Information Behavior of People Diagnosed with a Chronic Serious Health Condition: A Longitudinal Study

by

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Dedication

To my wife, Melissa Niswonger, for her unshakeable belief in me and her unwavering support

To my mother, Eleanor A. (Goslow) St. Jean, who gave me so many opportunities she had never had and who instilled in me a love of learning and an appreciation of the importance of a good education

To my father, Charles E. St. Jean, whose exuberance and sense of humor are sorely missed

To my sister, Susie, who was one of the primary inspirations for this work and whom we lost far too soon

And to all of my other brothers and sisters: Lynn M. Baker, Chucky E. St. Jean, Allen E. St. Jean, Larry E. St. Jean, Daniel T. St. Jean, Dorie A. Davis, and David S. St. Jean

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Abstract

This study consisted of a longitudinal investigation into the information behavior of people diagnosed with a particular chronic serious health condition, type 2 diabetes. This study sought to identify the factors that motivate or impede the information seeking and use of these individuals and to discover how these factors and their influences change across time. It also aimed to uncover how they become aware of and capable of articulating their information needs, how they look for and make use of health-related information, and how these processes change across time. Lastly, it sought to discover what sources and types of diabetes-related information they perceive to be useful and how their perceptions of usefulness change as their knowledge about, and their experience with, diabetes transform across time.

A longitudinal, mixed method approach was taken in which data were collected through two interview sessions spaced approximately four to six months apart. These sessions explored the experiences of 34 adults with type 2 diabetes, using a combination of qualitative and quantitative data collection techniques, including semi-structured interview, background questionnaires, health condition questionnaires, card-sorting exercises, and timeline elicitation. Both qualitative and quantitative techniques were used to analyze the data.

The findings from this study provide evidence that information behavior plays a very important role in enabling participants to physically, cognitively, and affectively cope with having diabetes. Participants who rated diabetes-related information as more useful rated their general health higher and indicated that they felt less confused, more optimistic, and more in control of their experience with diabetes. This study's findings also show that time forms a critical dimension within the context of consumer health information behavior. Participants' information seeking and use practices, as well as their perceptions regarding the usefulness of diabetes-related information, also underwent important transformations across time. Moreover, their willingness and ability to act on

this information also varied. Participants were not always immediately aware of their information needs and this state, termed “incognizance” here, sometimes led to serious health consequences. Having information at the point in time when it could be of the most use to them was of paramount importance.

Chapter 1

Introduction

"At first, I feared the diabetes, now I fear what I don't know about the diabetes. It's kind of a shift. And that's I think why I'm motivated to read information about it and learn about it… Because there may be something I don't know." (I06)

"I didn't know I needed to know until I found out something." (I32)

The central focus of this research is the important role that information behavior plays in enabling a person to cope with and manage a chronic serious health condition across time. More specifically, a longitudinal investigation was conducted in order to find out how people with type 2 diabetes become aware of their needs for information, seek information in order to fulfill these needs, and put this information to use. This study has uncovered novel findings that not only expand our knowledge of information behavior theory, but also suggest specific ways in which information professionals can better assist these individuals with the full range of their information activities.

1.1 Background

Consumer health information behavior (CHIB), which encompasses people's health-related information needs as well as the range of activities in which they engage (or not) in order to look for and make use of information related to their health condition, crucially influences a person's ability to cope with and manage a chronic serious health condition. People may interact with information in a wide variety of ways when attempting to cope with a chronic serious health condition. These interactions may range from active information seeking to passive reliance on information supplied, and even to purposeful avoidance of any potentially relevant information.

Consumer health information behavior has been found to be both situational and dynamic. Consistent with the central role of time found in nearly all information behavior and health-related behavior theories and models, preferences for these informational coping styles have been found to vary not only across individuals, but also across time and situation within each individual (Degner et al., 1997; Hack, Degner, & Dyck, 1994). These different ways of dealing with information – active seeking, passive acceptance, or purposeful avoidance – have significant implications for the extent and usefulness of the information these individuals have available to draw from when it comes time to make health-related decisions.

People's health outcomes, in turn, are fundamentally influenced by the health-related decisions that they make along the way. Therefore, a person's ultimate health outcome is likely to be significantly impacted by the ways in which they deal with information throughout the course of their illness. As Case, Andrews, Johnson, and Allard (2005) put it:

> The scope and nature of the information on which to base medical judgments, the repertoire of alternative courses of action known to the searcher, and ultimately the action taken are all affected by individuals' information-seeking behaviors (p. 360).

1.2 Problem Statement

The idea for this research originated at the intersection of three different literatures: (1) Empirical studies of consumer health information behavior, including a subset of studies that specifically focus on how people with diabetes learn self-management of the disease; (2) Theoretical treatises on relevance and closely related concepts, such as pertinence and usefulness; and (3) Theoretical treatises and empirical studies emphasizing the centrality of the dimension of time in people's information behavior. These three threads of literature were woven together to form the conceptual framework for this study – how the information needs and the information seeking and use practices of people with type 2 diabetes, particularly the sources and types of information that they deem to be useful, change over time.

Despite the fact that many empirical studies have resulted in the finding that consumer health information behavior is an inherently dynamic and situation-bound phenomenon, relatively few researchers have undertaken to investigate it in a longitudinal

manner (as pointed out by Ankem, 2006a; Kutner, Steiner, Corbett, Jahnigen, & Barton, 1999; and McCaughan & McKenna, 2007). Furthermore, very few studies of consumer health information behavior have focused on the experiences of people with diabetes. This study aims to help fill both of these gaps in the literature.

This study focuses on the information needs, information seeking, and information use of people diagnosed with the chronic, serious health condition of type 2 diabetes, with a special emphasis on how these processes change across time. This study is motivated by a belief that people's information behaviors, along with the types of information that they deem to be most useful, change as their health condition and their experience with their health condition unfold. It is posited that time forms an important dimension of consumer health information behavior and that studying this topic with a focus on the interactions between time and a person's information behaviors will yield findings with important implications for both information behavior theorists and consumer health information professionals.

1.3 Rationale for Focusing on Diabetes

Type 2 diabetes was selected as the health condition of focus for this study because of its current and projected prevalence and because it is an information-intensive health condition that needs to be managed over time. Most significantly, however, type 2 diabetes was chosen as the focus for this study because the information behavior of people diagnosed with this condition can have major implications for their ability to cope with and successfully manage this disease across time.

Diabetes is a very expensive and increasingly prevalent disease. As of 2007, the total estimated cost of diagnosed and undiagnosed diabetes (including pre-diabetes and gestational diabetes) in the U.S. exceeded 200 billion dollars (Dall et al., 2010). Globally, this figure is estimated at more than 418 billion (in international dollars) for 2010 (World Diabetes Foundation, 2011). And the cost to the individual who has diabetes is even steeper – not just in terms of money, but also in terms of pain and suffering. Diabetes is currently the leading cause of kidney failure, non-accident/injury amputations of the lower limbs, and new cases of blindness among adults in the U.S. Furthermore, it is the seventh leading cause of death in the U.S. (National Center for Chronic Disease Prevention and Health Promotion, 2011) Diabetes is not only a very costly problem, it is

also a rapidly growing one. Currently, approximately 10% of the adults in the U.S. have diabetes; however, this percentage is projected to double or triple by 2050 (Centers for Disease Control and Prevention, 2010). Globally, approximately 285 million people (6.4% of the adult population) currently have diabetes and this is projected to grow to 438 million people (7.8% of the adult population) by 2030 (World Diabetes Foundation, 2011).

Simultaneously, however, diabetes differs from many other diseases in two significant ways. First, people can have diabetes and not know it for years. For example, while approximately 24 million people in the U.S. have diabetes, 6 million of them have no idea that they have it (Centers for Disease Control and Prevention, 2010). In developing countries, less than half of the people with diabetes have actually been diagnosed with it (World Diabetes Foundation, 2011). The second way in which diabetes differs from many other diseases is that people can take specific steps to reduce their risk of getting diabetes, to delay the onset of diabetes, and to reduce their risk of developing diabetes-related complications. Diabetes, therefore, is a disease in which information *can* make an enormous difference. But for this to happen, people need to be aware as early as possible that they're at risk of developing diabetes or that they, in fact, already have diabetes. Furthermore, they must know what steps they can take to prevent and/or manage this disease and they must have this information at the appropriate time in their experience with diabetes. And they must be willing and able to act on this information.

1.4 Objectives

The overarching goals of this study are threefold: (1) To identify the factors that motivate or impede the information seeking and information use of people diagnosed with a chronic serious health condition and to discover how these factors and their influences change across time; (2) To investigate how people diagnosed with a chronic, serious health condition become aware of and capable of articulating their information needs and how they look for and make use of health-related information, along with how each of these processes change across time; and (3) To examine what sources and types of information are perceived to be the most useful and how this changes as people's knowledge about, and their experience with, their particular health condition transform across time.

1.5 Research Questions

The specific research questions driving this study are:

1. What are the factors that motivate or impede information seeking and information use by people diagnosed with a chronic serious health condition and how do these factors and the nature of their influences transform across time?

2. What are people's information needs and information seeking and use practices in relation to their health condition, and how do these change as their knowledge about, and experience with, their health condition change across time?

3. What sources and types of information do people with a chronic serious health condition find useful and how do these perceptions change as their knowledge about, and their experience with, their health condition change across time?

1.6 Methods

This study consisted of a series of two interview sessions conducted four to six months apart with 34 adults who had been recently diagnosed with type 2 diabetes or who had recently experienced some type of exacerbation in relation to this condition, such as going on insulin or developing a diabetes-related complication. Participants were recruited for this study using three different methods, including posting an ad on a University Website advertising health research studies to the public for their potential participation, displaying flyers at hospitals and clinics located throughout southeastern Michigan (USA), and handing out flyers at in-person meetings of diabetes-related support groups.

Although semi-structured interviewing was the primary data collection method used during both of the interview sessions, several other data collection methods were also implemented in order to contextualize and supplement the interview data. These additional methods included a background questionnaire which was administered at just the initial session, a health condition questionnaire which was administered at both the initial and the follow-up sessions, card-sorting exercises which were administered at both sessions, and a timeline exercise which was administered at just the follow-up session.

Data were analyzed both qualitatively and quantitatively. Interviews were audio-taped, transcribed, and then imported into NVivo 9 for qualitative data analysis. Structural coding schemes were developed deductively based on the structure of the interview sessions and a thematic coding scheme was developed both deductively and inductively based on all of the information provided by participants through all of the data collection methods. Data from the background questionnaires, health condition questionnaires, and card-sorting exercises were analyzed quantitatively using both Microsoft Excel and SPSS.

1.7 Significance

The theoretical significance of this research arises from its potential to uncover new knowledge about consumer health information behavior, particularly about how it unfolds across time. The methodological significance of this research lies in its incorporation of two novel adaptations of existing data collection methods, including card-sorting exercises and timeline elicitation. The practical significance of this research stems from the fact that the health-related information behavior of a person with a chronic serious illness such as type 2 diabetes can crucially impact his/her ultimate health outcome. The nature of a person's information needs, information seeking, and information use (such as engaging in healthy behaviors), as well as the interrelationships between these factors, are of critical importance. Figure 1 (see next page) provides a visual depiction of these interdependencies and the scope of this research.

As depicted in Figure 1, consumer health information behavior (CHIB) takes place within the context of a person's health condition and involves the person's needs for information as well as his/her information seeking and information use. In this figure, arrows with dotted lines were used to indicate that advancement, such as from information needs to information seeking or from information seeking to information use, cannot always be presumed. The types of information behaviors in which people engage or do not engage in order to cope with a chronic serious health condition directly impact the extent and usefulness of the information that they have available to them. For example, a more active information seeker is likely to have more information available to him/her, while a less active information seeker is likely to have a much more limited set of information available to him/her. In turn, people's ultimate health outcomes rely on

what information they have access to, what information they deem to be useful, and then whether and how they choose to make use of this information throughout the course of their illness.

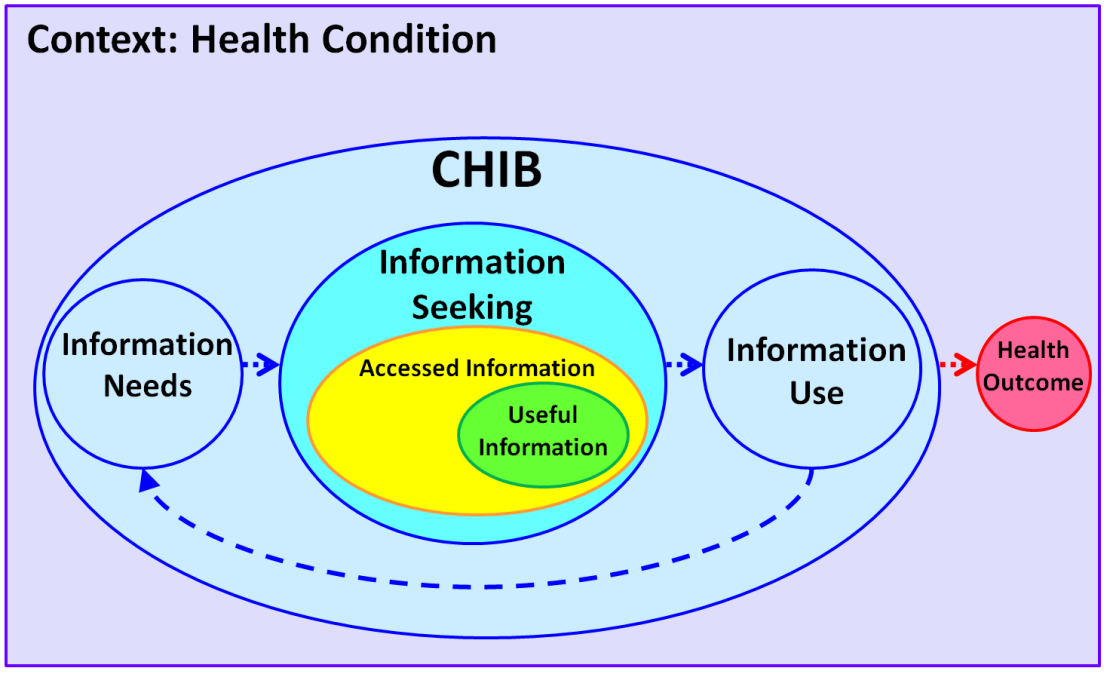


Figure 1: Scope of this Research

1.8 Structure of the Dissertation

This dissertation consists of six chapters. Chapter 2 provides a review of the relevant literature and then outlines the preliminary conceptual framework that was proposed for this study. Chapter 3 outlines the research methods that were used in conducting this study. Chapter 4 details the results from this study. Chapter 5 discusses the findings from this study and then offers a revised conceptual framework. Chapter 6 describes the implications and contributions of this research, offers several ideas for future research in this area, and then closes with some concluding remarks.

Chapter 2

Literature Review

This literature review covers three seemingly disparate strands of literature that, together, form the primary focus of this dissertation. In the first two subsections, many of the empirical studies that have looked at consumer health information behavior are reviewed. While the first subsection is more general in nature, the second focuses on diabetes and the information behavior of people with this specific health condition. In the third subsection, much of the primarily theoretical work that has been done on the umbrella concept of relevance and on closely related concepts such as pertinence and usefulness are discussed. The goal of this subsection is to explain and justify why the term 'usefulness' rather than the term 'relevance' is deemed the most appropriate for this research. In the last subsection, the focus is on the time aspect of information behavior. Three different approaches are taken. First, the ways in which people's perceptions of relevance, pertinence, and usefulness have been found to change over time are discussed. Next, some of the many information behavior models and theories that have been constructed to date are presented, with particular emphasis on the centrality of the time aspect that either explicitly or implicitly underlies many of them. Lastly, some of the few empirical studies that have looked specifically at the time dimension associated with people's consumer health information behavior are discussed. These three strands of literature are then woven together, forming the conceptual framework for this dissertation research – how people's consumer health information behavior, particularly what types of information they find to be useful, changes over time.

2.1 Consumer Health Information Behavior

2.1.1 Information Behaviors as Coping Mechanisms

Information plays an important role in people's ability to cope with illness. However, as described in the two subsections below, people may decide to cope by

attempting to use information to decrease uncertainty or they may decide to cope by attempting to avoid information in order to create and/or maintain a desired level of uncertainty about a particular health issue.

2.1.1.1 Role of Information Seeking and Acquisition

Several studies, as well as first-person accounts of the experience of being ill, which are termed "illness narratives", have identified the central role of information seeking and acquisition in enabling a person to cope with both the initial diagnosis and the ongoing impacts of a life-threatening illness (Ankem, 2006a; Clark, 2005; DeHart, 1996; Hack et al., 1994; Lazarus & Folkman, 1984; Mills & Davidson, 2002; Wong et al., 2000). Mills and Davidson (2002) point out that "Appropriate information, offered at the right time, has been recognized as a key factor in enabling patients to cope with a diagnosis of cancer" (p. 371). Furthermore, Davison et al. (2002) point out that Lazarus and Folkman's (1984) Transactional Model of Stress and Coping "identifies seeking information as the most frequent method used to cope with a stressful event about which information is limited" (p. 44). Similarly, Wong et al. (2000) state:

> Gathering information is a way in which some patients regain a sense of control over their cancer and the circumstances surrounding it. Providing sound information has been shown to have several positive effects, including pain reduction, speedier recovery, increased participation in decision making, greater satisfaction with the consultation, and improved mental health and better coping skills. (p. 13).

In her study of breast cancer support groups, another researcher, Clark (2005), found that information seeking is one of the central ways in which breast cancer patients cope with the emotional fallout from the disease. In fact, one of her interviewees stated, "When I'm faced with any kind of problem, I find out as much information as I can about it. If I know what I'm dealing with, I can cope with it better" (p. 176). However, people with a life-threatening illness may not always attempt to cope by seeking out information.

2.1.1.2 Information Avoidance

Many studies have identified a smaller subpopulation of patients with life-threatening illnesses who prefer to avoid information about their condition (Baker, 1998; Clark, 2005; Hack et al., 1994; Miller, 1995; Miller, Brody, & Summerton, 1988; Wicks

& Frost, 2008; Wong et al., 2000). For example, Wong et al. (2000) found that 1 to 2% of the men with prostate cancer that she surveyed indicated that they wanted no information about their disease and that these men tended to be less optimistic. Similarly, one of Baker's (1998) interviewees who was diagnosed with multiple sclerosis stated, "I wasn't really looking for more information about it. I think I would have loved to have somebody tell me 'oh, it's nothing,' but I knew that it wasn't" (p. 113).

However, these individuals do not always represent the minority. For example, Hack et al. (1994) found that slightly over half of his study participants, women with breast cancer, indicated that they would prefer to be told the best possible diagnosis rather than the most likely outcome. Similarly, Wong et al. (2000) found that only 63% to 68% of their study participants, men with prostate cancer, preferred to know the most likely outcome; the remaining participants preferred instead to be told either the best possible outcome (19% to 26%) or the worst possible outcome (11% to 13%). Patients generally want their doctors to be *both* honest and optimistic (Kutner et al., 1999); however, this combination may not always be feasible, as optimism will always yield the best possible diagnosis while honesty will tend to yield the most likely outcome.

Several researchers have advocated ascertaining and respecting people's preferences in terms of how much or which types of information they wish to be given (Ankem, 2006b; Bilodeau & Degner, 1996; Czaja, Manfredi, & Price, 2003; Hack et al., 1994; Miller, 1995; Wicks & Frost, 2008). In fact, physicians have been found to use euphemisms with their patients rather than the real name of a diagnosed disease (e.g., using 'tumor' or 'malignancy', rather than the word 'cancer') and to even withhold diagnoses from patients (Hack et al., 1994). In fact, one older study (Oken, 1961) found that 88% of the physicians surveyed indicated that they generally withhold cancer diagnoses from their patients. However, somewhat more recent studies (Hardy, Green, Jordan, & Hardy, 1980; Novack et al., 1979) provide evidence that there may be a trend towards more open sharing of cancer diagnoses with patients. One possible explanation for this trend is the increase in the ability of the medical profession to treat cancer.

Information avoidance and the resultant lack of information about one's disease has been linked with a wide array of negative outcomes, including patients being offered less information by their physicians (Brashers, Goldsmith, & Hsieh., 2002), an inability

to participate fully in treatment-related decision-making (Degner et al., 1997; Hack et al., 1994), and paternalistic treatment from physicians that led some patients to feel forced into making hasty decisions with insufficient time to look for or even consider information already acquired and to later question the quality of the decisions that they had made under these conditions (Clark, 2005).

On the other hand, however, provision and/or acquisition of information can have negative effects as well. At times, patients may prefer to maintain, or even increase, their level of uncertainty (Brashers et al., 2000; Case et al., 2005) as this may enable them to control their anxiety (Pifalo, Hollander, Henderson, DeSalvo, & Gill, 1997) and/or to retain some hope (Brashers et al., 2000). For example, 10% of the consumers who received information from a particular consumer health library indicated that this information actually increased their anxiety (Pifalo et al., 1997). Similarly, a new member of one of the breast cancer support groups observed by Clark (2005) was upset and terrified when a more experienced member shared information about how awful it was to undergo chemotherapy. Clark points out, "More information was not always better. Sometimes the information the women found was ambiguous, contradictory, or frightening" (p. 177). Miller (1995) similarly points out that providing information to "negativistic monitors" (i.e., pessimistic monitors) may actually push them into denial rather than helping them to cope with their illness.

2.1.2 Information Preferences and Decision-Making Preferences

Many studies have found unsurprising parallels between people's preferences for disease-related information and their preferences for participation in treatment-related decision-making processes. Patients vary along a continuum in terms of how actively they would like to participate in treatment-related decisions – some prefer to make these decisions themselves, some prefer that their doctor make these decisions on their behalf, and some prefer to make these decisions in collaboration with their doctors.

