subcode c	Positive experience	Refers to the positive experience of reading/otherwise interacting with videos	I like ‘healing path’ – just like I didn’t like the [gamma] knife. Why would they call this thing ‘the knife’? It’s so aggressive, where this sounds to me, gentler and positive. It’s healing. (P24)

Code no.	Code	Definition	Example
G	Websites	Refers to mention of websites	That's right because people actually put comments there as well. So, you can read their comments on the web page. (P17)
Subcode a	Authority	Refers to mention of authority in websites	so you looked at emedicine health, and Medscape and Medline Plus? P: Yeah. They seemed more academic. Based on the name. I was looking at a variation of PubMed. (P9)
Subcode b	Brevity and clarity	Refers to mention of brevity and clarity in connection with websites	I think the initial impact of the web page should be simple, direct and clear. (P24)
Subcode c	Familiarity	Refers to familiarity in connection with websites	I'm so aware of Wikipedia's layout, and it seems to me to be so efficient, that I trust it more, the more I go there. (P15)
Subcode d	Lack of authority—suspect motives	Refers to lack of authority in connection with websites	Why the Cochrane Review? P: One of the reasons [is] There's no conflict of interest. People there are all volunteers. They don't get any money. (P35)

10C. People Refers to mention of the choice of people as information sources

Code no.	Code	Definition	Example
A	Doctor-healthcare professional	Refers to mention of doctor-healthcare professionals	I would definitely go to a doctor. I'm not a very good friend of doctors and hospitals but if something is serious, life threatening, I would call 911. (P19)

Code no.	Code	Definition	Example
Subcode a	Doctor as authority	Refers to mention of doctors as authority figures	So who guided you? The doctor? P: The doctor, my doctor, my doctor. He got to help. (P11)
	Conversation with doctor	Refers to conversations that occurred with healthcare professionals (usually doctors)	I have a personal contact with my doctor and I have all my questions ready. (P15)
	Friend as authority	Refers to friends of participants who functioned as medical authorities	And you also went to, to talk to a friend as well? P: Well, she’s a yoga teacher. So yeah, I went to ask her for advice. (P2)

Code no.	Code	Definition	Example
Subcode b	Problems with doctors, medical system	Refers to problems that participants had with doctors or medical systems or actions taken as a result of these problems	'Cause I like to find where the doctors aren't telling people. Because I like to tell the doctor to smarten up (laughs). (P17)
	Conflict between doctors	Refers to one specific problem: the failure, as participants saw it, for doctors to present uniform opinions	So that's why I said I don't always take right away what the doctor says as the only option, because you go see a different doctor, they'll tell you something different, and yet they're both trained the same. (P21)
	Doctors have inadequate information	Refers to one specific problem related to doctors: the failure, as participants saw it, for doctors to present or possess adequate information	I find it's everybody's responsibility to do that. I've seen many doctors in my life and doctors only do trial and error. (P21)
	Doctors have no life info	Refers to one specific problem related to doctors having inadequate information: the failure, as participants saw it, for doctors to possess information about 'daily life' with a disease	And why do you go to an association; why not a doctor? P: I would go to a doctor, but usually the doctor they can't provide resource. (P18)
	Doctors are not updated	Refers to one specific problem related to doctors having inadequate information: the failure, as participants saw it, for doctors to possess current or updated information	On the whole, I do trust my doctor, but sometimes I do get the feeling that they can be pretty busy, and they're not kept up to date with current events, and the current health information. (P34)

Code	Definition	Example
Doctors have suspect motives	Refers to one specific problem with doctors: the tendency, as participants saw it, for doctors to have motives other than making people healthy for procedures/prescriptions	Sometimes they have a vested interest in doing more operations than others so, I'm not immediately gonna just think he's God, and I should just trust. (P29)

Code no.	Code	Definition	Example
B	Patients	Refers to mention of other patients as sources of information	Because when I look at these blogs, I think it's very interesting to see people's personal journeys. (P13)
Subcode a	Authority	Refers to mention of authority in connection with patients as sources of information	I went on YouTube to talk to people who'd done it because that's really interesting. How do you spend all your…? How do you eat? How do you eat? How do you walk to the bathroom? All of those questions. (P29)
Subcode b	Emotional support	Refers to mention of emotional support in connection with other patients as sources of information	Other people have it too, so we're like a group; we can share all our thoughts, and then, we can just share our tips. (P32)
Subcode c	Lack of authority	Refers to mention of lack of authority in connection with other patients as sources of information	It's anecdotal. Maybe later but I just got through seeing a specialist. And so maybe later I'll find out what Mary Smith does. But not right now. (P23)
Subcode d	Relevance and similarity	Refers to mention of relevance and similarity in connection with other patients as sources of information	I don't care what somebody else did. It's not gonna be the same. Nobody's pregnancy is the same. Nobody's eczema is the same, nobody's heartburn is the same. (P12)