Two distinct camps of patients have been identified across multiple studies (Ankem, 2006b; Clark, 2005; Davison et al., 2002; Degner & Sloan, 1992; Eheman et al., 2009; Hack et al., 1994; Mills & Davidson, 2002): (1) Patients who prefer an active role in treatment-related decision-making and who prefer to obtain as much information as possible about their disease and (2) Patients who prefer a more passive role in treatment-

related decision-making and who would rather rely on the expertise of their doctors than acquire, process, and understand information for themselves. These two distinct camps have been postulated to result from disparities in socioeconomic class (Clark, 2005), educational attainment (Degner & Sloan, 1992; Eheman et al., 2009; Hack et al., 1994), occupation (Eheman et al., 2009), age (Bilodeau & Degner, 1996; Degner & Sloan, 1992; Eheman et al., 2009; Mills & Davidson, 2002), gender (Butow, Maclean, Dunn, Tattersall, & Boyer, 1997; Degner & Sloan, 1992; Eheman et al., 2009); locus of religious control (Butow et al., 1997), marital status (Eheman et al., 2009), and/or health status (Butow et al., 1997; Degner & Sloan, 1992; Eheman et al., 2009).

Interestingly, clinicians have been found to simultaneously overestimate patients' desire to participate in decision-making and underestimate patients' needs for information (Strull, Lo, & Charles, 1984). These misunderstandings probably arise simply due to clinicians' innocuous and understandable inability to get outside of themselves – outside of their own knowledge bases and their own information and decision-making preferences. However, they seem likely to potentially have poor consequences for both camps of patients – the more passive patients will be pushed to participate in decision-making beyond the degree to which they wish to (as reported by 15% of Degner et al.'s (1997) participants) and the more active patients will be provided with insufficient information to enable them to optimally participate in decision-making processes. Additionally, clinicians' failure to sufficiently meet the information needs of more active patients could also decrease these patients' feelings of psychological control over their health (Taylor, S. E., 1986).

Of course, the two camps described in this section represent merely the polar opposites along a continuum, and there are many people who fall somewhere in the middle between these two extremes. Additionally, some researchers (Miller et al., 1988) have found that people who prefer more information do not necessarily want to play a more active role in the decision-making related to their health. Miller (1995) identifies two coping styles that people may adapt when facing information that is potentially threatening to them (such as a cancer diagnosis) – monitoring and blunting. She describes monitors as people who want more information but prefer to be more passive in their health-related decision-making and blunters as people who prefer to avoid any potentially

threatening information. However, it seems likely that a given person may not always use the same coping style regardless of the situation at hand. In fact, there is some evidence that people's information and decision-making preferences are not static (Butow et al., 1997; Degner et al., 1997; Eheman et al., 2009; Hack et al., 1994). Butow et al. (1997) state, "Information and involvement preferences do not appear to be fixed personality characteristics, but rather are highly responsive to a number of factors, such as changing disease status and the behavior of the doctor in the consultation" (p. 863). Another group of researchers states, "Perhaps it is only as patients learn to accept their illness or further their understanding of their illness that they prefer a more active role in their care as they strive to cope with their disease and its effects" (Hack et al., 1994, p. 287). People's information and decision-making preferences continually interact with, influence, and are influenced by, the factors that motivate and impede their health-related information seeking.

2.1.3 Motivating and Impeding Factors

Previous research studies have identified many different factors that can motivate or impede health-related information seeking. Some studies have found specific demographic characteristics to be tied with more active information seeking, such as younger age (Ankem, 2006a; Ankem, 2006b; Carlsson, 2000; Gollop, 1997; Mills & Davidson, 2002; Wong et al., 2000), higher educational attainment (Carlsson, 2000; Gollop, 1997; Hack et al., 1994), and being female (Carlsson, 2000). Additional personal variables that have been postulated to influence consumer health information seeking include marital status and employment status (Czaja et al., 2003), socioeconomic class (Clark, 2005), literacy (Gollop, 1997), illness severity (Hack et al., 1994), time since diagnosis (Degner et al., 1997; Hack et al., 1994; Luker, Beaver, Leinster, & Owens, 1996; Raupach & Hiller, 2002), past experience with the medical establishment (Matthews, Sellergren, Manfredi, & Williams, 2002), and level of access to sources of health information (Gollop, 1997). However, differences in consumer health information seeking motivation based purely on demographic or personal characteristics do not help to explain *why* people do or do not seek out information regarding a health condition. Many studies went beyond demographic-based differences, identifying specific reasons

that people engage in, or do not engage in, health-related information seeking and use behaviors.

Additional motivating factors mentioned in the literature include a desire to reduce negative affects such as uncertainty, anxiety, and dread, and to bolster self-efficacy (Clark, 2005); a desire to regain a sense of control (Wong et al., 2000); possession of medical familiarity and social support (Czaja et al., 2003); access to other patients who have had similar health experiences (Johnson, 1997; Matthews et al., 2002); a higher level of stress at the time of diagnosis (Czaja et al., 2003); a lower rate of negative reactions from physicians when asking questions about information they obtained elsewhere (Czaja et al., 2003); and a preference to be involved in health-care decision-making (Czaja et al., 2003).

Barriers mentioned include a lack of up-to-date and personally relevant information about a particular disease, inaccessibility of the physical environment, family's denial, and negative emotions such as fear and uncertainty (Baker, 1998); lack of literacy skills, self-confidence, and knowledge of their disease (Clark, 2005); mistrust of physicians (Matthews et al., 2002); inability to gather and process the requisite information (Clark, 2005); pressure from doctors to make decisions quickly and to rely solely on the doctors' expertise (Clark, 2005); inability to think of questions during regularly scheduled doctor visits (Hack et al., 1994); and inability to later recall information provided by their doctors (Ankem, 2006a; Brashers et al., 2000; DeHart, 1996; Hack et al., 1994; Holmes & Lenz, 1997; Luker et al., 1996; McCaughan & McKenna, 2007; Mishel, 1988).

Many of these motivating and impeding factors can be discerned from both health behavior change models and information behavior models. Health behavior change models depict the factors that can influence a person's decision to change (or not change) his/her health behaviors, such as quitting smoking, losing weight, and brushing and flossing one's teeth. Health behavior change models are relevant to consumer health information behavior since information behavior can both drive, and be driven by, the contemplation, planning, and execution of health behavior changes. Two health behavior models – the Health Belief Model and the Theory of Planned Behavior – as well as two

information behavior models – Johnson's Comprehensive Model of Information Seeking and Wilson's 1996 Model of Information Behaviour – are depicted and discussed below.

2.1.3.1 The Health Belief Model (HBM)

The Health Belief Model (HBM) was originally developed by the U.S. Public Health Service in the 1950s in order to explain why people were not participating in programs that had been set up to prevent and detect disease. During the past 50 years, the HBM has been one of the most commonly used conceptual frameworks of health behavior. It has been used not only to explain why people do or do not change and/or maintain health behaviors, but also to help guide the design of health behavior interventions. There is substantial empirical support for the predictive power of the HBM. (Janz, Champion, & Strecher, 2002)

As depicted in Figure 2, the HBM attributes a person's likelihood of behavior change directly to four factors: (1) their demographic factors, personality, and knowledge; (2) their perceptions about the level of threat posed to them by a particular disease; (3) any cues to action (e.g., seeing a public service ad on television that talks about the specific health risks associated with smoking) to which they may have been exposed; and (4) their perceptions about the potential benefits of, and the potential barriers to, changing their behaviors (Janz, Champion, & Strecher, 2002). Of all of these factors, perceived barriers has been found to be the most powerful single predictor of the likelihood of health behavior change while perceived severity has been found to be the least powerful predictor (Janz & Becker, 1984). All of these factors reflect potential motivations for, and barriers to, not only health behavior change but also consumer health information seeking. For example, cues to action may increase the salience of a particular disease in a person's mind, and thus, motivate him/her to look for information about this disease. On the other hand, a person's belief that he/she is incapable of engaging in a particular health behavior, such as quitting smoking, may serve to impede their information seeking about how to go about quitting smoking and/or about the potential benefits of doing so.

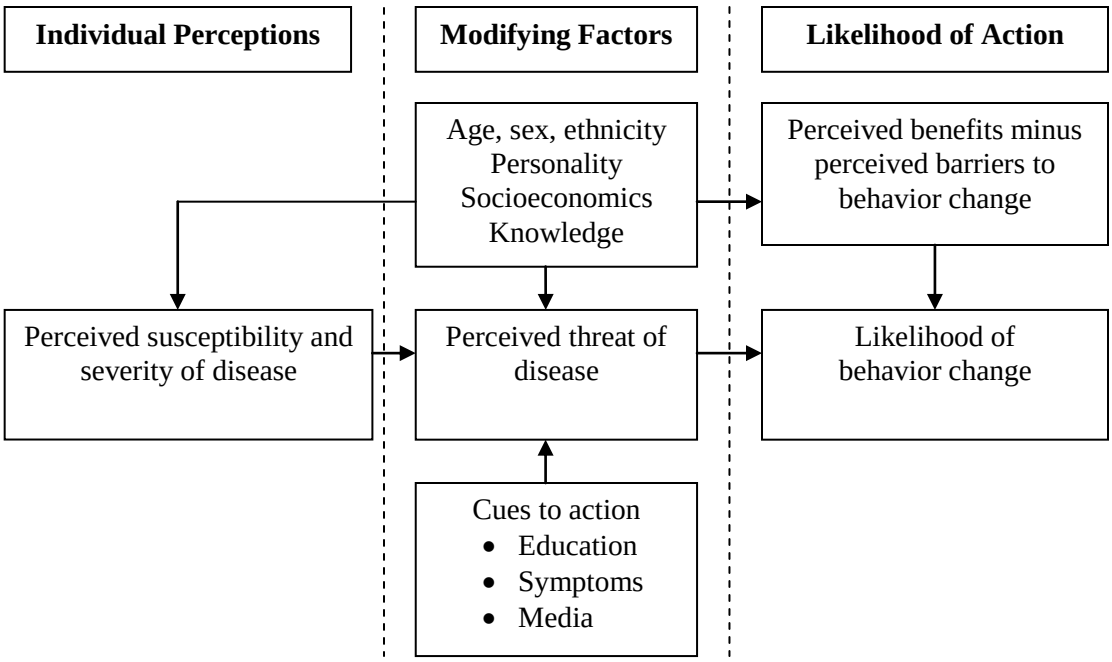


Figure 2: Health Belief Model (HBM) Components and Linkages (based on Janz, Champion, & Strecher, 2002, p. 52 and Strecher, 2007)

2.1.3.2 The Theory of Planned Behavior (TPB)

Another health behavior model that depicts similar motivating and impeding factors to health behavior change is the Theory of Planned Behavior. The Theory of Planned Behavior (TPB) is an extension of the Theory of Reasoned Action (TRA). The TRA was first developed by Fishbein in 1967 in order to try to understand the relationship between attitudes and behavior (Fishbein, 1967). Many earlier studies had concluded that the correspondence between attitudes and behavior was very low; however, most of them had looked at people's attitudes toward an object, such as breast cancer, rather than their attitudes toward a behavior, such as having a mammogram. Fishbein was able to show that people's attitudes toward a behavior are a much better predictor of that particular behavior than their attitudes toward the object at which that behavior is directed. (Montaño, D. E. & Kasprzyk, D., 2002)

Some twenty years after the TRA was introduced, Ajzen and his colleagues developed the TPB in order to extend the TRA's ability to predict health behaviors to

include behaviors over which people have incomplete control. They added the factor "perceived behavioral control" to the TRA in order to try to explain the transition from intention to perform a behavior to actually performing that behavior. (Montaño, D. E. & Kasprzyk, D., 2002) The TPB, along with the TRA which is the portion of the TPB that is shaded, is depicted in Figure 3.

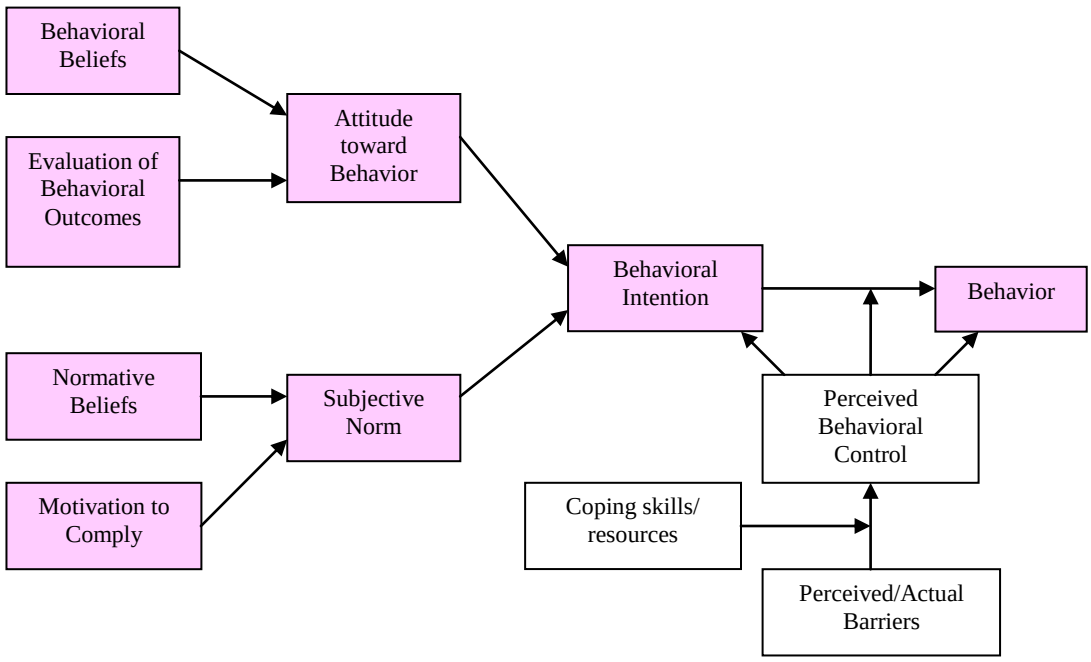


Figure 3: The Theory of Reasoned Action (TRA) (shaded regions) and the Theory of Planned Behavior (TPB) (based on Montaño & Kasprzyk, 2002, p. 68 and Strecher, 2007)

Each of the individual factors in the TPB (which incorporates the TRA in its entirety) is not completely self-explanatory. Basically, behavioral intention is directly modified by two factors, attitude toward behavior and subjective norm, while the relationship between behavioral intention and behavior is mediated by perceived behavioral control, aka self-efficacy. Attitude toward behavior represents a person's attitude toward the health behavior they are contemplating, such as getting a mammogram. Attitude toward behavior is influenced by both a person's behavioral beliefs and their evaluations of behavioral outcomes. Therefore, if a woman believes that

mammograms can detect breast cancer early and if she values that particular outcome, she will be more likely to form an intention to get a mammogram. Subjective norm is influenced by both a person's normative beliefs and his/her motivation to comply. To continue the example, a woman is more likely to form an intention to get a mammogram if she believes that her family feels it is important for her to get a mammogram and if it is important to her to comply with her family's wishes.

Finally, the relationship between behavioral intention and behavior is mediated by perceived behavioral control or self-efficacy, which in turn is influenced by both the perceived and actual barriers facing the person and his/her coping skills and resources. Therefore, a woman is likely to have higher perceived behavioral control, and thus be more likely to advance from merely intending a behavior to actually carrying it out, if she believes that she has the necessary coping skills to overcome any barriers that she perceives may prevent her from engaging in a desired behavior. As with the HBM, the factors in the TRA and the TPB can help explain and predict consumer health information behavior as well as health behavior change. For example, a person who believes that he/she can engage in behaviors that can prevent him/her from getting cancer may be more likely to look for information about what types of behaviors will help in this regard. Meanwhile, a person who believes that cancer cannot be prevented may be less likely to even try to find such information.

2.1.3.3 Johnson's (1997) Comprehensive Model of Information Seeking (CMIS)

Based on two health behavior change models (the HBM and the Transtheoretical Model), Johnson (1997) constructed his Comprehensive Model of Information Seeking (CMIS), which is depicted in Figure 4. This model has been empirically tested within both cancer (Johnson, 1993; Johnson & Meischke, 1993) and organizational contexts (Johnson, Donohue, Atkin, & Johnson, 1995) (as cited in Johnson, 1997, p. 33). Furthermore, it has since been used in NIH-funded studies of health communication (Case, 2007, p. 136).

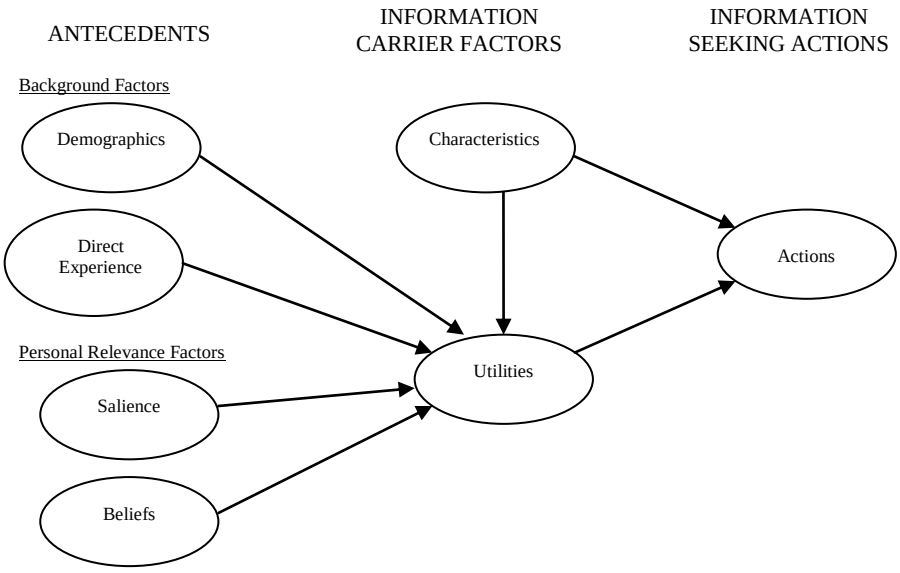


Figure 4: Johnson's (1997) Comprehensive Model of Information Seeking (CMIS) (p. 34)

The factors in Johnson's (1997) CMIS model are grouped into three major categories – antecedents, information carrier factors, and information seeking actions. It appears that Johnson pulled his antecedent factors of demographics, direct experience, salience, and beliefs from various health behavior models. For example, the demographics factor appears to have been drawn from the HBM, while the beliefs factor appears to have been drawn from the TRA/TPB.

The CMIS model postulates that a person's information seeking actions are directly driven by the characteristics and utilities of information sources, which in turn are influenced by the person's demographic background, direct experience with the disease (i.e., cancer), and his or her beliefs, as well as the salience of the disease to him/her. Demographic factors such as gender, age, race, ethnicity, education, and socioeconomic status, as well as direct experience factors which pertain to people's personal experience with cancer, influence people's choice of information channels. Meanwhile, factors associated with salience – the significance or applicability of cancer-related information for a person – and beliefs such as a person's level of self-efficacy and his/her beliefs about the ability of a particular medical procedure to cure cancer influence their motivation to seek information (Johnson, 1997).

The second set of factors in Johnson's (1997) CMIS model has been labeled "information carrier factors". These factors are basically about a person's information channel selection and usage. While the antecedent factors in the CMIS motivate information seeking in the first place, the information carrier factors determine the nature of this information seeking. The information carrier factor of "characteristics" incorporates both editorial tone, which is comprised of perceived credibility, perceived intents, and perceived accuracy of a channel, and communication potential, which is comprised of perceived comprehensibility and attractiveness of an information channel. The information carrier factor of "utilities" pertains to the perceived usefulness of various channels. (Johnson, 1997)

The last variable in the CMIS model is "information seeking actions". This variable incorporates different styles of information seeking, such as active information seeking and information avoidance, that are motivated by the antecedent and information carrier factors. As mentioned earlier, the antecedent variables motivate or fail to motivate information-seeking behavior and influence the intensity with which this activity is undertaken, while the information carrier factors shape a person's selection and usage of various information sources. Of all the antecedent variables, Johnson (19997) points out that it is salience that "provides the underlying motive force to seek information" (p. 72).

In a later paper, Johnson, Case, Andrews, Allard, & Johnson (2006) propose two alternative, but complementary, conceptions of information seeking – fields and pathways. Fields are basically the contexts in which people's information seeking takes place, while pathways represent people's navigations through these fields. Fields are made up of "resources, constraints, and carriers of information" (p. 571), while pathways consist of information seeking actions. These authors emphasize that people, through information seeking, can shape their information fields so that they become increasingly more conducive to motivated and ultimately successful information seeking. Thus, people can shape their own information environments so as to maximize the factors propelling them to look for information and so as to minimize the barriers impeding their information seeking.

2.1.3.4 Wilson's 1996 Model of Information Behaviour

Another model that depicts many of the different motivations and barriers to information seeking and use is Wilson's (1999) 1996 Model of Information Behaviour, Figure 5. In constructing this model, Wilson drew on research from many different fields other than information science, including health communication, consumer research, psychology, decision-making, and innovation. This model has been called "the global model… of the [information behavior] field" (Wilson, 2000, p. 53). The main idea depicted by this model is that there is a person-in-context who develops an information need, who then proceeds, or is impeded from proceeding, to engage in some form of information-seeking behavior, and who then proceeds to information processing and use and then loops back again to information need.

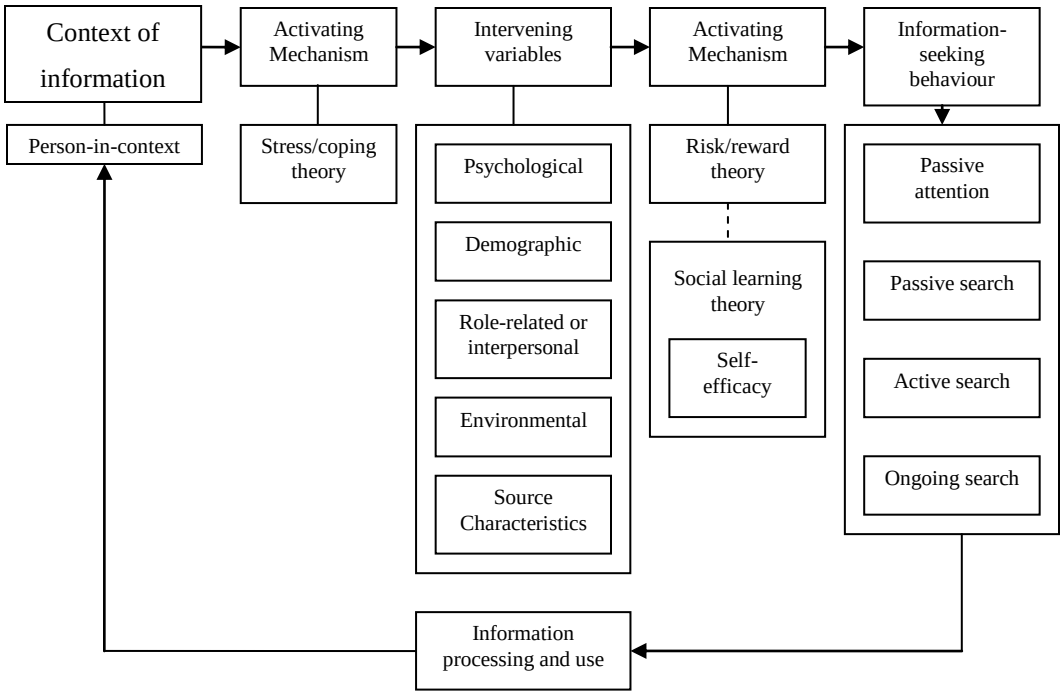


Figure 5: Wilson's 1996 Model of Information Behaviour (from Wilson, 1999, p. 257)

Both the activating mechanisms and the intervening variables depicted in this model represent motivating and impeding factors to information seeking and use. The first activating mechanism, stress/coping theory, helps to explain why some information needs trigger information seeking and why some do not. The second activating

mechanism consists of a couple of different theories – risk reward theory, which can help to explain people's information source selections and social learning theory, which can help to explain the role of self-efficacy in a person's decision to seek information or not. Wilson's intervening variables include factors that can either support or prevent information use. As depicted in his model, intervening variables can by psychological, demographic, role-related or interpersonal, environmental, or related to the characteristics of a particular source. Wilson (1997) points out that although intervening variables are only depicted at one point in the model, they may actually intervene between other pairs of stages as well, including between context of information need and activating mechanism, between activating mechanism and information-seeking behaviour, and between information-seeking behaviour and information processing and use.

All four of these models, along with many other information behavior models, depict some of the wide variety of factors that can motivate or impede a person's information seeking and use. Many of these diverse factors are incorporated and reflected in people's preferences in terms of the amounts and types of information that they would like to have and in terms of how actively they wish to be involved in treatment-related decision-making. They also contribute to people's judgments about whether or not they feel that they have sufficient information about their health condition.

2.1.4 Information Perceptions: Enough Information?

Interestingly, conflicting findings have been reported about whether patients feel that they have enough information about their particular health conditions. Several researchers (Carlsson, 2000; Gollop, 1997; Kutner et al., 1999; Warner & Procaccino, 2004) have found that a vast majority (often between 85% and 90%) of their study participants report that they have all of the information that they want or need about their condition. Other researchers (Baker, 1998; Degner et al., 1997; Hack, Degner, Farber, & McWilliams, 1992; Mills & Davidson, 2002), however, have found that people are not satisfied with the amount and/or types of information about their condition that is available to them. Although many people may accurately report that they have all of the information that they need or want about their condition, it seems possible that this finding may, at times, be reached in error. There are several possible reasons that this finding could be reached in error, such as biased recruitment or data collection methods,

people's tendency to satisfice, and some people's preference to deny that they have a particular health condition.

The finding that people feel they have all of the health information they need may arise simply due to a bias in the pools of study participants. The vast majority of studies recruit participants who are "linked in"; that is, they recruit people from locations that tend to be rich in information resources, such as doctor's offices, hospital waiting rooms, and community clinics. Because such participants are far easier to gain access to, they tend to make up the bulk of participant pools in nearly every study. However, participants who are not "linked in" may strongly disagree with the statement that they have all of the health information that they need.

Another possible explanation for people feeling that they have all the information that they need or want about their health condition is that many data collection efforts are carried out in waiting rooms or other physical areas tied with a person or group of people who is/are typically expected to provide such information. Thus, the data may reflect a positivity bias (Groves et al., 2004, p. 223) – people may indicate that they are satisfied with the information that they have received simply because they want the study results to reflect positively on their doctor or clinic.

Another perhaps more likely explanation for people reporting that they have all the information they need or want about their health condition is people's tendency to satisfice. Simon (1996) describes satisficing as involving the initial processes of a person determining the attainable based on his/her expectations and then defining his/her aspirations accordingly. An alternative is then said to "satisfice" if it matches the person's aspirations. Thus, satisficing, unlike optimizing, is inherently bound by a person's expectations. People cannot aspire to have information of which they are unaware. This idea is reflected in Belkin, Oddy, and Brooks' (1982) Anomalous States of Knowledge (ASK) concept and Taylor's (1968) four levels of information need, which both also relate to the difficulty people have with formulating what it is that they do not know. Furthermore, what people actually do know affects how they make relevance judgments about additional pieces of information. For example, Yuan, Belkin, & Kim (2002) found that people with ill-formed ASKs were more likely to base their relevance judgments on how well-written, credible, and understandable they found the information to be, while

people with well-formed ASKs were more likely to base their relevance judgments on aspects of the source, such as their familiarity with either the author or the source.

One other potential explanation for people feeling satisfied with the amount of health information that they are able to access is denial of their health condition fueled by the desire to preserve hope and/or to control negative emotions, such as fear and anxiety. Several researchers (Baker, 1998; Chesser & Anderson, 1975; Matson & Brooks, 1977; Miller, 1995) have found that when people are in denial about a health condition, they tend to indicate that they are satisfied with the information given to them and that they do not need or want any more information. For example, Miller (1995) states, "Even though blunters had more minimal knowledge, nonetheless, they reported that their knowledge was sufficient because they did not wish to receive any further information" (p. 170).

The reasons that people have given for feeling that they do *not* have sufficient information about their condition vary widely, ranging from lack of personally relevant information (Baker, 1998), to lack of the right types of information (Baker & Pettigrew, 1999; Kutner et al., 1999), to lack of information from specific types of sources (Dervin, 2005; Kutner et al., 1999). Within her sense-making framework, Dervin has defined information from the user's perspective as "whatever helps" (Harris & Dewdney, 1994, p. 19). During the process of sense-making, people's situations along with their perceptions of their situations and, correspondingly, their information seeking and use strategies, evolve. Dervin (2005) points out that people who are trying to make sense of their situation sometimes "want to turn to facts, sometimes to authorities to show them the way, sometimes to peers who have traveled the same road before" (p. S79).

Similarly, Baker and Pettigrew (1999) referring to a personal communication with Quintana and Dewdney, state that these authors note "the goal of some individuals diagnosed with cancer is to take an active part in decision making about treatment alternatives, whereas the goal of others is simply to gain a feeling that 'I am not alone – others have walked this path before me'" (p. 446). They point out that people with the first type of information need may seek out facts about different kinds of treatments available, while people with the second type of need may seek out support groups or stories of other people who also have cancer.

Thus, the types of information people need and the types of sources they would prefer to consult are both highly dependent on their particular goals at the moment. One particular source, family members and friends, are often consulted by people with a health-related information need (Ankem, 2006a; Bilodeau & Degner, 1996; Carlsson, 2000; Courtright, 2005; Davison et al., 2002; DeHart, 1996; Matthews et al., 2002; Mills & Davidson, 2002; Morey, 2007; Warner & Procaccino, 2004; Wathen, 2006). For this reason, it is important to extend an analysis of the information behaviors of a patient to also include the information behaviors of the individuals who surround him/her on a daily basis.

Several studies (Ankem, 2006a; Baker, 2004; Brashers et al., 2002; Davison et al., 2002; Mills & Davidson, 2002) have emphasized the importance of studying the information needs not only of patients, but also of their families and friends. Patients' abilities to retain information provided to them at the time of diagnosis (or at the time of medical procedures) have been found to falter (Ankem, 2006a; Brashers et al., 2000; DeHart, 1996; Hack et al., 1994; Holmes & Lenz, 1997; Mishel, 1988). A patient's family members and friends can serve as sources of information for the patient (Ankem, 2006a; Carlsson, 2000; Davison et al., 2002; DeHart, 1996; Mills & Davidson, 2002) and can help them to process the information they are given (DeHart, 1996). Ankem (2006a) points out that "family and friends are instrumental in the process of managing a complex disease when the patient's ability to comprehend all the information they receive may be impaired due to the stress of illness."

In an editorial comment appended to DeHart's (1996) illness narrative about his experience with prostate cancer, DeHart's doctor, Dr. Ian Thompson, states:

> Patients frequently do not retain much information from their initial visit (when the biopsy diagnosis is given) and only begin to understand information after the second visit. Methods that help include handouts... and videotapes. I encourage patients to take these items home, show them to those who are part of their social support structure, and bring them to the office for the second visit to assist them in the decision-making process. (p. 177)

One study (Davison et al., 2002) further found that spouses who have read about or personally experienced cancer in the past are of more help to patients during medical appointments than those who do not have this prior knowledge and/or personal experience with the disease.

2.1.5 Information Use vs. Usefulness Judgments

Several studies (Ankem, 2006a; Gollop, 1997; Harris, Wathen, & Fear, 2006; Mills & Davidson, 2002) have uncovered the surprising finding that people tend to make more use of information sources that are perceived to be less useful and less use of information sources that are perceived to be more useful. For example, whereas physicians have been found to be the most frequently consulted source of information by the great majority of health information behavior researchers included herein (Bilodeau & Degner, 1996; Estabrook, Witt, & Rainie, 2007; Friedman & Hoffman-Goetz, 2003; Gollop, 1997; Hogan & Palmer, 2005; Kutner et al., 1999; Matthews et al., 2002; Morey, 2007; Pennbridge, Moya, & Rodrigues, 1999; Warner & Procaccino, 2004), they are sometimes rated by patients as one of the less helpful sources of information (Ankem, 2006a; Mills & Davidson, 2002). Additionally, other less formal sources of information that tend to be less often consulted by patients have often received higher usefulness ratings from them (Ankem, 2006a; Gollop, 1997; Harris et al., 2006; Mills & Davidson, 2002; Raupach & Hiller, 2002; Schapira, Meade, McAuliffe, Lawrence, & Nattinger, 1999).

Although hospital consultants were the primary source of information for 95% of the cancer patients participating in Mills & Davidson's (2002) survey, they were rated as only the third best source. General Practitioners (GPs) were the second most common source of information for these individuals; however, GPs were rated to be one of the least valued sources by these same respondents. In fact, GPs were rated the ninth most valued source. Although over half of the respondents used hospital written information and books, many respondents rated these to be poor sources of information. In contrast, the two top-rated sources of information, Specialist and Macmillan nurses[1], were consulted by only 53% and 19%, respectively, of these respondents. Although less than 10% of these respondents indicated that they had used the Internet to look for health information, the Internet was selected as the highest quality media source and 76% of the

[1] Macmillan nurses are "expert nurses" that "offer much-needed advice, information and support to people with cancer. They help them make informed decisions about their treatment and guide them through the maze of different services. They also offer emotional support and help people with cancer deal with their symptoms and pain. Macmillan nurses support people when they are first diagnosed and throughout their illness. They also offer help and information to families, friends, carers and local communities" ("Macmillan Nurses Fact Sheet", 2009).

patients who used it rated it as either excellent or good. One source for which this use-usefulness disparity was not found was family and friends – 70% of respondents indicated that they obtained information from family and friends and 61% rated family and friends as an excellent source of information.

Ankem's (2006a) meta-analysis of 12 individual studies of cancer patients' information needs yielded similar findings. Although healthcare professionals and medical pamphlets were the two most consulted information sources, they were outranked in terms of helpfulness by medical and cancer-related books. While 86% to 100% of respondents consulted healthcare professionals and 34% to 79% of respondents consulted health pamphlets, just 32% to 68% consulted the source rated to be the most helpful – books. Based on her meta-analysis, Ankem was able to identify several studies that internally exhibited this same sort of use-usefulness disparity. She mentions that Schapira et al. (1999) found that although books and support groups were rated to be helpful, just 32% and 5%, respectively, of respondents indicated that they used them. Ankem (2006a) also mentions that Raupach & Hiller (2002) found that: (1) support groups were rated as the most helpful source of information by the few cancer patients who reported attending them; and (2) although much fewer people consulted their families for information (n=21) than consulted a surgeon for information (n=111), the same percentages of these two groups of respondents indicated that they were highly satisfied with the information that they obtained from these sources.

What seems to be consistent across all of these instances of use-usefulness disparities is that people are tending to turn to more formal sources – high-level medical sources such as hospital consultants and general practitioners – and finding them to be less useful, while simultaneously not availing themselves of more informal sources – lower-level medical sources such as nurses, books, the Internet, support groups, and friends and family – that are found to be more useful than the more formal sources by the people who do, in fact, use them.

Some studies have found high helpfulness ratings of some other similar types of informal sources. For example, narratives were rated the third most helpful information source in one study (Carlsson, 2000) and other women with the same disease (i.e., breast cancer) were rated the fourth most helpful information source in another study (Raupach

& Hiller, 2002). Similarly, libraries have been identified as a very helpful, but little used, resource for health information (Gollop, 1997; Harris et al., 2006).

There are several potential explanations for these use-usefulness disparities. These explanations are of three types: (1) Ones having to do with the accuracy of the reported data itself; (2) Ones having to do with the use aspect; and (3) Ones having to do with the usefulness aspect.

Regarding the first type, perhaps these findings are clouded by social desirability bias (Groves et al., 2004, p. 155). People may be reporting the sources they feel they *should* use, rather than the ones they actually use. In fact, the results of a recent Health Information National Trends Survey (HINTS) conducted by the National Cancer Institute (2003) seem to support the idea that what people say they would do does not match what they actually do. For example, when asked where they would look for cancer information if they needed to, approximately equal percentages (about 40%) of respondents selected "healthcare provider" and "Internet". However, when asked where they actually did look for cancer information, just 11.4% selected healthcare provider while 46.5% selected the Internet. Although this seems to lend support to the idea that people's actual actions may not match their reported or projected actions, it may also be the case that these findings indicate a low level of satisfaction with cancer-related information from the Internet and a high level of satisfaction with cancer-related information obtained from healthcare providers. Thus, people may be simply expressing this satisfaction/dissatisfaction in indicating that their future information seeking will be more likely to include their healthcare provider and less likely to include the Internet. Interestingly, although the 2005 HINTS data (National Cancer Institute, 2005) support the general pattern suggested by the 2003 data, the disparity between what people say they will do and what they actually did do is quite a bit less. While 45.6% of respondents indicated that they will go to their healthcare provider and 37.9% indicated they will turn to the Internet if they have a strong need for cancer information, 25.4% of respondents consulted their healthcare provider and 41.7% turned to the Internet the most recent time they wanted cancer information. However, the differences between these two datasets could have more to do with wording changes made to the survey questions than to actual changes in people's behaviors and/or their relative preferences for particular information sources.

The second class of explanations – those having to do with use of formal sources and non-use of more informal sources – could include reasons such as lesser awareness of the less formal sources, an inherent bias against using these sources, or a perhaps incorrect preconception that these sources will be less useful.

The third class of explanations – those having to do with usefulness—need to address the questions of why these more formal sources are failing to fulfill people's information needs and how it is that these more informal sources are turning out to be of more help to people than the more formal sources. As mentioned above, information provided during an anxiety-provoking situation, such as receiving a diagnosis of a serious disease or receiving medical treatment of some type, is difficult for many patients to comprehend and/or retain (Ankem, 2006a; Brashers et al., 2000; DeHart, 1996; Hack et al., 1994; Holmes & Lenz, 1997; Luker et al., 1996; Mishel, 1988).

Additionally, some studies have shown that formal sources are sometimes found to be less useful because they are perceived to be less personally relevant and trustworthy (Chatman, 1996; Dervin, 2005) and/or they are found to be incomprehensible (Cooley et al., 1995; DeHart, 1996). Regarding this latter point, one study of the reading ability of ambulatory cancer patients found that just 27% of these patients could reasonably be expected to be able to understand the thirty American Cancer Society and National Cancer Institute pamphlets most commonly provided to cancer patients (Cooley et al., 1995).

Formal sources may be perceived to be less useful than informal sources because of the type of information that they provide. Several researchers (Kutner et al., 1999; Phillips, 1986; Wicks & Frost, 2008; Wong et al., 2000) have distinguished between information about a patient's disease and information about the experience of having a particular illness. The first type of information has been termed "disease-related information" while the second type has been termed "illness-related information" (Kutner et al., 1999). Disease-related information focuses on medical information related to diagnosis, prognosis, and treatment of a disease. Illness-related information, on the other hand, centers on the patient's experience with the illness – how the disease affects them both personally and socially. Illness-related information has been found to be of equal or

greater importance than disease-related information to terminally ill patients (Kutner et al., 1999) and to those recently diagnosed with cancer (McCaughan & McKenna, 2007).

It seems likely that formal sources are more likely to provide disease-related information, while informal sources such as other people with the same disease and illness narratives tend to provide illness-related information. However, some sources blur this line, such as a booklet that was produced by healthcare providers based on their interviews eliciting the personal experiences of people who had been living with chronic arthritis (Swift & Dieppe, 2005). The introductory section of this booklet explains:

> This book has been written for people with chronic arthritis. This booklet does not set out to provide information about the medical side of arthritis. What it does try to present is the "human" side of a disease like arthritis. Its aim is to illustrate the reality of living day to day with arthritis, in the words of those who have to do so. (p. 117)

In contrast to formal sources of information, this booklet presents the patients' expertise rather than the expertise of healthcare professionals. While healthcare professionals' expertise tends to focus on disease-related information, it is the patients who are experts in what it is like to live with a disease. Kutner et al. (1999) state:

> Authoritative information (presumably from a physician source) is relevant for discussion of disease-related issues, such as medications or treatments, but may have little relevance in the illness arena, especially with regards to terminal illness. (p. 1350)

Many information behavior researchers (Case, 2007; Dervin, 2005; Harris & Dewdney, 1994) have pointed out that people like to get information from people like them and nearly all of the health information behavior researchers (Ankem, 2006a; Baker & Pettigrew, 1999; Brooks & Matson, 1987; Carlsson, 2000; Clark, 2005; Davison et al., 2002; DeHart, 1996; Fox & Rainie, 2002; Frost & Massagli, 2008; Hogan & Palmer, 2005; Kivits, 2004; Matthews et al., 2002; McCaughan & McKenna, 2007; Philips, 1986; Warner & Procaccino, 2004; Wathen & Harris, 2006; Wicks & Frost, 2008; Wong et al., 2000) whose work is included in this review have provided confirmation for this, finding that patients like to get information from people with the same disease as them.

2.1.6 Summary: Consumer Health Information Behavior

Information clearly plays a very important role in helping people to cope with an illness; however, the specific nature of this role can vary from person to person and from situation to situation. Sometimes people gather a lot of information and actively participate in health-related decision-making because this helps them to feel in control of their disease; however, other times, people limit their exposure to certain types of information because this helps them to establish and/or maintain a desired level of uncertainty around their illness. The different ways in which people interact with various types of information and various sources of information during the course of their illness can have a profound impact on their emotional and physical experience of their disease, as well as their knowledge about their disease and their ability to make informed decisions in relation to their health. In the following section, the focus narrows to type 2 diabetes and the information behavior of people with type 1 or type 2 diabetes.

2.2 Type 2 Diabetes and the Information Behavior of People with Diabetes

2.2.1 What is Type 2 Diabetes?

2.2.1.1 Overview

Type 2 diabetes is a serious chronic health condition in which either the beta cells in a person's pancreas fail to make sufficient insulin or the person's body becomes unable to effectively use the insulin that is produced. Insulin is a hormone that is required in order for glucose to enter cells. Without sufficient insulin or without the ability to effectively use insulin, glucose builds up in a person's bloodstream instead of supplying requisite energy to the cells throughout his/her body. Because cells are not supplied with the energy they need, a person with type 2 diabetes can develop problems with their eyes, kidneys, nerves, heart, and/or blood vessels. (American Diabetes Association, 2009, pp. 1-3; Becker, 2007, pp. xxii & 4-10).

2.2.1.2 Causes, Risk Factors, and Incidence

Type 2 diabetes is caused by a complex interaction between a person's genetics, his/her lifestyle, and environmental factors (American Diabetes Association, 2011). Risk factors for type 2 diabetes include having immediate family members who have it, being overweight, being older (generally, at least 40 to 45 years old), being physically inactive,

and having pre-diabetes (American Diabetes Association, 2009, p. 5; Mayo Clinic, 2010, pp. 11 & 16-17). Also, people of some races/ethnicities such as African American, Latino, Native American, Asian American, and Pacific Islander, are more likely than others to get type 2 diabetes (American Diabetes Association, 2009, p. 5; Mayo Clinic, 2010, pp. 11 & 16-17). The overall incidence of diabetes in the U.S. has increased dramatically in recent years (Mayo Clinic, 2010, pp. 7 & 9). From 1980 to 2009, the crude prevalence of diagnosed cases of diabetes within the U.S. increased by 164% (Centers for Disease Control and Prevention, 2011). Currently, approximately 25.8 million people in the U.S., representing 8.3% of the population, have either diagnosed (*n* = 18.8 million people) or undiagnosed (*n* = 7.0 million people) diabetes (National Center for Chronic Disease Prevention and Health Promotion, 2011, p. 1). Type 2 diabetes makes up approximately 90% to 95% of the diagnosed cases (National Center for Chronic Disease Prevention and Health Promotion, 2011, p. 11). Diabetes is currently the seventh leading cause of death in the U.S. (National Center for Chronic Disease Prevention and Health Promotion, 2011, pp. 1 & 7; Mayo Clinic, 2010, p. 9).