Code no.	Code	Definition	Example
Subcode e	Survival	Refers to mention of survival in connection with patients as sources of information	If I could clarify; you're looking for people personal stories, but you want the beginning to the end. You don't want the middle.... P: ...I do. (P13)

11 **Social** Refers to instances of mention by participants of social/societal motives for searching or avoiding information

Code no.	Code	Definition	Example
A	Connection with others	Refers to mention of connection with others in association with information seeking or avoiding	so you went to a lot of discussion forums? P That's correct, yes. I felt I was isolated when I was in the States, you know. I didn't have that many friends and I went to these people. (P27)
B	Education of friends and family	Refers to mention of education of friends and family in association with information seeking or avoiding	But if my friends knows about it, they're able to help me; no, [name], you're coming out today. (P18)
C	Independence	Refers to mention of independence in association with information seeking or avoidance	I got to my friends, actually, just * for company but I don't go for knowledge. My imagination is that I have what I need up there. (P15)
D	Maintenance of social norms	Refers to mention of 'maintenance of social norms', i.e., friendship norms, in association with information seeking or avoidance	I think it's something private. I wouldn't ask somebody. That's just not me. Maybe people just don't want to talk about it… and maybe it's upsetting. (P16)

Code no.	Code	Definition	Example
E	Support from family, friends, etc.	Refers to mention of support from family and friends in association with information seeking or avoidance	Once I can talk my problem over with somebody, then that's it. It's as good as done. (P19)

12 **Social achievements** Refers to mention of social achievements in association with information seeking or avoidance

Code no.	Code	Definition	Example
A	Abuse of system	Refers to mention of abuses (in the words of the participants) of the medical system	I think a lot of people are so quick to run. Every little problem. Think of the billions of dollars of health care costs that are spent on things that are completely unnecessary. (P13)
B	Digital divide	Refers to mention of the digital divide	So I did not have much education about the computer, first of all. I don't have a computer at home. (P11)
C	Gender	Refers to mention of gender as a reason for information seeking/avoidance	Men are like that, though. Men are in denial about illness because illness is a feminine; it's not a masculine thing. That's why he would look up fitness. (P21)

Code no.	Code	Definition	Example
D	Information seeking	Refers to information seeking in association with social achievements	A sense of controlling my own health and directing my own health, and making my own choices, and keeping myself informed is a healthy way to be that will lead to a better health outcome. (P20)

Code no.	Code	Definition	Example
Subcode a	Becoming authority	Refers to the process of becoming an authority on the part of the participant	So there wasn't a page; I don't know maybe I should write a page. Maybe people do experience that a lot. (P2)
Subcode b	Contrasts to proper information seeking	Refers to contrasts between the information seeking of the participant and that of others the participants know/have heard of	But, to be honest, a word of mouth is not so valuable to me as Wikipedia because people, a lot of them, they seem to take the easy route – take the pill – without 'This pill is gonna kill me' – that seems to be their attitude. (P15)
Subcode c	Skill at information seeking	Refers to mention of skill in information seeking on the part of the participant	When you search for keywords, you know what to enter to get a better search result. (P25)
Subcode d	Use of information seeking to maintain health	Refers to use of information seeking to maintain the participants' health	But I do find out things that will help me to better my lifestyle even more. (P34)

Code no.	Code	Definition	Example
E	Mental strength	Refers to mental strength on the part of the participant	I value my own decisions about my body quite a bit (P15)
F	Overcoming the stigma	Refers to mention of overcoming any stigma associated with the participants' medical problems	At first, my paediatrician and my family doctor would think I'm a little crazy, but that 's okay, but it's like I started presenting them with certain information, and they started being more accepting with certain things I want to do. (P4)

Code no.	Code	Definition	Example
G	Self-efficacy	Refers to mention of being able to heal oneself from any medical problem	So a lot of times I feel like you're overprescribing; this person doesn't need anything; a lot of times the body heals itself. (P13)