2.2.1.3 Symptoms and Tests

There are many symptoms commonly associated with type 2 diabetes, including excessive thirst; frequent urination; lack of energy; constant hunger; blurred vision; dry, itchy skin; tingling, numbness, or pain in hands or feet; skin, gum, bladder, and/or vaginal infections that are slow to heal and that tend to recur (American Diabetes Association, 2009, p. 3; Chase, 2007, p. 11; Mayo Clinic, 2010, p. 15). However, some people with this condition have no symptoms at all and only find out that they are diabetic because their doctor runs a blood test and ascertains that they have it (American Diabetes Association, 2009, p. 3; Mayo Clinic, 2010, p. 14). Common blood tests that are used to diagnose diabetes include the fasting plasma glucose test (FPG) and the oral glucose tolerance test (OGTT). Both of these tests determine whether the amount of glucose being carried in the bloodstream is too high. (American Diabetes Association, 2009, p. 3)

2.2.1.4 Potential Complications

Diabetes can lead to quite serious complications involving a person's heart, brain, kidneys, eyes, legs and feet, blood vessels, and/or nerves. These complications are caused by the prolonged presence of excessive glucose in the bloodstream, which is toxic to the beta cells in the pancreas. Some of the possible consequences of this process include atherosclerosis, which is hardening of the arteries; heart attack; ischemic stroke; hemorrhagic stroke; kidney disease and/or failure; retinopathy, which is damage to the blood vessels in the eye, cataracts, and glaucoma; poor circulation in the legs and feet; hypertension, which is high blood pressure; high levels of fats in the blood, such as high cholesterol and high triglycerides; and neuropathy, which is nerve damage. (American Diabetes Association, 2009, pp. 97-115)

2.2.1.5 Strategies for Managing Type 2 Diabetes

Although type 2 diabetes is associated with a wide range of potential complications, there are many actions that people with this condition can take in order to reduce their risk of ever having them actually occur (American Diabetes Association, 2009, pp. 9 & 97; Becker, 2007, pp. xvii-xviii & 59; Centers for Disease Control and Prevention, 2007; Chase, 2007, pp. 49 & 87; Mayo Clinic, 2010, pp. 20 & 48; National Center for Chronic Disease Prevention and Health Promotion, 2011). In fact, Becker (2007) points out that getting a chronic disease is the best way to ensure your longevity as it "makes you take care of yourself" (p. xxii). However, this assumes, of course, that one receives a timely diagnosis of the chronic disease and that one is motivated and able to acquire the necessary information about their disease and to undertake the requisite behavior changes.

The most important thing a person with diabetes can do in order to prevent long-term complications is to maintain control over his/her blood glucose level (Mayo Clinic, 2010, p. 24). In fact, effective management of the amount of glucose in the blood has been found to reduce the risk of complications involving the eyes, kidneys, heart, and nerves by more than 50 percent (Chase, 2007, p. 87). Behaviors that help one to successfully manage their blood glucose levels include making appropriate food choices, exercising, maintaining a healthy weight, and taking diabetes medications (American

Diabetes Association, 2009, pp. 5-7 & 131; Chase, 2007, pp. 11-12; Mayo Clinic, 2010, p. 24).

Regular testing of blood glucose levels is a critically important strategy for managing this disease (American Diabetes Association, 2009, pp. 7-9; Chase, 2007, p. 49; Mayo Clinic, 2010, pp. 23-24). In addition to regularly tracking one's own blood glucose levels using a blood glucose meter or glucometer, people with type 2 diabetes should have an A1C, or glycated hemoglobin, test performed by their doctors at least twice per year and possibly even more often (American Diabetes Association, 2009, p. 9; Mayo Clinic, 2010, p. 133 & 136). Whereas the first type of test just provides a snapshot of a person's blood glucose level at that one particular point in time, an A1C test provides an average across approximately the past three months. The results of this test tell a person with type 2 diabetes how well they have been doing over the past several months in terms of controlling their blood glucose levels overall (American Diabetes Association, 2009, pp. 8-9). There is some disagreement as to what is a "good" A1C test result; however, people with type 2 diabetes are often told to aim for an A1C of less than 6 or 7 (American Diabetes Association, 2009, p. 8; Becker, 2007, pp. 52-53; Chase, 2007, pp. 49-50; Mayo Clinic, 2010, p. 19). It has been found that, in general, a one-point drop in an A1C test result (e.g., 8.0 to 7.0) can reduce a person's risk of microvascular complications (those relating to the eyes, kidneys, and nerves) by 40% (National Center for Chronic Disease Prevention and Health Promotion, 2011, p. 10).

Although these strategies enable people with type 2 diabetes to mitigate their risk for potential complications, they cannot be implemented without the requisite information and knowledge. Knowing what their physical symptoms may mean and knowing to get tested for diabetes are just the beginning. Upon learning of their diagnosis, patients are faced with the need to learn a lot about their condition and how to manage it. Becker (2007) states, "Diabetes, perhaps more than any other chronic disease, must be managed in large part by the patient" (p. xxiii). The American Diabetes Association (2009) similarly tells patients, "nearly all of your diabetes treatments will be things you do yourself or decisions you make…" (p. 5). The American Diabetes Association's (2009) admonitions to people with type 2 diabetes to make appropriate choices about what foods to eat and in what combinations, when to eat, and how much to

eat, as well as choices about how to exercise and when to exercise require people to possess a great deal of general knowledge about how these choices are likely to affect their blood glucose levels. This knowledge must then be further tweaked through the use of a glucometer to measure the actual effects of these choices on one's *own* blood glucose levels (American Diabetes Association, 2009, pp. 7-8). Developing the knowledge required to make the best possible choices necessitates convenient access to information that is both understandable and usable to the person with this condition. In the following section, some of the studies that have investigated the information behavior of people with diabetes will be described.

2.2.2 Empirical Studies of the Information Behavior of People with Diabetes

Diabetes is the fourth (following behind allergies, cancer, and heart disease) most commonly researched diseases among Internet users (Larkin, 2000). However, it appears that relatively little has been written within the Library and Information Science field specifically focused on the information behavior of people with diabetes. This is especially true in comparison to the much more extensive literature covering the information behavior of people with other diseases, such as cancer and HIV/AIDS. For example, as of early 2010, a search in the LISA (Library and Information Science Abstracts) database for records with descriptors containing the word "information" and titles containing the word "diab*" yielded just 14 records. In contrast, a similar search substituting "cancer*" for "diab*" yielded well over 100 records and substituting "HIV" or "AIDS" for "diab*" yielded over 200 records. As of July 2011, this disparity remains. The search for records with descriptors containing the word "information" and titles containing the word "diab*" yielded 20 records, while a similar search for "cancer*" yielded 146 records and a search for "HIV*" or "AIDS" yielded 220 records. This relative lack of coverage of diabetes is interesting because it seems likely that diabetes is potentially more amenable to patient control than cancer or HIV/AIDS, which suggests that the link between information behavior and ultimate health outcome may be even stronger for people with diabetes than for people with either cancer or HIV/AIDS. In the remainder of this section, some of the studies that have been done within the LIS field, as well as in other closely allied fields such as nursing and communication, will be briefly discussed. Although not all of these studies set out to specifically study information

behavior, the importance of information in enabling people with diabetes to manage their condition shines through nonetheless.

Felton and Revenson (1984) investigated the consequences of patients' use of different coping strategies when dealing with a chronic illness and whether the impact of these strategies is influenced by the degree of controllability of a person's particular chronic illness. They conducted initial interviews and follow-up interviews with people with rheumatoid arthritis, cancer, hypertension, or diabetes. The first two of these illnesses, rheumatoid arthritis and cancer, were deemed less controllable than the latter two, hypertension and diabetes. These researchers measured the degree to which participants were using each of two coping strategies – an instrumental strategy (information seeking) and a palliative strategy (wish-fulfilling fantasy). They hypothesized that information seeking would be a more adaptive strategy for those with a more controllable illness and that wish-fulfilling fantasy would be a more adaptive strategy for those with a less controllable illness. However, they found that information seeking was a more adaptive strategy regardless of the controllability of a person's particular illness. Felton and Revenson conclude, "people with more accurate and extensive information about how to care for themselves may be better informed about the meaning of their symptoms or may engage in more appropriate health practices" (p. 351). They further explain that their findings suggest that "the value of information seeking extends beyond the value of the information obtained" (p. 351).

Biddle (2004) surveyed 49 diabetics, asking them to rank order different information topics based on how important they felt they were for newly diagnosed diabetics. She found that the topic rated to be the most important for people newly diagnosed with type 2 diabetes was the "importance & availability of regular eye testing" (p. 14). Interestingly, this outranked "Self-monitoring: why, when & how to test the glucose and urine levels" (p. 14) for type 2 diabetics, but not for type 1 diabetics. Also, while males rated "importance & availability of regular eye testing" (p. 14) as the most important topic for newly diagnosed diabetics, females selected "understanding the relationship between blood glucose levels, dietary intake & physical activity" (p. 14). Biddle concludes that it is important to take into account diabetics' personal

characteristics (such as gender and type of diabetes) when attempting to ascertain individual information needs.

Schoenberg, Amey, and Coward (1998) interviewed 51 women aged 65 or over who had been diagnosed with type 2 diabetes in order to investigate their diabetes-related information source use, the relationship between their information source use and their scores on a diabetes knowledge test, and the relationship between their source use, their scores on this test, and their ethnicity (African American or white). They found that both groups of women used a wide variety of sources to obtain diabetes information and that there was little variation between the two groups for this variable. The only information sources for which there was a significant difference were religious affiliations and informal networks. African-American women were almost four times more likely to report receiving information through a religious affiliation, while white women were more likely to report receiving information through informal networks. Another difference that didn't quite reach statistical significance is that African-American women were more likely to report getting diabetes information from the TV or radio. Schoenberg et al. found very little relationship between people's sources of diabetes information and their scores on the diabetes knowledge test. The only source that was found to impact one's test results was use of informal sources. People who reported getting diabetes-related information from an informal network, that is their family members and friends, scored 13.8 points lower on the test. Test scores did differ based on ethnicity – African-American women scored significantly lower than white women; however, neither group did very well. African-American women averaged 36% correct while white women averaged 47% correct. The authors determined that this difference in test scores was actually due to a disparity in educational attainment across the two participant groups. They conclude that although people's specific sources of diabetes-related information have little influence over their diabetes knowledge, their educational backgrounds need to be taken into account. They call for diabetes education efforts that are appropriate to targeted groups' educational levels and point out that this will benefit everyone as "People under stress have limited ability to understand, and otherwise-able readers prefer their information brief and concise" (p. 323). Furthermore, they emphasize that diabetes education needs to be ongoing in order to enable participants to keep this information

fresh in their mind years after receiving their initial diagnosis and to have access to updated information as it becomes available.

Heisler, Bouknight, Hayward, Smith, & Kerr (2002) surveyed 1,314 people receiving diabetes-related care through a Veterans' Affairs facility, asking them to evaluate their doctor's participatory decision-making and communication styles, as well as their own understanding of diabetes self-care and their actual performance of diabetes self-management activities, such as taking prescribed medications, adhering to an eating plan, getting regular exercise, testing blood sugar levels, and checking their feet for sores. They found strong associations between patients' reported performance of self-management activities and their perceptions about their doctor's decision-making and communication styles. Overall, participants' perceptions about their doctor's imparting of information to them were more predictive of their self-management activities than were their perceptions about their doctor's participatory decision-making style. Heisler et al. state:

> Patients who rated their physicians as providing more information and involving them more in decision making had significantly better self-reported understanding of diabetes care, and it was patient understanding that had the strongest independent effect on self-management. (p. 250)

Burke, Earley, Dixon, Wilke, and Puczynski (2006) conducted focus groups with type 2 diabetes patients in order to learn about their experiences with diabetes and about their goals for their regular doctor appointments. On the basis of these focus groups, they identified six interrelated themes – "complications and comorbidities, time, control, information, family influences, and the physician-patient encounter" (p. 107). Participants expressed an ongoing need for reliable information that would help them to manage their diabetes, both in terms of maintaining glycemic control and self-control. They also expected their doctors to tell them about the resources available to them, such as specific types of specialists or certain types of equipment that might help them to manage their condition. One participant was unhappy with doctors' inability to give him useful information about living with diabetes and successfully managing it. He stated, "There are very few doctors that are diabetics… they just, you know, they could talk about a lot of the medical side of it, but the living side of it you've just got to find out yourself more or less" (pp. 109-110). In addition to doctors, participants also reported

getting diabetes-related information from family members, print materials, and the Internet. Some participants also mentioned acquiring information from observing the experiences of family members with diabetes. Burke et al. conclude, "In general, physicians underestimate patients' desire for information (Waitzkin, 1984). Physicians may be especially prone to underestimate the information needs of patients who have been receiving treatment for a long time" (p. 110).

Hoffman-Goetz, Donelle, and Thomson (2009) recently performed a content analysis of conversations that took place in an online health forum for retired Canadians. They identified all responses to posted questions pertaining to non-insulin-dependent type 2 diabetes and compared these responses with published guidelines for Canadian clinical practice. They identified seven requests for information that resulted in 17 responses containing a total of 35 recommendations. These questions and answers covered several topics, including goals for A1C tests, diet, exercise, neuropathy, and retinopathy. They found that, contrary to concerns about the accuracy of online recommendations from peers about diabetes care and management, 91% (32 of 35) of the recommendations offered were consistent with best practice clinical guidelines. The authors speculate:

> Our findings may represent a group of older Internet users who have developed and continue to develop interactive health literacy skills enabling reliable information seeking and sharing. This may reflect a shift in type II diabetes management, where increasingly knowledgeable individuals, or "lay experts", with a high level of interactive health literacy, become their own Internet information and management resources. (p. 96)

In conclusion, they call for research "to determine whether consumer self-care practices that deviate from 'accurate' information are harmful or if they simply represent tailored adaptations to self-care regimens made by lay experts with high interactive health literacy skills" (p. 97).

2.2.3 Summary: Type 2 Diabetes and the Information Behavior of People with Diabetes

Type 2 diabetes is a chronic serious health condition that is potentially controllable. However, people with this condition have both initial and ongoing needs for information that must be satisfied in order for them to be able to successfully manage this disease. In order to fill these needs for information, people turn to several different

sources, including doctors, family members, friends, and other people with diabetes. They also use a variety of different media types, including written materials, radio, TV, and the Internet. Some of the factors that have been found to be relevant to the information behavior of people with this disease are their gender, age, and educational attainment, as well as the ways in which their doctors impart information to them and the extent to which their doctors involve them in decision-making related to their health.

Information behavior, whether diabetes-related or not, is largely driven by people's perceptions about the likely potential usefulness of various types and sources of information. This illuminates the need to investigate what it is that motivates people's judgments about the potential or actual usefulness of various types of information. In the following section, the concept of usefulness will be analyzed, beginning with two related terms that are more commonly mentioned in the information science literature – relevance and pertinence.

2.3 Relevance, Pertinence, and Usefulness within Information Behavior

This section of the literature review focuses on the extensive body of literature that has speculated on, and attempted to define, the concept of relevance and the closely related concepts of pertinence and usefulness. This section is of particular importance as it delineates the rationale for choosing to use the term 'usefulness' as opposed to the more commonly used term of 'relevance' for this research.

2.3.1 Relevance

Before surfacing within the context of information science, the concept of relevance has been explored within several different fields, including logic, philosophy, sociology, cognitive psychology, and linguistics (Saracevic, 1975; Saracevic, 1996). Across these various fields, relevance has been deemed to be: an interdependent set of three systems of relevance – topical, motivational, and interpretational (Schutz, 1970); a subjective, comparative assessment of the effort required to optimally process a stimulus versus the cognitive effects that will result from such processing (Sperber & Wilson, 1995); and an objective assessment of whether a particular plan will enable a specific person to reach a particular goal (Gorayska & Lindsay, 1993). Saracevic (1975) writes,

"It has remained for information science to struggle with relevance in relation to communication" (p. 323).

Although relevance has been credited with being the key notion behind both the emergence of the field of information science (Mizzaro, 1997; Saracevic, 1975, 1996, & 2007a) and the very definition of information (Borlund, 2003; Furner, 2004), it remains a somewhat elusive concept that is neither fully understood nor agreed upon (Froehlich, 1994; Mizzaro, 1998; Schamber, 1994; Schamber, Eisenberg, & Nilan, 1990). Over thirty years ago, Wilson (1973) noted that "relevance is not a single notion, but many" (p. 457). Relevance has been referred to as an "intuitive, primitive, "y'know" notion" and as a "fundamental aspect of human communication" (Saracevic, 1975, p. 324). It has more recently been described as simultaneously cognitive and subjective; situational; complex and multidimensional; dynamic; and systematic, observable, and measurable at a specific point in time (Barry & Schamber, 1998; Schamber et al., 1990). Relevance has been more specifically defined as "a dynamic concept that depends on users' individual judgments of the quality of the relationship between information and information need at a certain point in time" (Schamber et al., 1990). Similar conceptualizations have been reached by both Barry (1994) and Park (1993 & 1994). Barry (1994) coined the term "user-defined relevance", defining it as "any connection that exist[s] between the users' information need situations and the information provided by documents" (p. 152). Using the similar term "user-based relevance", Park (1994) states:

> A user's view of relevance is concerned with the topic of the problem but also includes much more. It involves an individual's goal and task in terms of one's information need in that particular situation (moment): such as why one needs information, for what purpose, and how one will find the information in addition to what one already knows about the problem at hand, what previous experience one has, what stage of research one is in, what time frame exists, what the anticipated product is, and so forth. (p. 136)

More formally, relevance has been defined as encompassing both a relation between two entities along some particular property and a measure of that relation (Saracevic, 2007a). The types of entities that could be involved in this relation include information or an information object on the one hand, and contextual variables such as situations (which are comprised of variables such as a person's problem or task, intent, and information need), cognitive states, and/or affective states on the other. The types of

properties along which this relation can be evaluated include notions such as topicality, utility, and cognitive match (Saracevic, 2007a). This description of relevance helps to illuminate the fact that not only are there multiple types of relevance, but an investigation into any one of these types of relevance necessitates the study of the many different dimensions of which that type of relevance is composed.

Many different types of relevance have been defined in the information science literature. Saracevic (2007a) groups all of them into the following five major categories: (1) system or algorithmic relevance; (2) topical or subject relevance; (3) cognitive relevance or pertinence; (4) situational relevance or utility; and (5) affective relevance. The first type of relevance, system relevance (including the form of topicality that "concerns itself only with a restricted form of language – with terminology representing the topics of question statements and document records" (Harter, 1992, p. 613)), has been termed "objective relevance" and "weak relevance", while the last three have been termed "subjective relevance", the major distinction being that subjective relevance takes the user into account while objective relevance does not (Harter, 1992). Borlund (2003) further points out that algorithmic relevance is context-free, while the subjective (or user-based) forms of relevance are context-dependent.

According to Saracevic (2007a), system relevance simply refers to the ability of an information system to retrieve relevant objects. Topical relevance, which forms the basis for system relevance (Borlund, 2003), represents the degree to which information is about the desired topic. Cognitive relevance reflects the degree of fit between the universe of information available and the information a user already has, on the one hand, and the information retrieved or made available, on the other. Situational relevance is about the relationship between information and a person's particular problem, task, or situation. Affective relevance, which Saracevic (2007a) points out actually underlies all other forms of relevance, reflects the relationship between information and a person's intents, goals, emotions, and motivations. Borlund (2003) argues that affective relevance is not an independent type of relevance since it is "characteristic of all of the subjective types of relevance" (p. 915).

For each type of relevance, people use different criteria when making relevance judgments (Saracevic, 2007a). For example, topical relevance is inferred based on

aboutness while cognitive relevance is inferred based on various types of cognitive criteria, such as informativeness, novelty, and information quality. Similarly, situational relevance is inferred based on usefulness of information for a particular problem or goal while affective relevance is inferred based on various affective factors, such as a person's degree of satisfaction or perceived level of success. Clearly, these various criteria are not limited to just objective characteristics of the information, itself. In fact, Rieh (2002) identifies the following additional, more subjective, categories of relevance criteria: a user's knowledge, including both their system-related and domain-related knowledge and both their knowledge based on their own first-hand experience and their second-hand knowledge; a user's situation; and a user's general assumptions (p. 153).

Rieh (2002) points out that although a large number of relevance criteria have been identified across empirical studies of people's relevance judgments (Barry, 1994; Cool, Belkin, Frieder, & Kantor, 1993; Park, 1993; Schamber, 1991; Spink & Greisdorf, 2001; Wang & White, 1999), there are two factors that tend to appear consistently throughout these studies – information quality and cognitive authority. Drawing on R. S. Taylor's (1986) definition of quality from his development of the Value-Added model and Wilson's (1983) definition of cognitive authority, Rieh (2002) states, "It is believed that they [information quality and cognitive authority] may be more important relevance criteria than any other criteria identified in the previous studies" (p. 145). Rieh (2002) further points out that Bateman's (1999) study provides support for this belief, finding that the constructs of information quality (i.e., accurate, understandable, consistent, current, and focused), information credibility (i.e., credible, about my topic, and well-written), and information completeness (i.e., suitably general or specific, detailed, and comprehensive) jointly explain 48% of the variance in her respondents' positive relevance judgments. The participants in Rieh's (2002) study expressed information quality in terms related to the information's "goodness, accuracy, currency, usefulness, and importance" (p. 152), while they expressed cognitive authority in terms related to the information's "trustworthiness, reliability, scholarliness, credibility, officialness, and authoritativeness" (p. 153). Rieh emphasizes that information quality and cognitive authority are not independent concepts – users' information quality judgments are often influenced by their cognitive authority judgments and vice-versa.

Furthermore, Rieh (2002) points out that people assess information quality and cognitive authority by making two different types of judgments – predictive and evaluative. Whereas predictive judgments describe people's beliefs and expectations about the likely usefulness of information they have not yet accessed, evaluative judgments describe their assessments of the actual usefulness of information once they have accessed it. Rieh found that people use different criteria for these judgments depending both on the specific task in which they were engaged and the particular type of judgment they were forming – predictive or evaluative. The criteria most often associated with people's predictive judgments of information were the system knowledge and domain knowledge they had developed through both first-hand experience and through acquisition from other people (i.e., second-hand knowledge). In contrast, the criteria most often associated with people's evaluative judgments of information were characteristics of the information objects, such as the type of information object, its content, and its presentation. However, source characteristics were found to be important criteria regardless of whether the person was making a predictive judgment or an evaluative judgment.

Although Saracevic's (2007a) five categories of relevance, along with the various criteria that users apply in order to assess various types of relevance, are highly interdependent and likely to all be simultaneously operational to a greater or lesser degree within any given human information behavior, it seems that cognitive relevance is the only type that must absolutely be present in order to reach the next most restrictive form of relevance, pertinence, and that situational relevance must then be additionally achieved in order to reach what would seem to be the most restrictive form of relevance, usefulness.

2.3.2 Pertinence

Like the concept of relevance, the concept of pertinence has been assigned different definitions by various researchers (Foskett, 1972; Goffman & Newill, 1966; Kemp, 1974; Lancaster, 1979; Soergel, 1994) over the years. However, what seems fairly consistent among these definitions is that pertinence is a subjective form of relevance and that cognitive relevance is a necessary precondition for pertinence. For example, Soergel (1994) states that information is pertinent if "it is topically relevant and if it is appropriate

for the person, that is, if the person can understand the document and apply the information gained" (p. 590). Similarly, Kuhlthau (2004) states:

> Pertinence is a determination that information has a more decisive and significant relationship to a topic than relevance and is related to personal information need. Pertinent information is to the point and contributes to understanding or the solution of a problem. (p. 42)

Although Soergel and Kuhlthau require both topicality and some degree of cognitive relevance for pertinence, a stronger view about the centrality of cognitive relevance rather than topicality to the overarching concept of relevance is expressed by Harter (1992). Harter's concept of psychological relevance completely subordinates the importance of topicality to that of cognitive relevance. He explains "In information retrieval, references on the topic may be less important than relevant references on the topic – references that allow the making of new intellectual connections or cause other cognitive change" (p. 612).

Interestingly, Harter's (1992) contention that topicality is neither necessary nor sufficient for achieving relevance was predated by 15 years by an observation made by a researcher (Hutchins, 1977) who wrote about the inadequacies of the subject indexing practices of the time. Hutchins points out that indexers do a disservice to users by adhering to the commonly accepted definition of "aboutness". Rather than indicating what a document is about by simply summarizing its contents, Hutchins recommends that subject indexers leave content summarization to abstracting services and that they instead focus on summarizing the knowledge that a document's author presupposes in his or her readers. He felt that this would help a reader to be able to seek out documents with more confidence that he "will in fact learn something 'new' about the topic" and that he will be "brought into contact with documents which have the potential to enlarge his present state of knowledge". Hutchins' recommendation seems to have been an early attempt to advance information systems from retrieving results that were deemed relevant based on mere topicality to retrieving results that were deemed to be relevant based on a form of relevance that takes the user's existing stock of knowledge into consideration – cognitive relevance.

Another significant concept that seems highly related to Hutchins' proposed alternative form of aboutness, and thus, to pertinence, is "uncertainty absorption" (March

& Simon, 1993). Uncertainty absorption is the process that "takes place when inferences are drawn from a body of evidence and the inferences, instead of the evidence itself, are then communicated" (p. 186). As mentioned above, cognitive relevance reflects the degree of fit between the entire pool of information available and a person's existing knowledge, on the one hand, and the information that he or she has retrieved or encountered, on the other. The degree to which uncertainty has been or is perceived to have been absorbed, as well as the specific ways in which it has been or is perceived to have been absorbed, are highly likely to greatly influence this degree of fit.

Whereas the term 'relevance' has been used to refer to many different types of relevance, the term 'pertinence' seems to have mostly been used to refer to cognitive relevance. Some authors (Goffman & Newill, 1966; Kemp, 1974; Rees, 1963) have distinguished between relevance and pertinence by pointing out that relevance is something that can be determined by people other than the user, while pertinence can only be determined by the user who has the actual information need. As Rees (1963) puts it, "relevancy is a property which corresponds to a question, while pertinency is a property which corresponds to a need" (p. 358). Similarly, Goffman and Newill (1966) state, "The difference between relevance and pertinence is that the relevant documents answer the user's query and the pertinent documents answer the user's information need" (p. 22). On a related note, Kemp (1974) points out that relevance has to do with public knowledge – what is known about a particular subject area – while pertinence has to do with private knowledge – what a user already knows on the subject. However, Kemp's definition of pertinence goes even farther, seeming to cross the line into both situational relevance and the most restrictive form of relevance, usefulness. Kemp states, "Pertinent documents are those which [a user] finds useful, because they have a bearing on his particular situation" (p. 37). Foskett (1972) similarly defines pertinence as "adding new information to the store already in the mind of the user, which is useful to him in the work that prompted the request" (p. 77). Foskett further points out that scientific revolutions are fueled by information that is pertinent even though it is not relevant; that is, by information that is pertinent but that is not already part of the existing universe of generally accepted knowledge in a particular field. In the next section, how information that is deemed to be pertinent becomes deemed to be useful will be discussed.

2.3.3 Usefulness

In order to be useful, information needs to be both cognitively relevant and situationally relevant – that is, it must be cognitively understandable and usable to the person with the information need and it must fit his/her perceived situation as reflected in his/her particular task, problem, or context at the given moment. Wilson (1973) defines situational relevance as "relevance to a particular individual's situation – but to the situation as he sees it, not as others see it or as it 'really' is" (p. 460). However, he further restricts this definition, indicating that information is situationally relevant only if it relates to an aspect of a person's situation that is currently of concern to him/her. Furthermore, Wilson coins the term "significant situational relevance", indicating that situationally relevant information is only significant if "it is new information to the recipient at the time of its receipt" (p. 467). He points out that although it is impossible for information systems to do so, "we serve each other as sources of significant situationally relevant information, and do so by virtue of our knowledge of each other's views of the world, preferences, and learning styles" (p. 470). It seems likely that information is most useful when the uncertainty absorption process has been performed by either someone who knows us quite well or by someone who shares our world view, preferences, and learning styles.

Just as with 'relevance' and 'pertinence', the term 'usefulness' has been defined differently by different researchers and has been used interchangeably with other related terminology. Based on Saracevic's (1975 & 2007a) and Mizzaro's (1997) literature reviews on relevance, it appears that relatively few relevance researchers (Cool et al., 1993; Cooper, 1971 & 1973; Janes, 1994; Rees, 1966; Rees & Schultz, 1967; Saracevic, Kantor, Chamis, & Trivison, 1988) have actually used the term 'usefulness'. The term 'utility' appears to have been far more common. In some cases, utility has been equated with usefulness (Cooper, 1971 & 1973; Janes, 1994; Saracevic et al., 1988; Soergel, 1994), while in others (Kochen, 1974) it has been defined in more of an economic sense; that is, in terms of a utility function that is based on a user having known and completely expressible preferences. In fact, one researcher (Regazzi, 1988) concludes basically that there is no difference between relevance (i.e., topicality) and utility (i.e., usefulness) in the context of evaluating documents retrieved from an information retrieval system.

Saracevic (2007a) defines usefulness simply as one of the criteria by which situational relevance or utility is inferred. In contrast, Cooper (1973) defines the term 'utility' (or usefulness) much more broadly as a "catch-all concept involving not only topic-relatedness but also quality, novelty, importance, credibility, and many other things" (p. 92). He points out that "the purpose of a retrieval system is (or at least should be) to retrieve documents that are useful, not merely relevant" (p. 92). Schamber et al. (1990) state, "We feel it is Cooper's conceptualization of utility that suggests the broadest range of meanings underlying relevance from the user's perspective" (p. 764).

Cooper's (1973) definition is also much more similar to the ways in which many consumer health information behavior researchers define the term 'relevance'. For example, in her empirical study of women's perceptions of the quality of health information available online, Marton (2003) defines quality as consisting of both relevance and reliability and she then defines relevant health information for her survey respondents as "health information that is needed and useful with respect to your health and/or the health of those you care for. It is often considered to be comprehensive and timely" (p. 199). Similarly, consumer health information behavior researchers Crystal and Greenberg (2006) define relevance as "usefulness to an individual's information need in the context of his or her background and interests (i.e., 'situational relevance'; Borlund, 2003)" (p. 1372).

A definition of usefulness that seems particularly well-suited to a study of consumer health information behavior is offered by Saracevic (1975), who describes that information that has utility is information "that helps to directly resolve given problems, that directly bears on given actions, and/or that directly fits into given concerns and interests" (p. 334). This definition seems to be an ideal definition for 'usefulness', as it clearly incorporates both cognitive relevance and situational relevance. Hersh (1994) takes this even one step further, indicating that relevance must incorporate not only cognitive relevance and situational relevance, but also an assessment of the impact and the ultimate outcome of having interacted with an information system or of having had access to specific information. Similarly, Xu and Chen (2006) state, "the term *relevance*… encompasses both cognitive and situational relevance. We define it as the

perceived cognitive and pragmatic impact of the *content* of a document in relation to the user's problem at hand" (p. 962).

Due to the extensive and highly inconsistent use of the term 'relevance' and the resultant obfuscation of this concept, as well as to the more restrictive connotations that tend to be associated with the term 'usefulness', the latter term seems most appropriate for this proposed research. Whereas 'relevant' is defined in an everyday dictionary (Agnes, 2003) as "relating to the matter under consideration; pertinent" (p. 544), 'useful' is defined as "that can be used; serviceable; helpful" (p. 710). Thus, the concept of usefulness not only incorporates perceived relatedness, but also both usability and ultimately, helpfulness. The conceptualization of the term 'usefulness' here is intended to encompass not only Saracevic's (2007a) concepts of cognitive relevance, affective relevance, and situational relevance, but also Hersh's (1994) and Xu and Chen's (2006) extension of the definition of relevance to incorporate impact/outcome. Saracevic's (2007a) concept of topical relevance may or may not be encompassed by the conceptualization of usefulness proposed here, since (apparently) topical information may prove not useful and apparently non-topical information may prove useful. As described by Taylor (1968) and Belkin, Oddy, and Brooks (1982), people's information needs, their understandings of their information needs, and their ability to articulate these needs evolve; therefore, an individual's ability to successfully recognize topically relevant information or to effectively and efficiently dismiss non-topically relevant information may vary across time. Thus, topical relevance may be, but does not have to be, incorporated in the concept of usefulness. Support for this contention can be found in Spink and Greisdorf (2001), who found that two of the reasons that their study participants rated documents to be only partially relevant was because they were on topic, but not useful or they were useful, but not "on target" (p. 169).

The way the concept of usefulness is being defined for the purpose of this research is most closely related to Cooper's (1971 & 1973) concept of utility; Foskett's (1972), Kemp's (1974), and Kuhlthau's (2004) definitions of pertinence; Wilson's (1973) and Saracevic's (2007a) conceptualizations of situational relevance; Schamber et al.'s (1990) and Barry and Schamber's (1998) dynamic, situational definition of relevance; Barry's (1994) user-defined relevance and Park's (1994) user-based relevance; Hersh's

(1994) and Xu and Chen's (2006) definitions of the concept of relevance that extend to include the eventual impact/outcome of having been able to find and access particular information; Janes' (1994) "Big Black Question Mark"; R. S. Taylor's (1986) concept of value from his Value-Added Model; Rieh's (2000 & 2002) and Rieh and Belkin's (1998 & 2000) interdependent concepts of information quality and cognitive authority; and Cole et al.'s (2009) definition of usefulness that incorporates relevance as one of the possible criteria by which usefulness may be judged. See Table 1 for a recap of these authors' definitions of these terms.

Table 1: Glossary of Terms Most Closely Related to the Conceptualization of 'Usefulness' Employed for this Research

Umbrella Concept	Term	Author (Year)	Definition	Contribution to Conceptualization of 'Usefulness'
Utility	Utility	Cooper (1971)	"has to do with the ultimate usefulness of the piece of information to the user" (p. 20)	These older definitions of utility are quite similar to the conceptualization of usefulness proposed here; however, they do not contribute as much as later definitions of the related term 'relevance' because they are not very specific.
	Utility	Cooper (1973)	"a cover term for whatever the user finds to be of value about the system output, whether its usefulness, its entertainment, or aesthetic value, or anything else" (p. 89) "a catch-all concept involving not only topic-relatedness but also quality, novelty, importance, credibility, and many other things" (p. 92)	
Pertinence	Pertinence	Foskett (1972)	"adding new information to the store already in the mind of the user, which is useful to him in the work that prompted the request" (p. 77)	These definitions of pertinence are also very similar to the conceptualization of 'usefulness' proposed here. In fact, the definitions proposed by all three of these researchers seem to equate 'pertinence' with 'usefulness'.
	Pertinence	Kemp (1974)	"pertinent documents are those which [a user] finds useful, because they have bearing on his particular situation [3]" (p. 37) "pertinence is assessed subjectively, by the user against his need (and in the light of other factors which affect the usefulness of a document in meeting that need)" (p. 38)	

Umbrella Concept	Term	Author (Year)	Definition	Contribution to Conceptualization of 'Usefulness'
Pertinence (Cont'd.)	Pertinence	Kuhlthau (2004)	"Pertinence is a determination that information has a more decisive and significant relationship to a topic than relevance and is related to personal information need. Pertinent information is to the point and contributes to understanding or the solution of a problem. Pertinence is the determination that information is germane to the focus of a research topic and is considered most useful in a search for information" (p. 42)	
Relevance	Situational Relevance	Wilson (1973)	"relevance to a particular individual's situation – but to the situation as he sees it, not as others see it or as it 'really' is" (p. 460) "items of information are situationally relevant if they answer, or help answer, questions of concern" (p. 463)	These definitions of 'relevance' are all highly applicable to the conceptualization of 'usefulness' proposed here, particularly because of their emphasis on the subjective, dynamic, and situation-bound nature of relevance. In fact, the last two definitions in this section of the table (those of Hersh, 1994 and Xu & Chen, 2006) appear to even encompass the very manifestation of the usefulness of information – its ultimate impact on the outcome of a person's current situation.
	Situational Relevance	Saracevic (2007a)	"Relation between the situation, task, or problem at hand, and information objects (retrieved or in the systems file, or even in existence). Usefulness in decision making, appropriateness of information in resolution of a problem, reduction of uncertainty, and the like are criteria by which situational relevance is inferred" (p. 1931)	
	Relevance ("a dynamic, situational definition")	Schamber, Eisenberg, & Nilan (1990)	"a *dynamic* concept that depends on users' individual judgments of the quality of the relationship between information and information need at a certain point in time" (p. 771)	

Umbrella Concept	Term	Author (Year)	Definition	Contribution to Conceptualization of 'Usefulness'
Relevance (Cont'd.)	Relevance	Barry & Schamber (1998)	"We assume that relevance is (1) cognitive and subjective, depending on users' knowledge and perceptions; (2) situational, relating to users' information problems; (3) complex and multidimensional, influenced by many factors; (4) dynamic, constantly changing over time; and yet (5) systematic, observable and measurable at a single point in time" (p. 221)	
	User-defined Relevance	Barry (1994)	"it is the user who ultimately decides if the retrieved documents are useful and in some way satisfy the need that brought the user to the system" (p. 150) "Within this study, relevance was conceptualized as any connection that existed between the users' information need situations and the information provided by documents. This concept was operationalized as users' decisions to pursue or not pursue documents" (p. 152)	
	User-based Relevance	Park (1994)	"a user's view of relevance is concerned with the topic of the problem but also includes much more. It involves an individual's goal and task in terms of one's information need in that particular situation (moment): such as why one needs information, for what purpose, and how one will find the information in addition to what one already knows about the problem at hand, what previous experience one has, what stage of research one is in, what time frame exists, what the anticipated product is, and so forth" (p. 136)	

Umbrella Concept	Term	Author (Year)	Definition	Contribution to Conceptualization of 'Usefulness'
Relevance (Cont'd.)	Relevance	Hersh (1994)	"deciding on a definition of relevance depends on the context in which it is being applied… Topical relevance is useful for certain types of evaluation, and situational relevance is useful for others. Ultimately, however, we must search for measures of relevance and retrieval that enable us to demonstrate an improved outcome resulting from the use of retrieval systems" (p. 202)	
	Relevance	Xu & Chen (2006)	"the term *relevance* has been used to refer to any position in the continuum from topicality to situational impact by different authors (Harter, 1992)… In this study… the term *relevance* refers to the portion of the relevance continuum beyond topicality; it encompasses both cognitive and situational relevance. We define it as the perceived cognitive and pragmatic impact of the *content* of a document in relation to the user's problem at hand" (p. 962)	

Umbrella Concept	Term	Author (Year)	Definition	Contribution to Conceptualization of 'Usefulness'
Usefulness	"The Big Black Question Mark"	Janes (1994)	"Perhaps what we have called 'topicality', 'utility', 'satisfaction', 'pertinence', and a variety of other names are in fact dimensions of a larger, multidimensional, dynamic concept, as discussed by Schamber et al. they called this concept 'relevance,' but that word too carries baggage in people's minds and may be causing problems of its own. At present, we conceive of this concept in the abstract, encompassing much that is described by previous definitions and instantiations, but more as well. For lack of a term, and referring to Figure 3, we call this concept the Big Black Question Mark, and leave its refinement for further discussion and research" (pp. 167-168) [Note: Figure 3 on page 168 shows the Big Black Question Mark as encompassing topicality, pertinence, relevance, satisfaction, and utility. The author states, "these concepts overlap, interact, contradict, and are possibly part of a much larger entity, as yet unnamed"]	All of these definitions are very highly related to the conceptualization of 'usefulness' proposed for this research. They emphasize the multidimensionality of the concept of usefulness. Furthermore, they offer some speculation as to what types of characteristics might make information useful. In fact, the last definition (that of Cole et al., 2009) proposes that relevance is, in fact, one of the criteria upon which usefulness may be judged.

Umbrella Concept	Term	Author (Year)	Definition	Contribution to Conceptualization of 'Usefulness'
Usefulness (Cont'd.)	Value	R. S. Taylor (1986)	"The value of information is user based… value is not something intrinsic to, that is, contained within, an information message. An information message is given value by someone who 'uses' it" (p. 4) "In the context of this approach, the value of information, then, has meaning only in the context of its usefulness to users" (p. 13) "The determination of usefulness rests entirely on the decision as to what to do *with* a letter, not what is done as a result of a letter. It is this decision that determines the usefulness *at that moment* of the letter: Throw it away; file it…; file it because one feels that it will be useful sometime; or act on it. Note that each of these decisions implies something about the usefulness (i.e., value) of a message to a receiver who is in a particular environment at a certain time" (p. 16)	

Umbrella Concept	Term	Author (Year)	Definition	Contribution to Conceptualization of 'Usefulness'
Usefulness (Cont'd.)	Information Quality and Cognitive Authority	Rieh (2000 & 2002) and Rieh & Belkin (1998 & 2000)	"When searching for 'useful' information, people often base their actions on the concepts of quality and authority" (Rieh & Belkin, 2000, p. 25) "At an operational level, information quality is identified as the extent to which users think that *the information is useful, good, current and accurate*" (Rieh, 2000, pp. 64-65) "Cognitive authority is operationalized as to the extent to which users think that they can trust the information" (Rieh, 2000, p. 65) "making judgment of quality and authority… was found by this study to be subjective, relative, and situational. Usefulness of information is not necessarily determined by objective characteristics of information objects or sources, but by users who ultimately make judgments of usefulness of information" (Rieh, 2002, p. 157)	
	Usefulness	Cole, Liu, Belkin, Bierig, Gwizdka, Liu, Zhang, & Zhang (2009)	"Usefulness is specifically distinguishable from relevance in several dimensions. Most strikingly, a usefulness judgment can be explicitly related to the perceived contribution of the judged object or process to progress towards satisfying the leading goal or a goal on the way... Usefulness, then, is more general than relevance. This does not deny the importance of relevance as a specific measurement to be used in appropriate circumstances to determine usefulness… Measuring usefulness relies on adopting appropriate and varied criteria…" (p. 3)	

All of these terms, along with their associated conceptualizations, contribute to an overarching, yet more restrictive, concept of usefulness. In choosing the concepts that appear to be most similar to the conceptualization of usefulness suggested here, concepts that appear to be defined in such a way that they are limited to only a particular subset of types of relevance have been excluded. For example, Rees' (1966) definition of relevance, Soergel's (1994) definition of pertinence, Sperber and Wilson's (1995) definition of relevance, and Harter's (1992) definition of psychological relevance all seem to be primarily restricted to cognitive relevance.

2.3.4 Summary: Relevance, Pertinence, and Usefulness

Although relevance is often the driving concept behind information behavior studies, the term 'usefulness' is employed for this study. As described above, the term 'relevance' has come to take on many meanings, ranging from mere relatedness to understandability to situation-appropriateness. In contrast, the term 'pertinence' has been assigned much more consistent definitions, usually ones having to do with cognitive relevance. However, this study focuses more broadly on information that is not only cognitively relevant, but also situationally and affectively relevant. In order to be truly useful, information must not only be understandable to its potential user, but it must also be perceived by its potential user to fit his/her current conception of his/her situation. Furthermore, it must be perceived by its potential user to fit with his/her current affect, including his/her hopes and fears.

Harris & Dewdney (1994) have defined information simply as "whatever helps" (p. 19). This definition seems to be a very fitting operationalization of the conceptualization of the term 'usefulness' being proposed here. Information can help only if it is recognized as potentially useful by an individual given his or her particular situation at a particular moment in time. The conceptualization of usefulness delineated above attempts to capture not only this core concept of helpfulness, but also one of the most important and traditionally overlooked (particularly before Dervin and Nilan's (1986) call for a paradigm shift from a system focus to a user focus) aspects of the concepts of relevance, pertinence, and usefulness, which is their non-static, evolving nature.