Code no.	Code	Definition	Example
H	Taking care of self	Refers to moments when participants talk about taking care of themselves in connection with information seeking/avoidance	But once again, the information that I looked at was not scary; I was just seeking it out; it was something that I was doing preventatively. (P3)
Subcode a	Going to the doctor	Refers to going to appointments with doctors and other healthcare professionals	What kind of things would you go to the doctor for? P To the doctor? Maybe for regular examinations. Like paps, physical exam, or vaccinations. (P34)
Subcode b	Good health	Refers to mention of 'good health' on the part of participants	Do you feel like you work on your health? P I do put some effort into it, work on it, in that I'm always either interested in topics that are my issues, or interested in topics that are of the population. (P30)
Subcode c	Maintain health	Refers to mention of health maintenance of the part of participants	For the past month, I haven't been able to swim. Swimming is part of my staying healthy strategy. (P8)

13 **Sources** Refers to mention of an information source

Code no.	Code	Definition	Example
A	Book	Refers to mention of 'book' or 'books' as an information source	I still have some books. I do still like to own books. I still buy books. (P22)
B	Community organization	Refers to mention 'community organization' or 'organizations' as an information source	I started with Open Door, so they do the recreational therapy, so I did Dragon Boat with them, and because it's funded through Coastal Health, so I don't have to pay. (P18)

Code no.	Code	Definition	Example
C	Internet	Refers to mention of 'the Internet' or something similar as an information source	And the Internet has really opened the door for people that do that because you don't just get the information that your doctor's telling you, but you can access way more information than what the doctor tells you. (P17)
Subcode a	Blogs	Refers to mention of 'blog' or 'blogs' as an information source	Getting back to the information you looked at; you looked at lots; you looked at blogs; you looked at news; you looked at websites. P: I don't want to miss any interesting thing. (P35)
Subcode b	Forums	Refers to mention of 'forum' or 'forums' as an information source	Anecdotal stories – again, that's all on the Internet too in forums (laughs). (P28)
Subcode c	Journals	Refers to mention of 'journal,' 'journal article' or 'articles' as an information source	I didn't do the journal articles because I know in the past, they're so long that I feel it's not a good starting point. (P3)

Code no.	Code	Definition	Example
Subcode d	News	Refers to mention of 'the news' as an information source	And after that, you went down, and you looked at the news. …Why did you go to that one? P I know the name Pearl Jam, but I don't really know the actual musicians. (P16)
Subcode e	Videos	Refers to mention of 'video' or 'videos' as an information source	You looked at Surgical Options for Bells Palsy…. P I was trying to figure out exactly what it meant by 'surgical options' because you're dealing with the face here. (P19)
	Youtube	Refers to mention of 'Youtube' as an information source	if I want to, on my own, learn about Bells Palsy, Wikipedia and the YouTube is good enough. (P19)
Subcode f	Websites	Refers to mention of 'website' or something similar as an information source	Again, EMedicine – I don't trust anything. (P12)
	Wikipedia	Refers to mention of 'Wikipedia' as an information source	What kinds of things do you think people should read? P: Well, I looked at Wikipedia first, because I rely on Wikipedia a lot for different things. (P21)
D	Library	Refers to mention of 'the library' as an information source	We would just sign books out of the library, textbooks even, buy psychology textbooks in the second hand store, and read through the relevant chapters or things that might give more insight. (P28)

Code no.	Code	Definition	Example
E	People	Refers to mention of people as an information source	
Subcode a	811	Refers to mention of '811' as an information source	I would call 811. Depends how serious? I prefer talking. (P35)

Code no.	Code	Definition	Example
Subcode b	Doctors	Refers to mention of 'doctor' or 'doctors' as an information source	I suffer from HIV, and all the information that I have when I suffer from HIV is from the doctors. I ask questions from the doctors. (P11)
Subcode c	Family	Refers to mention of 'family' or something similar as an information source	My mom, or people in my family who took the medication and had bad experiences with it. (P28)
Subcode d	Friends	Refers to mention of 'friends' or something similar as an information source	Where do you find this information? R I do have friends, too, but I also look at websites, health websites. (P34)
Subcode e	Self	Refers to mention of 'self' as an information source, either speaking of previous knowledge or intuition	And how did you find out that meaning? P: That's just using my own intuition. A problem with the ears: I don't want to hear. (P2)
F	Positive living magazine	Refers to mention of 'Positive Living magazine' as an information source	Positive Living Society produces a magazine; it's kind of interesting. There's stuff there that I didn't know. (P20)