In the following section, the time dimension within existing models and theories of information behavior are discussed, along with some of the time-related findings from empirical studies of consumer health information behavior.

2.4 Time Dimension of Information Behavior

This section of the literature review focuses on the importance of looking at information behavior along a continuum of time. Time has been called "one of the main contextual factors of information seeking" (Savolainen, 2006, p. 110). Savolainen points out that, although the information-seeking literature is full of expressions that imply temporal contexts, very little has been written about the conceptual issues surrounding temporal factors and "temporal factors remain implicit in many models of information seeking" (p. 111). Attempting to begin to fill this gap, Savolainen describes three ways in which the temporal context has been approached within the information-seeking literature: "(i) time as a fundamental attribute of situation or context of information seeking, (ii) time as qualifier of access to information, and (iii) time as an indicator of the information-seeking process" (p. 110). While the first approach emphasizes the dynamic nature of contexts and situations, the second approach emphasizes that temporal factors (such as time pressure) influence both the process and potential outcome of information seeking. The third approach focuses on information seeking as an iterative process that unfolds over time, proceeding from problem or task, to information need, to identifying potential sources of information, to accessing those information sources, to judging the relevance of information, to interpreting the information, to assessing whether one's information need has been met, and then either to stopping information seeking or looping back to a new or modified information need.

Information needs, seeking, and use are all impacted by the passage of time. For example, a particular person's health information behavior is unlikely to remain static across different health conditions or across situations and time within any one particular health condition. The first subsection below looks at how people's relevance, pertinence, and usefulness judgments change across time as other factors in their lives evolve. The following subsection looks at the central role of time in selected models and theories of information behavior. The final two subsections discuss time-related findings from

empirical studies of consumer health information behavior, first in general and then in relation to diabetes-related studies in particular.

2.4.1 Changes in Perceived Relevance/Pertinence/Usefulness across Time

As emphasized by Barry (1994), Barry and Schamber (1998), Borlund (2003), Bruce (1994), Cooper (1973), Nilan, Peek, and Snyder (1988), Park (1993 & 1994), Rees (1966), Rieh (2000 & 2002), and Schamber et al. (1990), relevance is not only subjective, but also dynamic. People's judgments about which information is relevant or pertinent or useful, as well as their relative use of the various criteria on which they base these judgments, change over time as:

- they interact with an information retrieval system (Anderson, 2005; Bateman, 1999; Bruce, 1994; Rieh, 2000 & 2002; Spink, Greisdorf, & Bateman, 1998; Spink, Greisdorf, & Bateman, 1999; Tombros, Ruthven, & Jose, 2005);
- they advance over the stages of a task (Park, 1993 & 1994; Saracevic, 2007b; Tang & Solomon, 2001; Taylor, Cool, Belkin, & Amadio, 2007; Tombros et al., 2005; Vakkari & Hakala, 2000; Wang, 1997; Wang & White, 1995; Wang & White, 1999; White & Wang, 1997);
- they acquire new knowledge (Anderson, 2005; Barry, 1994; Bateman, 1999; Bruce, 1994; Cooper, 1973; Foster, 2004; Harter, 1992; Mizzaro, 1997 & 1998; Park, 1993 & 1994; Rees, 1966; Regazzi, 1988; Rieh, 2000 & 2002; Saracevic, 1975; Spink, Greisdorf, & Bateman, 1998; Vakkari & Hakala, 2000; Wang, 1997; Wilson, 1973);
- their mental state changes (Harter, 1992);
- their concerns change (Wilson, 1973);
- their problem, or how they define their problem, changes (Bruce, 1994; MacMullin & Taylor, 1984; Mizzaro, 1997; Spink & Greisdorf, 2001; Spink et al., 1998);
- their situation, or how they perceive their situation, changes (Dunne, 2002; Schamber, 2000);

- their evaluations of their present circumstances, in relation to both their perceptions of their past and their beliefs about their future, change (Nilan, Peek, & Snyder, 1988);
- their "information need situation," which is defined as encompassing "all factors that the user brings to the situation: previous knowledge, awareness of information that is available, affective or emotional factors, the expected use of the information, any time constraints under which the user is working and so on" (Barry, 1994, p. 149), changes (Barry, 1994; Schamber et al., 1990);
- their beliefs change (Barry, 1994; Johnson, 1997; Wilson, 1973);
- their attitudes change (Barry, 1994);
- their preferences change (Kochen, 1974);
- different stimuli, such as information, information sources, information needs, and/or events, become relatively more salient than others in their environment (Case, 2007; Johnson, 1997);
- they gain experience with using alternative sources of information (Anderson, 2005; Savolainen & Kari, 2004).

2.4.2 Centrality of Time in Information Behavior Models and Theories

Explicitly or implicitly underlying most information behavior models and theories is the dimension of time. In fact, Wilson (1999) defines information behavior models as primarily "statements, often in the form of diagrams, that attempt to describe an information-seeking activity, the causes and consequences of that activity, or the relationships among stages in information-seeking behaviour" (p. 250). Furthermore, he makes the important point that information behavior models must include feedback loops since "progression towards a goal is hardly ever unproblematic" and he emphasizes that we must view "behaviour as iterative, rather than one-off" (p. 268).

This section discusses the role of time in seven different models and theories of information behavior. The following six models/theories have been selected for inclusion here based not only on their emphasis on the dynamic and evolving nature of human information behavior, but also on their potential applicability to a wide variety of contexts, including everyday life information seeking: (1) Taylor's (1968) four levels of

information need; (2) Belkin, Oddy, and Brooks' (1982) Anomalous States of Knowledge; (3) Bates' (1989) berrypicking and evolving search; (4) Pirolli and Card's (1999) information foraging theory; (5) Chatman's (1996) Theory of Information Poverty; and (6) Dervin's (1992 & 2003) sense-making. The last model that will be covered in this section is Kuhlthau's (2004) Information Search Process model, along with her Uncertainty Principle. Although Kuhlthau's work is, in one sense, of limited applicability to the research being proposed here due to its genesis solely from the study of *library users'* information seeking, it actually is of great significance due to its central focus on the *process* of looking for information and on the attendant changes in people's cognition, affect, strategies, actions, and mood that tend to occur as this process unfolds.

2.4.2.1 Taylor's (1968) Four Levels of Information Need

In his seminal article on the process of question negotiation that takes place between a reference librarian and an information seeker, Taylor (1968) points out that information seekers have to develop their questions through four different levels of information need: (1) visceral; (2) conscious; (3) formalized; and (4) compromised. He describes a visceral need as an "actual, but unexpressed need for information," a conscious need as the "conscious, within-brain description of the need," a formalized need as a "formal statement of the need," and a compromised need as "the question as presented to the information system" (p. 182). Taylor advocates that reference librarians should not work directly with people's compromised needs. They should, instead, "work with the inquirer back to the formalized need…, possibly even to the conscious need…, and then… translate these needs into a useful search strategy" (p. 183). Taylor explains that this process helps to "compress both the boundaries of the interview and the time span" (p. 183) and to increase the relative frequency of *relevant* communications between librarians and inquirers. His schematic representation of this process is shown in Figure 6 on the following page.

As depicted in Figure 6, the time dimension is quite central to Taylor's (1968) work on question negotiation. In fact, the question negotiation process appears to involve three separate, although perhaps somewhat overlapping and likely iterative, sub-processes: (1) The inquirer working forward in time to develop his visceral information need into a compromised need; (2) The librarian and the inquirer working together to

back up to the inquirer's formalized or conscious need; and (3) The librarian then formulating a useful search strategy based on this "less noisy" description of the true information need.

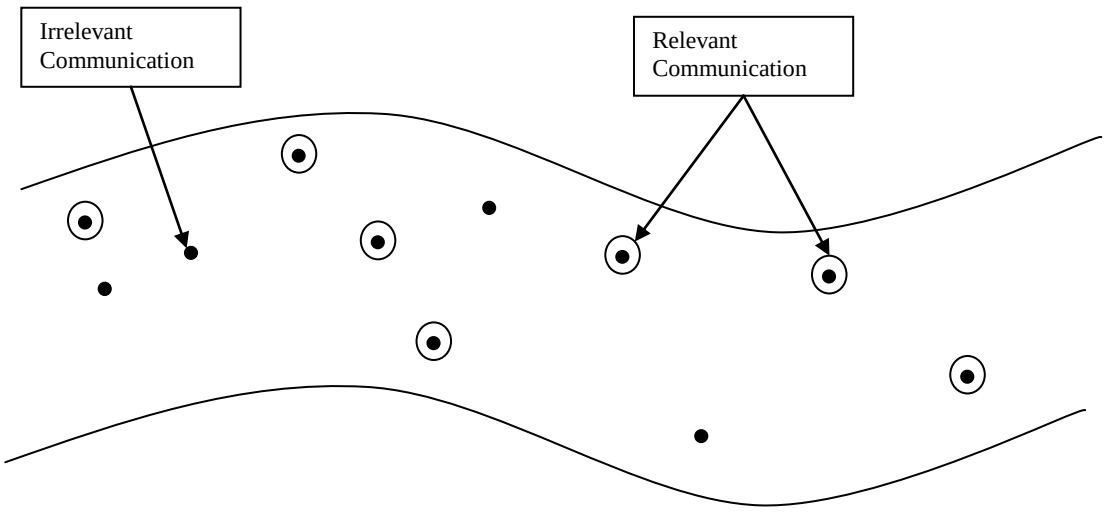


Figure 6: Taylor's (1968) Schematic Representation of Communication between Inquirer and Librarian during the Question Negotiation Process (p. 184)

2.4.2.2 Belkin et al.'s (1982) Anomalous States of Knowledge (ASK)

Closely tied with Taylor's (1968) visceral and conscious need constructs is Belkin et al.'s (1982) concept of Anomalous States of Knowledge (ASK). Belkin (1980) explains that an ASK is a perceived inadequacy in a person's state of knowledge and that this concept "shares characteristics of Taylor's levels one [visceral need] and two [conscious need]" (p. 137). Belkin, et al.'s (1982) ASK hypothesis postulates that because an information need arises precisely because of a lack of knowledge about some particular topic, it may be more suitable to ask the user of an information retrieval system to describe his/her ASK rather than to come up with a formal statement of their information need that is suitable for the system. Belkin, et al. (1982) propose an alternative information retrieval mechanism that would work with people's description of the problematic situation that gave rise to their information need, rather than requiring them to articulate what it is that they do not know. They emphasize that an ASK-based information retrieval system must be interactive and iterative, enabling back-and-forth

communication between the system and the user through which the user can provide feedback to the system about the information retrieved so far, about the retrieval strategy used by the system to pull these retrievals, and about whether the user's information need has changed. The crux of their proposed information retrieval system is a feedback loop that enables the user to state her problem, the system to respond to the user, the user to respond to the system's responses, and the user to iteratively revise her problem statement as required. Time forms one of the fundamental dimensions of this feedback loop. As the user's ASK evolves, the user is able to iteratively revise her problem statement so that it more accurately reflects the current state of her information problem, thus enabling the system to adapt its behavior to reflect these changes as well.

2.4.2.3 Bates' (1989) Berrypicking

Sharing Belkin, et al.'s (1982) rejection of the traditional information retrieval notion that information retrieval is a one-shot deal is Marcia Bates (1989). Bates points out that people's actual information retrieval behavior rarely consists of a static information need and one single best retrieved set that can be obtained by simply matching a person's initial query to the contents of a database. Instead, people often retrieve information a bit-at-a-time and their information need, along with their representation of their information need, iteratively evolves. Bates calls this bit-at-a-time type of information retrieval "berrypicking" and this type of information search an "evolving search". In a berrypicking, evolving search (as depicted in Figure 7 on the following page), people's information needs, queries, search techniques, and the sources they search all tend to shift as they work towards resolving their information need.

As can be seen by the path and directionality displayed in Figure 7, time is a crucial element underlying Bates (1989) concepts of "berrypicking" and "evolving search". Bates (1989) explains, "The continuity represented by the line of the arrow is the continuity of a single human being moving through many actions toward a general goal of a satisfactory completion of research related to an information need".

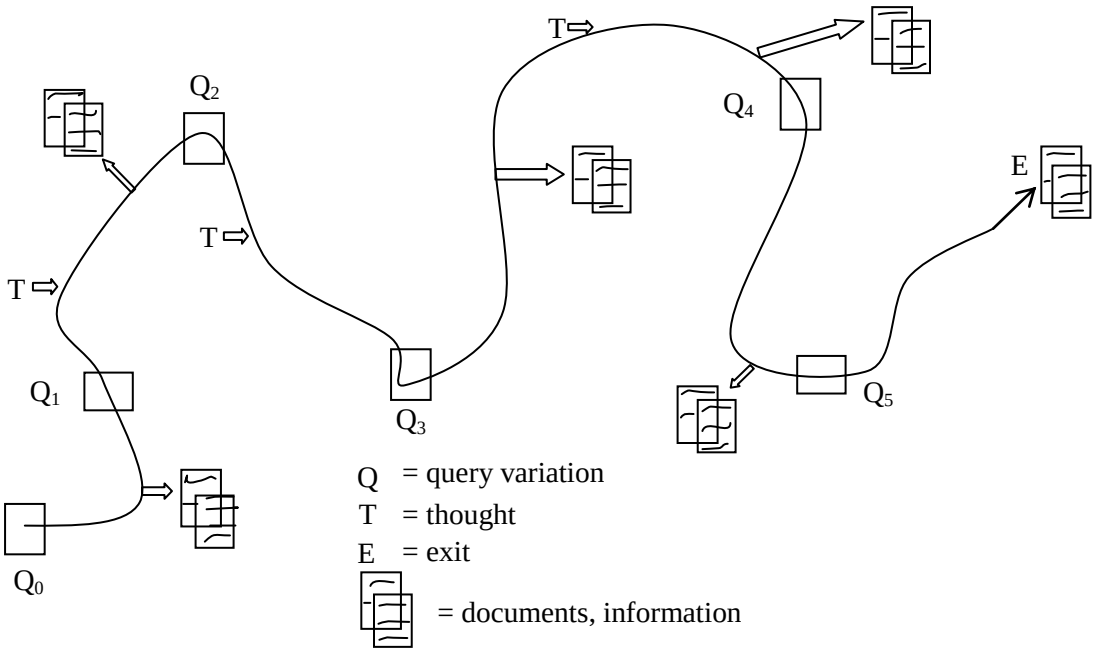
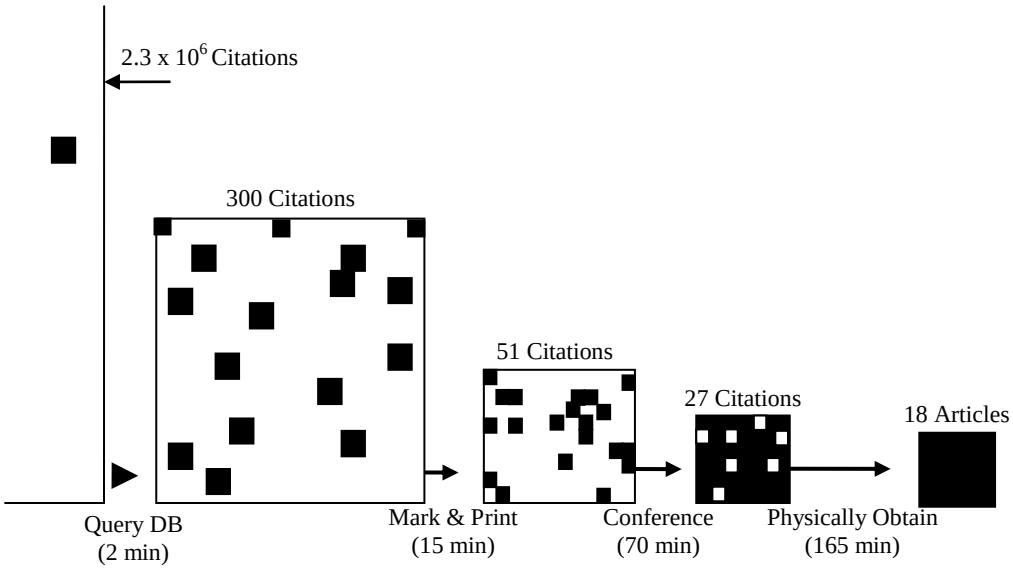


Figure 7: Bates' (1989) Berrypicking, Evolving Search

2.4.2.4 Pirolli and Card's (1999) Information Foraging Theory

In keeping with Bates' ecological metaphor, Pirolli and Card (1999) developed "information foraging theory". The basic tenet of this theory is that people and their information environments co-adapt; that is, people adapt their information-seeking strategies, as well as their environments, with the ultimate goal of maximizing the amount of useful information they gain per unit cost. The costs associated with information foraging include "access, recognition, and handling costs" (p. 644). Pirolli and Card define the optimal information forager as the "one who best solves the problem of maximizing the rate of valuable information gained per unit cost, given the constraints of the task environment" (p. 645). Such constraints include the potential profitability of various sources, as well as the cost to find and access each of them. Basically, information foraging theory is about how people allocate a scarce resource, their attention, in today's culture of information overload. As the authors put it, "the problem is one of maximizing the allocation of human attention to information that will be useful" (p. 643).

Pirolli and Card (1999) state: “Information foraging is usually a task that is embedded in the context of some other task. The value and cost structure of information foraging are consequently defined in relation to the embedding task, and this often changes dynamically over time.” (p. 645). Figure 8 depicts the information foraging processes of a team of MBA students who were performing research in preparation for writing a strategic analysis report. This figure shows that, over time, the team simultaneously reduced the size of, and increased the relevance density of, their information diet so that future foraging could be done with less cost and more value per unit time.



Information from the strategic management analysis example. Width indicates time investment in activities, height indicates total documents, dark fill indicates relevant documents, and white fill indicates irrelevant documents. Times in parentheses are cumulative. DB = database.

Figure 8: Information Foraging Example (from Pirolli & Card, 1999, p. 650)

Clearly, the dimension of time is quite central to information foraging theory. Not only is information scent dynamic, but also the information environment itself, along with the potential gains and costs associated with a particular patch/source of information, are unlikely to remain static. Pirolli and Card indicate that, as a person performs information foraging tasks, they expect that their “cognitive structures and strategies will also evolve to maximize information gains per unit cost, given the opportunity to evolve through learning and practice” (p. 644). People’s information diets

depend on their ability to use information scent to optimize their journey within and between information patches. Since information patches, as well as both the scent emanating from a particular patch/piece of information and the ability of an information forager to perceive this scent, are unlikely to all remain static, a person's information foraging strategies, and thus, his/her information diet, are likely to adaptively co-evolve with the changes in his/her information environment.

2.4.2.5 Chatman's (1996) Theory of Information Poverty

In contrast to Pirolli and Card's (1999) finding that people tend to work towards maximizing the amount of useful information they can acquire per unit effort, Chatman (1996) found that there is a certain subpopulation for whom information seeking is thwarted by negative affects such as fear, hopelessness, and mistrust and by a need to comply with social norms. Chatman's Theory of Information Poverty arose out of her studies of the information behavior of three marginalized populations – women workers who were heads-of-households and who were participating in a federally-sponsored employment program (Chatman, 1983), janitorial workers at a southern university (Chatman, 1990 & 1991), and older women living in a retirement community (Chatman, 1992).

Based on her study of janitorial workers, Chatman (1991) proposed (and found support for) a limited time horizon among this population. She states:

> Though the respondents were aware of more beneficial opportunities requiring some investment in the future, they were either resigned to their present position or convinced that the effort was not worth it, because somehow events were stacked against them. (p. 445)

Time, within Chatman's Theory of Information Poverty, leads not to adaptation but to a detrimental absence of crucially needed information resulting from a pernicious, maladaptive, closed loop in which the person's negative affects, self-protective behaviors, and experienced and expected outcomes feed into one another and prevent the person from being able to escape and engage in more adaptive information behavior.

2.4.2.6 Dervin's (1992 & 2003) Sense-Making

One information needs, seeking, and use theory in which time appears to play a particularly central role is Dervin's (1992 & 2003) sense-making. Dervin and her

colleagues have been developing sense-making since 1972, although they did not actually use this terminology until 1983. Sense-making is simultaneously a theory, a methodology, a set of methods, and a body of findings. Its primary focus is on how people make sense of things in their everyday lives and its core assumption is the constancy of discontinuity in both the human condition and the environment in general. Sense-making focuses on the behaviors that people undertake in order to make sense of their worlds despite the pervasiveness of discontinuity. These behaviors are of two types – gap-defining and gap-bridging. Gap-defining is the process whereby a person perceives that he or she is unable to move forward because his/her ability to make sense has run out. Gap-bridging is the process whereby the person figures out how to make new or different sense so that he or she can cross the gap and continue to move forward. Sense-making looks at how a person defines and perceives a gap, how she conceptualizes and makes use of a bridge that allows her to cross the gap, and how she continues on after crossing the bridge.

Dervin (2003) emphasizes that "movement is the one irreducible of the human condition" (p. 141) and that sense-making focuses on people's "movement through time-space" (p. 142). In fact, two of the metaphors that she has used to depict sense-making both imply movement. Dervin's Sense-Making Triangle (Dervin & Foreman-Wernet, 2003, p. 278) depicts movement from situation to gap to use/help, although Dervin emphasizes that this movement may be neither linear nor purposive. Dervin's Sense-Making Metaphor (depicted in Figure 9 on the following page) involves "moving across time and space, facing a gap, building a bridge across the gap, and then constructing and evaluating the uses of the bridge" (Dervin & Foreman-Wernet, 2003, p. 238).

Dervin (2003) states, "By definition, Sense-Making focuses on movement and fluidity, even when that movement and fluidity involves repetitions and habits" (p. 147). Sense-making is all about the sense-making and "sense-unmaking" (p. 140) processes that people undertake during their journeys through everyday life. As situations unfold and gaps are revealed, people face the challenge of conceptualizing, constructing, and making use of bridges that will enable them to successfully cross the gaps and carry on with their journeys. Sense-making assumes that "humans and their worlds are constantly

evolving and becoming, sometimes decentered, sometimes centered, sometimes fluid, sometimes rigid" (p. 141).

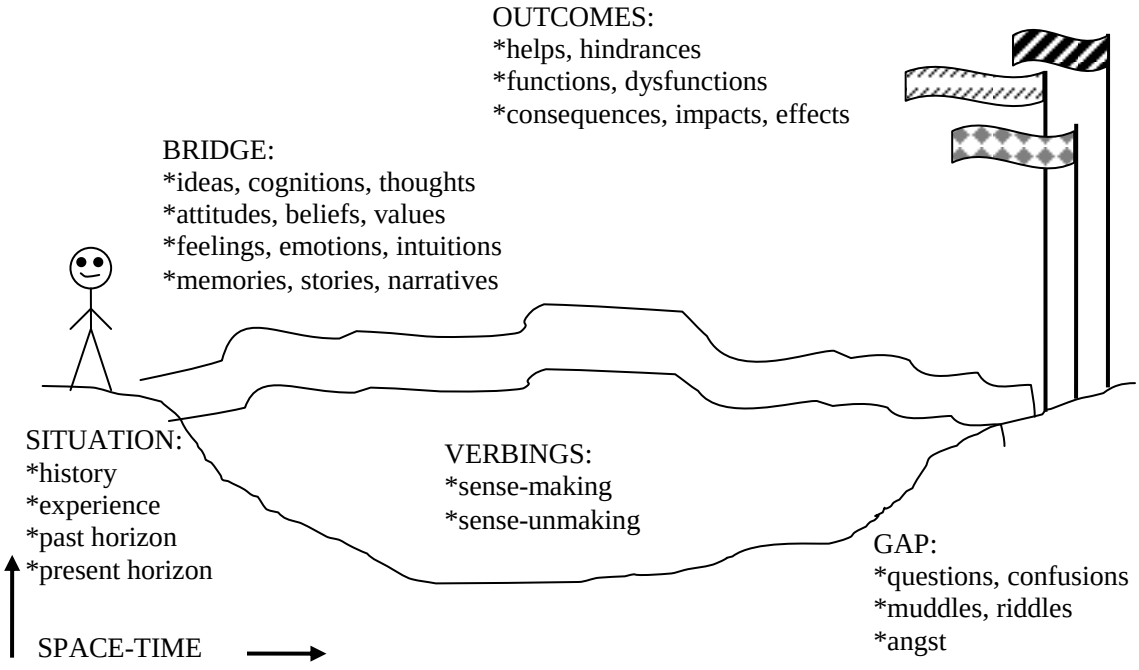


Figure 9: The Sense-Making Metaphor (based on Dervin & Foreman-Wernet, 2003, p. 238)

2.4.2.7 Kuhlthau's (2004) Information Search Process (ISP) Model and Uncertainty Principle

Similar to Dervin's Sense-Making in its focus on movement and process is Kuhlthau's (2004) Information Search Process Model and Uncertainty Principle. Kuhlthau developed this model and this principle based on her study of the information-seeking processes of academically capable high school seniors working on research papers that they were assigned for their English class. The two research questions driving this study were: (1) "Do users have common experiences in the process of information seeking that can be articulated and described?" and (2) "Do users' experiences resemble the phases in the process of construction?" (p. 31). Using an assortment of qualitative data collection techniques, including journals, search logs, short written statements about students' chosen topics, conceptual maps (i.e., flowcharts and timelines), interviews, and

teachers' assessments of the degree of focus reflected in each student paper, as well as a perceptions questionnaire, Kuhlthau sought to understand the user's experience of the information-seeking process. Based on her analysis of the data that she collected using these various methods, Kuhlthau recognized that there were common patterns across students' experiences and that these patterns appeared to suggest six different stages, each characterized by particular types of thoughts, feelings, and actions. Furthermore, she identified the tasks, strategies, and mood (invitational vs. indicative) that appear to be most productive at each of these stages. These stages describe a progression in students' thoughts from unclear and vague to clear and focused and a concomitant progression in students' emotions from confusion, frustration, and uncertainty to confidence, certainty, relief, and either satisfaction or disappointment.

Kuhlthau (2004) later verified and refined this model by conducting four additional studies – two similar studies with more diverse populations of library users including lower-performing high school students, undergraduate students, and public library users, and two follow-up studies with some of the original participants of her earlier studies. In addition to providing support for her original model of the information search process, Kuhlthau's follow-up studies with some of her original participants yielded the important finding that people don't proceed through each of the six stages in a completely linear fashion. Instead, they experienced this process as a more iterative and recursive process of gradual movement toward clarity and focus. These studies also yielded the finding that some of the stages are not separate and discrete, but rather they actually overlap and merge with one another. As Kuhlthau explains, "The participants described a more heuristic, spiral process in which emerging thoughts were changing and evolving, rather than a distinct formulation point" (p. 83).

Although Kuhlthau's (2004) Information Search Process Model and Uncertainty Principle were constructed based solely on studies of the search processes of library users, it still holds a great deal of relevance for this research. In fact, one of the motivations for undertaking this study was to see whether consumer health information behavior exhibits its own characteristic patterns and stages and whether particular tasks, strategies, and moods at given stages emerge as being more helpful than others. Also, just as Kuhlthau found that the crucial turning point in her participants' information behavior

was the formulation of a focus, there may be parallel turning points in consumer health information behavior, such as the initiation of symptoms or the receipt, comprehension, and/or acceptance of a diagnosis. Kuhlthau's Uncertainty Principle, as well as her conclusion that "Information seeking is a complex learning process that involves finding meaning. Thoughts evolve, feelings change, and confidence rises as a search progresses" (p. 57), seemed likely to be quite applicable to consumer health information behavior. In fact, this very idea of seeking meaning is brought up in Matson and Brooks' (1977) study of the stages of adjustment experienced by the chronically ill, which will be discussed in the following section. The central role of time underlying many different information behavior models and theories is supported by the findings of many empirical studies of consumer health information behavior. In the next section, some of the findings in this regard will be presented.

2.4.3 Empirical Findings Regarding the Centrality of Time in Consumer Health Information Behavior

Although few studies have actually looked at people's health-related information needs, seeking, and/or use across time (as pointed out by Ankem, 2006a; Kutner et al., 1999; and McCaughan & McKenna, 2007), many studies directly mention or strongly imply the dynamic nature of people's preferences as to how actively they wish to engage in information seeking (Baker, 1998; Wicks & Frost, 2008) and in health-related decision-making (Hack et al, 1994), as well as the types of information they need (Clark, 2005; Degner et al., 1997) and the types of information sources they consult (Ankem, 2006a; Chesser & Anderson, 1975; Gollop, 1997; Harris & Dewdney, 1994; Luker et al., 1996; Mills & Davidson, 2002; Wathen, 2006).

People diagnosed with a chronic illness, specifically multiple sclerosis, have been found to advance through one or more of four stages of adjustment to their disease: Denial, resistance, affirmation, and integration (Matson & Brooks, 1977). Upon initial diagnosis, patients are likely to enter the denial phase. During this phase, they look for an authority who will contradict the diagnosis and they do not seek out others with the same disease. They will also attempt to prevent other people from finding out about their diagnosis and they will resist others' attempts to help them.

As time progresses, patients may begin to accept their diagnosis. At this time, they enter the resistance phase. It is during this phase that patients begin to actively seek information about their disease and potential cures. During this time, patients are attempting to achieve some degree of control over their disease. They become interested in meeting other patients with the disease and in joining patient groups in order to obtain more information. During this second phase, they may begin to accept help from other people, albeit reluctantly.

Patients who enter the third phase, affirmation, realize that they must rearrange their priorities. During this phase, they grieve for their former selves and work on constructing new meanings for their conditions. They begin to publicly admit that they have this disease and become interested in explaining the disease to others. They also begin to accept help from others without feeling that it devalues them.

The final phase, integration, is only reached after a considerable time spent with the disease. Furthermore, it may need to be reached repeatedly, as each new exacerbation may remind the patient of his vulnerability. During this phase, the patient switches the focus of his energy and thought from his disability to other matters.

In their description of these phases, Matson and Brooks (1977) emphasize that these stages are neither guaranteed nor linear – some patients may never advance beyond one particular stage, some patients may not advance through them in this order, and some patients may regress to an earlier stage during an exacerbation of the disease. Baker's (1998) interviews with multiple sclerosis patients about their information needs confirmed this finding. Upon experiencing an exacerbation of their disease, some of Baker's interviewees delayed seeking medical attention and information, hoping that their symptoms would disappear. Baker notes that this behavior is consistent with a regression back to the denial stage of Matson and Brooks' model – a stage during which information is not usually sought.

Researchers studying diseases other than multiple sclerosis have also verified that patients' information behavior is not static and changes over time. McCaughan and McKenna (2007) developed a theory they called "Never-ending making sense" based on their interviews with people recently diagnosed with cancer for the first time. Their theory identifies three stages that their study participants seemed to go through during the

months following their diagnosis: (1) Being traumatized; (2) Taking it on; and (3) Taking control. These stages appear to roughly mirror the four phases identified by Matson and Brooks (1977). The first stage – being traumatized – is similar to Matson and Brooks' denial phase. During this stage, McCaughan and McKenna's participants, stunned and traumatized by their diagnosis, blocked cancer-related information, either shutting down completely or being selective in what they chose to hear. The second stage – taking it on – is very similar to Matson and Brooks' resistance phase. During the "Taking it on" stage, participants felt the need to face their cancer diagnosis and began to actively seek out information from many different sources. One of the major ways in which participants sought to make sense of their situation during this stage was to learn about other people's experiences with cancer and then compare them with their own experience. During the last stage, "Taking control," which appears similar to appears similar to Matson and Brooks' affirmation and integration phases, participants began to take control over their situation and their lives. During this time, they became much more discerning and selective in their search for information. The act of taking control gave participants "some sense of ownership over their illness and their lives, which they felt had been taken away from them after their first diagnosis of cancer" (p. 2102). Like Matson and Brooks, McCaughan and McKenna emphasize that their participants' progression through these three stages was neither linear nor guaranteed. They point out that some patients never reached the last stage and that some regressed to earlier stages.

Degner et al. (1997), who studied the information needs and decisional preferences of women with breast cancer, found that women who were more recently diagnosed were more interested in information about the chance of a cure while women who were further from the time of their diagnosis were more interested in information about self-care. This phenomenon also seems consistent with Matson and Brooks' (1977) adjustment model, as it seems likely to reflect an advancement from the resistance phase to the affirmation phase.

Similarly, Raupach and Hiller (2002) found that women with breast cancer make less use of many different types of information sources, including surgeons, cancer specialists, breast cancer nurses, peer support program volunteers, books, brochures, and friends, as they advance further from the time of their diagnosis. Similar findings were

reached by Satterlund, McCaul, & Sandgren (2003) who found that women with breast cancer were more likely to report using specific information sources at eight months after diagnosis than at sixteen months after diagnosis. Both of these sets of findings also seem consistent with advancement away from the more information-intensive stage of resistance in Matson and Brooks' (1977) model. Several researchers (Chesser & Anderson, 1975; Harris & Dewdney, 1994; Wathen, 2006) have found that people tend to advance along a continuum from informal sources, such as family members and friends, to more formal sources, such as doctors and community agencies. This could possibly reflect a progression from the denial phase to the resistance phase.

In the following section, some of the time-related findings from empirical studies of diabetes-related consumer health information behavior are presented.

2.4.4 Empirical Findings Regarding the Centrality of Time in *Diabetes-Related* Consumer Health Information Behavior

Many studies that have touched on the information behavior of people with type 1 or type 2 diabetes have focused more broadly on how these individuals learn self-management of the disease. Many researchers (Ellison & Rayman, 1998; Paterson & Sloan, 1994; Paterson & Thorne, 2000; Price, 1993) have identified a series of stages or phases that people with diabetes seem to go through in developing this competence. Although these researchers use different names for these phases or stages, there appears to be quite a few commonalities across their findings in terms of what types of behaviors, cognitions, and affects characterize each stage. The findings of these researchers are detailed in the following paragraphs.

Price (1993) interviewed 18 adults with type 1 diabetes to investigate how these individuals learned diabetes self-management. Although Price set out to specifically look at these people's experience with the uncertainty associated with diabetes, she found that uncertainty is actually experienced as part of the broader process of learning self-management of this disease. Based on her findings she developed a diabetes self-management model depicting the two phases and five stages which patients go through in learning self-management. During the first phase, "getting regulated," participants described four stages – "trying it out", "figuring it out", "trial and error", and "basic routine that works for me". The second phase, "being regulated," was found to consist of

two additional phases – "basic routine maintained" and "plans for new situation." During the first stage, "trying it out", participants reported rigidly adhering to regimens that were prescribed for them. As a result of either "life-style disruption" or "negative body responses", participants advanced to the second stage, "figuring it out." During the second stage, participants began to modify their regimens to make them fit better with their daily schedules and/or to try to reduce unwanted physical responses to the regimen. Nearly all of the participants reported moving on to stage three, "trial and error," as a result of negative physical effects or undesirable impacts on their lifestyle.

During stage three, participants intensified their efforts to modify their prescribed regimen in an attempt to find out what would work for them. They experimented with diet, exercise, and different types of situations to see how they would impact their blood glucose levels. They strove to find a self-management regimen that would fit with their lifestyle and that would make them feel physically well. In order to move beyond stage three, participants had to be able to recognize patterns in order to determine what would work for them. Participants described being motivated to learn more about diabetes at this point because they felt it would enable them to understand how their body was responding to the experimentation they were conducting. Having recognized what works for them, participants moved on to stage four, "basic routine." During this stage, participants were able to determine what works for them and to implement a routine for themselves.

Price's (1993) phase 2 ("being regulated") begins with stage 4, which is really a continuation of stage three. Participants maintain the basic routine that they have established and begin to develop greater capacity for flexibility in their self-management activities. Participants were deemed to be in stage 5 when they were able to adapt their basic routines to changing situations, such as during trips or times of illness. At times, however, participants found themselves temporarily returning to stage three ("trial and error") activities in order to successfully adapt their basic routine to these new types of situations. Of Price's 18 participants, seven appeared to be in the last stage depicted in her diabetes self-management model. These participants "indicated that their theoretical knowledge of diabetes management was adequate, and their understanding of how their

bodies responded to the treatment regimen within a variety of situations was exquisite" (p. 42). These participants were both confident and flexible in their self-management.

Price (1993) identified four principal factors that seemed to influence how participants moved through the different stages – personal considerations, monitoring, cognitive skills, and control. The second factor, monitoring, was found to consist of four different types of monitoring – monitoring one's blood glucose levels, monitoring one's body responses ("body listening"), "secondary monitoring by others," and "secondary monitoring by the health care professional" (p. 44). The last two types of monitoring refer to obtaining diabetes self-management information from other people such as family members, friends, co-workers, and healthcare providers. Price points out that participants enacted different types of monitoring depending on their stage of self-management. The last two types of monitoring were more prevalent during the first phase, which took place directly following their diagnosis. And although they continued during the second phase, they gradually receded as blood glucose testing and body listening became more prevalent in the later stages. Thus, participant learning of diabetes self-management was found to advance from reliance on information sources outside of oneself to reliance on information obtained from one's own body.

Ellison and Rayman (1998) conducted a similar study in which they investigated how women with type 2 diabetes become experts at self-management. Through interviews with women classified as experts in self-management based on their lack of diabetes-related hospitalizations within the past year, their maintenance of A1C values of 7% or less during the preceding year, and their active participation in self-management, as well as their confidence and their flexibility in managing the disease, these researchers identified a series of three phases that these women seemed to go through, although not necessarily in a linear fashion. During the first phase, "management-as-rules", which seems similar to Price's (1993) first stage of "trying it out," participants learned the official rules of diabetes management and felt fearful and alone. These emotional responses often impacted their ability to make good decisions until they were able to reach a point where they could manage their emotions. Feeling a need to "get on with life" (p. 327) heralded a transition into the second phase, "management-as-work". This second phase appears fairly similar to Price's (1993) second and third stages, "trying it

out" and "trial and error." During this phase, they felt less fear and became more willing to interpret information for themselves and experiment. They took responsibility for, and felt successful at, routines related to self-management. Feeling successful at self-management heralded a transition to the third phase, "management-as-living". This third phase seems quite similar to Price's (1993) fourth and fifth stages, "basic routine" and "plans for new situation." By the time they reached this third phase, participants had learned numerous strategies for self-management and felt confident in their ability to make decisions. In fact, they had begun to take on most of the responsibility for making management-related decisions, consulting healthcare professionals in order to obtain updated information about diabetes that would help them in their self-management. However, they turned to healthcare professionals infrequently, "usually only after exhausting their own strategies and carefully evaluating their situation and the questions for which they needed answers" (p. 328). They also began to share their expertise with other people diagnosed with diabetes. In conclusion, the authors point out that while doctors may deem "management-as-rules" to be successful, these participants found this first phase to be chaotic, uncomfortable, and lonely and defined success for themselves as "management-as-living."

Similar findings were reached by Paterson and Thorne (2000) who investigated how people with type 1 diabetes become experts at self-management. Through a series of longitudinal interviews, a modified think-aloud technique, and post-think-aloud interviews with 22 self-nominated and physician-nominated self-management experts, these researchers collected information about participants' past and current self-management experiences and about their self-management decisions within their everyday life contexts. Based on an analysis of the data they collected, Paterson and Thorne identified four phases that participants moved through in becoming experts at self-management: (1) passive compliance; (2) naïve experimentation; (3) rebellion; and (4) active control. In an earlier study, Paterson and Sloan (1994) identified four analogous phases, terming them the infancy, toddler, adolescent, and adulthood stages of diabetes. Eight of Paterson and Thorne's 22 participants reported moving through all four of these phases and in this particular order. Other participants went through just two or three of these phases and/or experienced them in a different order. The authors point out

that these phases were sometimes indistinct and overlapped at times. There was also some backward movement; however their participants emphasized, "you never go back to where you were before" (p. 409).

Paterson and Thorne's (2000) first phase – "passive compliance" – is quite similar to Ellison and Rayman's (1998) "management-as-rules" phase. Participants reported being shocked by the diagnosis and complying rigidly with the management rules told to them by health care professionals and family members. There was some recognition among participants that passive compliance was destructive and dangerous to one's health. The next phase – "naïve experimentation" – is similar to Ellison and Rayman's (1998) "management-as-work" phase. During "naïve experimentation", participants reported experimenting with their prescribed regimen; however, this phase tended to be short-lived as their experimentation tended to impact their health negatively. For at least one participant, this phase helped him to realize how little he knew about diabetes and how much he still needed to learn in order to be able to control his diabetes.

During Paterson and Thorne's (2000) third phase – rebellion—participants denied having diabetes and didn't perform the necessary activities in order to maintain control over it. For some participants, this phase preceded naïve experimentation, rather than followed it. Both of these phases resulted in poor health outcomes. Participants entered the fourth phase – "active control" – upon making a conscious decision to take control over the management of their diabetes. This last phase is similar to Ellison and Rayman's (1998) "management-as-living" phase. Several factors propelled participants to enter the "active control" phase, including the influence of other people, particularly other people with diabetes who knew the importance of taking control from their own experience with the disease. In order to reach this phase, participants had to have enough confidence in their ability to make the right decisions, enough competence to do so based on their learning about diabetes and based on their own personal experiences with the disease, and enough social support. Although participants' paths through these phases were highly individualized, their main goal throughout all of these stages was to take control in the management of their disease. In conclusion, Paterson and Thorne propose a mentoring program in which newly diagnosed patients are paired with experts in self-management

so that they can learn about the possibility of taking control of their own diabetes management and about how this might be achieved.

2.4.5 Summary: Time Dimension of Information Behavior

Time is one of the most significant dimensions of the context in which people's information behaviors are embedded. The centrality of time in information behavior has been recognized and depicted by many information behavior theorists. Information behavior does not consist of an isolated moment in time. It is a complex process which is rarely linear and which often involves not only forward movement, but also regression and iteration. Changes in people's information behavior across time have been linked with changes in their thoughts, feelings, and actions, as well as changes in their situations.

Although few researchers have studied people's consumer health information behavior across time, those who did were able to identify some characteristic patterns or stages. Many of these patterns involve an initial stage of denial during which time information is not sought, followed by a stage of engagement during which time information is avidly sought from multiple sources. This stage is then followed by a stage during which people take control of their situation and get on with their life. People's preferences in terms of sources of information and types of information content were found to vary depending on their current stage. However, many researchers emphasize that these stages are neither guaranteed nor linear. For example, a person may never reach the last stage or may reach it multiple times due to repeated regression to previous stages spurred on by events such as exacerbations of their illness.

Researchers who specifically studied how people with diabetes learn self-management identified a similar set of stages. In contrast to the more general consumer health information behavior studies, denial was not identified as the first stage. During the first stage of learning diabetes self-management, people rigidly adhere to the instructions given to them by their doctor. Feeling a need to get on with their life, people then advance to the second stage during which they work on adapting these instructions so that they fit their own lives better. As they experience some success with these efforts, they enter the third stage. During this last stage, they take control of managing their diabetes. When they reach this stage, they tend to consult healthcare professionals for

information a lot less frequently and they begin to share the expertise they have developed with other people diagnosed with diabetes. As with the researchers studying consumer health information behavior within the context of other types of illnesses, these researchers highlight that these stages are neither linear nor guaranteed. They further point out that these stages are, at times, indistinct and overlapping.

2.5 Summary: Literature Review

This review covered literature from three different areas – empirical studies of consumer health information behavior; theoretical treatises discussing the terms relevance, pertinence, and usefulness; and both theoretical works and empirical studies related to the role of time in people's information behavior. The first section of the literature review shows that information plays a very important role in helping a person to cope with an illness, though the nature of this role varies depending on the particular person and on his/her current situation. The second section of this literature review explores the term 'relevance' and several other related terms, concluding that the term 'usefulness' is most appropriate for this research as the purpose of this study was to investigate how information is of help to the person diagnosed with a chronic serious health condition. The final section of this literature review provides support for the notion that time forms one of the most significant dimensions of the context in which an ill person's information behaviors are embedded. These three literatures intersect to form the basis for this research – an investigation into the information behaviors of people diagnosed with type 2 diabetes and how these behaviors change across time, with a special focus on what constitutes useful information for this population and how this changes as a person's understanding and experience of their health condition both unfold over time.

2.6 Conceptual Framework

The three main strands of literature covered in the literature review above, consumer health information behavior; relevance, pertinence, and usefulness; and the time dimension of information behavior, come together in the concept of situation. Like the terms relevance and pertinence, situation (along with its umbrella term, context), has no agreed-upon definition (Cool, 2001). Cool (2001) defines situation as the "dynamic

aspect of context" (p. 31) and recommends that researchers focus not on coming up with one definition of situation, but rather on formulating conceptualizations of situation that are most likely to address their particular research questions. In this vein, and drawing on the work of Chatman (1983, 1990, 1991, 1992, 1996), Dervin (1992, 2003), Dervin and Foreman-Wernet (2003), Kuhlthau (2004), and Matson and Brooks (1977), a situation for the purpose of this research will be defined as a person's experiences in relation to their chronic serious health condition and is seen as encompassing all aspects of their experience, including not only their physical experiences, but also any of their associated cognition, affect, social experiences, and behaviors (including information behavior).

This study focuses on people's movement through their situation involving a chronic serious health condition. This movement is encapsulated in the notion of a "path." Johnson et al. (2006) define "pathway" as "the route someone follows in the pursuit of answers to questions" (p. 572). The conception of "path" here is quite similar to these researchers' conception of "pathway"; however, it is somewhat broader in two regards. First, this study does not presume that people will always seek answers to their questions nor that they will necessarily even always hold this as their goal. Second, the term 'path' is used within this research to refer to multiple kinds of paths, not just information seeking. Here, the term "path" is meant to incorporate multiple aspects of a person's movement through his/her situation with a chronic serious health condition, including his/her related behaviors (which encompasses their information behaviors), cognitions, physical experiences, social experiences, and affects.

Problems (such as health conditions), behaviors (including information behavior), social situations, cognition, and affect do not remain static over time. As Taylor (1991) points out, "Problems are not static. They change all the time in response to new information and in relation to the actor's position and perceptions" (p. 225). A person's health condition and his/her associated behaviors, social situation, cognitions, and affect continually evolve across time, sometimes co-evolving and sometimes evolving independently of each other. Each of these factors influences, and is influenced by the others. For example, affective and cognitive factors related to a health condition can lead someone to need, seek, or use information, just as these activities can ultimately lead to a change in the person's affect, cognition, behavior, or even in the health condition itself.

An individual's information behavior, health behavior, and desire to be involved in treatment-related decision-making at any particular point in time are likely influenced by various dynamic situational factors associated with the progression of the individual's disease and the progression of his or her information needs, seeking and use journey, as well as the complex interactions that take place between these two types of factors. Referencing a book chapter written by Cohen and Lazarus (1979), Davison et al. (2002) state:

> The amount of information and preference was seen as dependent on the individual's perception and evaluation of personal and situational factors and the continuous interaction between the individual and his or her environment (both personal and medical). (p. 44)

Whether information is desired at all and what specific types of information will be found useful are likely to vary according to one's current position (as well as one's past and expected or desired future) along the multi-dimensional path (including both their health condition path and their information behavior path) through their situation involving a health condition. This has been pointed out by several other information behavior researchers. McKenzie and Davies (2002), for example, emphasized that a person's information behavior at any given moment is heavily influenced by an "awareness of past and future" (p. 3) and by where he/she is at along his/her own journey. McCaughan and McKenna (2007) pointed out that people's abilities to absorb and act on information are not static. Johnson et al. (2006) similarly stated with regard to their concepts of information fields and information pathways:

> I move within my matrix making decisions about how I will go about pursuing the information I want related to particular topics, which information I will accept and discard, and whether or not I need to continue my journey within the matrix. My path within this matrix is dependent on what I find and how I react to this information. So, '… an entity's current state can be understood only in terms of the history of events that preceded it' (Poole, Van de Ven, Dooley, & Holmes, 2000, p. 12) and the impact of critical events (Poole et al., 2000). (p. 572)

The conceptual framework proposed for this study reflects both a synthesis of the literature included in this review and a very general hypothesis for this study. It is based on all of the work included in the literature review; however, it has been heavily influenced by both Kuhlthau (2004) and Dervin (Dervin & Foreman-Wernet, 2003). Work by these authors has contributed both conceptually and methodologically to this

research. Kuhlthau's Information Search Process model, with its central focus on the process of looking for information and the attendant changes in people's cognition, affect, strategies, actions, and moods inspired my idea to conduct a parallel study within the context of consumer health information behavior. Dervin's sense-making, with its similar focus on process and movement, has also been very influential. Methodologically, this research incorporates adaptations of both Kuhlthau's elicitation of timelines and Dervin's Micro-Moment Time-Line Interview approach.

Figure 10 depicts the initial conceptual framework proposed for this study.

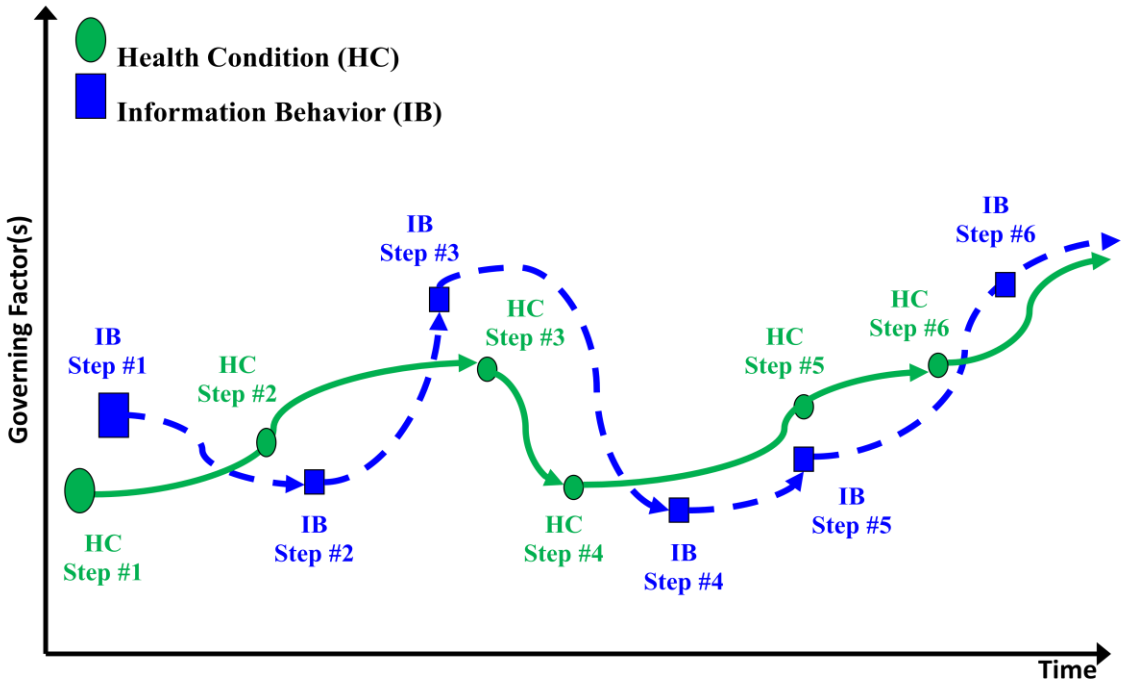


Figure 10: Initial Conceptual Framework

Figure 10 portrays two strands of the multi-dimensional path that people take through their situation with their health condition. The x-axis represents the passage of time, while the y-axis represents one or more factors that govern people's handling of this situation. The series of ovals on the "health condition" path in this figure depict steps along a path that concerns what is happening in relation to their health condition, while the series of rectangles along the "information behavior" path depict steps along a path that concerns what is occurring in relation to their information behavior.

To make this discussion more concrete, let's take a hypothetical example of someone (say, Jane) facing a situation in which she begins to experience some specific physical symptoms and is subsequently diagnosed and treated for some particular health condition. Figure 11 depicts Jane's health condition and information behavior paths.

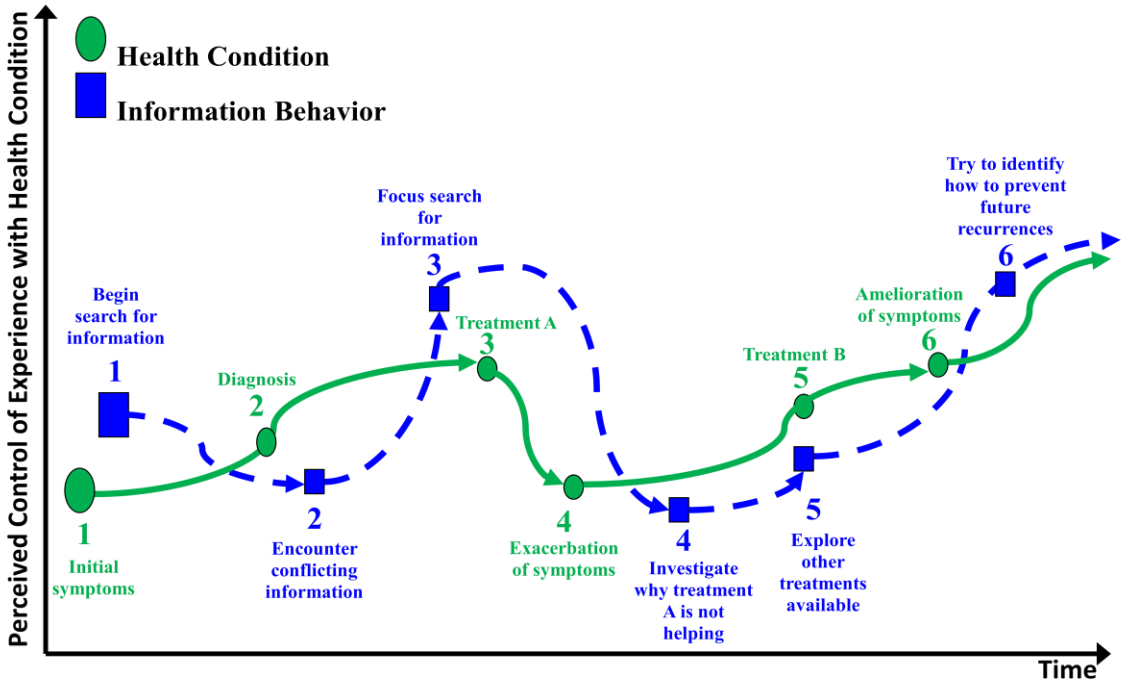


Figure 11: Example of the Evolutionary Paths of a Person through a Situation involving a Chronic Serious Health Condition

For Jane, the factor governing her traversal through her situation with her health condition is her desire to feel in control of her experience with her health condition. In this particular example, Jane first experiences some initial symptoms and begins to look for information about her symptoms. Receiving a diagnosis for her health condition helps her to feel like she has more control over her experience with her health condition and helps her to focus her search for related information; however, encountering conflicting information has the opposite effect. Upon receiving an initial treatment ("Treatment A"), Jane's symptoms become worse, leading her to try to find out why this treatment is not helping her and making her feel less in control. This prompts her to look for other treatments that might help her and she then tries a second treatment ("Treatment B"). As

this second treatment helps to ameliorate her symptoms, her sense of control increases. She then decides to try to further increase her sense of control by trying to learn how to prevent future occurrences of this particular health condition.

As shown in Figure 10 and Figure 11 (above), one's health condition path and one's information behavior path are not linear, are not always parallel, and tend to intersect with, drive, and be driven by one another. A person's health condition and her associated information behavior continually evolve across time, sometimes co-evolving and sometimes evolving independently of each other. Each influences, and is influenced by the other – factors related to a health condition can lead someone to need, seek, or use information, just as these activities can ultimately lead to a change in the health condition itself. Although not depicted in this figure, a person's cognitions, affects, and social experiences are also likely to influence (and be influenced by) both her health condition and her related information behavior. For the particular person whose paths are depicted in Figure 11, information is deemed useful if it serves to decrease her uncertainty and if it makes her feel more in control of her experience with her health condition. However, as discussed in the literature review, not everyone defines usefulness in this way.

Figure 10, in addition to depicting the intersection of the three strands of literature covered in the literature review for this research, also forms a conceptual framework for this study. In the following chapter, the specific methods used to investigate people's actual paths through situations involving a particular chronic serious health condition are laid out. Type 2 diabetes was selected as the chronic serious health condition of focus for this study because it is a relatively common health condition and because it is a very information-intensive health condition that requires people to consciously and carefully manage it across time. More significantly, type 2 diabetes was chosen because the information behavior of people diagnosed this health condition can have major implications for their ability and willingness to improve their health behaviors and to thereby positively influence the ultimate trajectory of the disease.

This study focused broadly on the entire situation of each participant, encompassing all aspects of their diabetes-related experience, including the physical, the cognitive, the affective, the social, and the behavioral. However, the major focus of the study was on people's information-related behaviors and how these related to, and

interacted with, other aspects of their situation in regard to their experience with type 2 diabetes. In the next chapter, the specific methods that were used to carry out this study are described.

Chapter 3

Research Design

This chapter first provides an overview of this study's research design, including the research problem and research questions that it addresses. Then, the specific methods used for participant recruitment, data collection, and data analysis are described.

3.1 Overview

The overarching research problem that this study addresses is how people who have been recently diagnosed with a chronic serious health condition or who have experienced a recent exacerbation of a chronic serious health condition look for and make use of information related to their condition and how this varies across time. Additional goals of this study include investigating the factors that motivate and impede these individuals' information seeking and use processes and discovering what information helps people to deal with their health condition at various points in time and how this information helps.

The specific research questions guiding this study are:

1. What are the factors that motivate or impede information seeking and use by people diagnosed with a chronic serious health condition and how do these factors and the nature of their influences transform across time?
2. What are people's information needs and their information seeking and use practices in relation to their health condition, and how do these change as their knowledge about, and experience with, their health condition change across time?
3. What sources and types of information do people with a chronic serious health condition find useful and how do these perceptions change as their knowledge about, and their experience with, their health condition change across time?

These research questions are investigated using a research design that is primarily longitudinal and qualitative. Information behavior researchers have lamented, "Traditional information needs and uses studies have attempted to predict user behavior according to static, across time-space models… It is as if a still photograph were taken of a scene that would be more adequately portrayed by moving pictures" (Dervin & Nilan, 1986, p. 14). Savolainen (2006) recently pointed out that this gap remains, stating, "One of the greatest methodological challenges for empirical studies is to explore the context of information seeking as a temporally sensitive process" (p. 123). The current study has attempted to address this gap within the context of consumer health information behavior.

In order to effectively address the aforementioned research questions, a longitudinal approach was imperative because of the centrality of the themes of change and transformation with which these research questions are imbued. Kuhlthau (2004) has pointed out that longitudinal studies differ from studies that take a snapshot approach in that they have "the power to reveal the complex cognitive process that takes place over a period of time involving the whole person, emotionally as well as intellectually" (p. 75).

Within the context of a series of two interview sessions, a combination of different qualitative and quantitative data collection methods were implemented, with semi-structured interview constituting the main data collection tool. However, these sessions also included a background questionnaire, a health condition questionnaire, card-sorting exercises, and a timeline exercise. An overview of the data collection instruments used in this study, along with brief descriptions of each of them, is depicted in Table 2 below.

Table 2: Overview of Data Collection Instruments

Data Collection Tool	Session(s)	Approx. Time Spent	Description	Appendix
Background questionnaire	Initial	10 minutes	Collected basic demographic information, as well as information about participants' computer and Internet usage and their experience with type 2 diabetes	Appendix D

Data Collection Tool	Session(s)	Approx. Time Spent	Description	Appendix
Semi-structured interview	Initial and follow-up	1 hour	Open-ended questions focused broadly on participants' experience with type 2 diabetes, including their physical, social, cognitive, and affective experience; however, main focus was on participants' information behavior	Initial: Appendix E Follow-up: Appendix H
Health condition questionnaire	Initial and follow-up	20 minutes	Primarily Likert scale-type questions that collected information about participants' perceptions regarding their physical, social, cognitive, and affective experience with type 2 diabetes	Appendix F
Card-sorting exercises	Initial and follow-up	30 minutes	Collected participants' ratings as to the usefulness of different types of people, media types, Internet site types, and content types; Also collected the frequency with which different types of goals motivated them to look for diabetes-related information	Appendix G
Timeline	Follow-up	20 minutes	Participants were asked to jot down on a timeline any important points (such as test results they received, events, setbacks, decisions, turning points, questions they had or got answered, help they needed or received) along their journey with diabetes	Appendix I

The use of both qualitative and quantitative data collection methods and the collection of both qualitative and quantitative data enabled this research to benefit from the advantages of both types of methods/data and to overcome some of the disadvantages associated with each of them. For example, interviewing made it possible to uncover deeper and more personally relevant information, including answers to more complex how and why questions, while the questionnaires and card-sorting exercises enabled the collection of more systematic, quantitatively analyzable data related to the subject of this study. Further, this study's incorporation of multiple data collection methods and multiple data analysis methods enabled the use of triangulation, which enabled this research to result in a broader and richer picture of people's health-related information behavior.

Analyzing the interviews and the timelines inductively enabled the actual voices of the study participants to be heard and presented, without imposing personal

preconceptions. In fact, the specific combination of time-line interviewing and inductive content analysis has "proven extremely useful for exploring and describing users' perceptions in various situational contexts" (Schamber, 2000, p. 734) and has "yielded not only an enormous amount of data, but also extremely rich data that could be examined for contextual implications" (Schamber, 2000, p. 740).

3.2 Participant Recruitment

Participant recruitment for this study focused on people who were 18 years of age or older and who had been diagnosed with type 2 diabetes. More specifically, the population sought was adults who had recently either been diagnosed with type 2 diabetes or experienced some type of exacerbation in relation to this condition, such as going on insulin, developing a diabetes-related complication, or beginning a new medication for this condition. The goal of this study was to concentrate on people's reports of their information behavior provided during the first 12 to 18 months following their initial diagnosis or their most recent exacerbation related to this condition. The decision to focus on the short-term past was made in order to try to minimize any potential memory-related problems, such as decay, interference, and forward and backward telescoping.

A total of 34 participants were recruited for initial interviews from July through October of 2010. Three different recruitment methods were used:

(1) Posting an ad on the Michigan Institute for Clinical & Health Research's (MICHR) **engage Website** (http://www.umengage.org/index.html) [Note: This Website has since been renamed 'UMClinicalStudies'. See: http://umclinicalstudies.org/];

(2) Displaying **flyers** at the University Hospital and associated health clinics throughout the Washtenaw County area, such as the Briarwood Center for Cardiology and Diabetes and the Ypsilanti Health Center; and

(3) Passing out flyers at **diabetes-related support group meetings** (such as the Diabetes Weight Loss Support Group of the Diabetes Center of Foote Hospital in Jackson and the Diabetes Sharing Group held at the Chelsea Community Hospital).

Fourteen (41%) of the 34 participants were recruited through the engage/UMClinicalStudies Website, 17 (50%) people were recruited through flyers posted at the University Hospital and associated health clinics throughout the Washtenaw County area, and three (9%) people were recruited at diabetes-related support group meetings.

The ad that was posted on the engage Website is shown as Appendix A; the recruitment flyer is shown as Appendix B. As indicated in these documents, participants were offered $40 in cash to participate in an initial interview about their experience with type 2 diabetes and were told that the interview would take up to two hours. Potential participants were asked to contact the researcher via e-mail or telephone. As potential participants expressed an interest in the study, they were screened for eligibility with respect to age and date of diagnosis/exacerbation. Interviewees were asked where they would like to meet for the initial interview. This was often the interviewee's home or a nearby café or public library branch location.

Figure 12 shows the distribution of the locations chosen by participants for their initial interview.

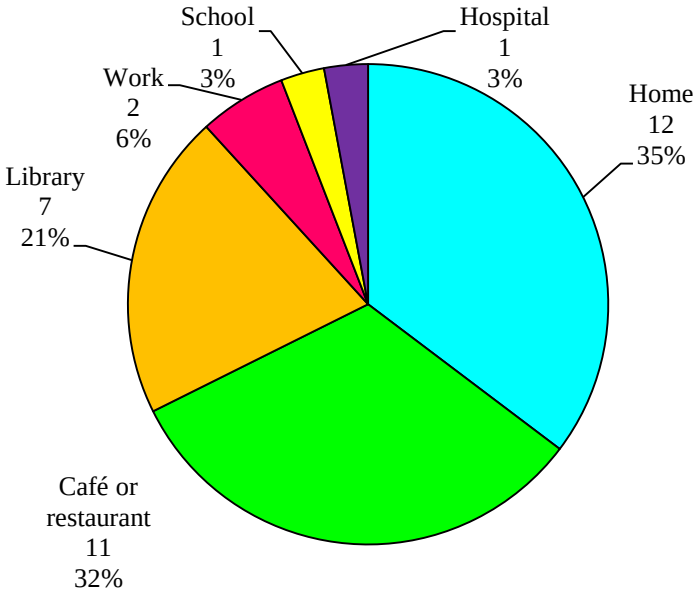


Figure 12: Locations of Initial Interviews

For the initial interview, just over one-third of the participants (n=12; 35%) elected to meet at their homes, just under one-third chose to meet at a café or restaurant (n=11; 32%), and approximately one-fifth (n=7; 21%) of the participants chose to meet at a library near them. Everyone who elected to meet at a library chose a public library branch location with the exception of one participant who requested to meet at the University of Michigan's Hatcher Graduate Library. The remaining four participants chose to meet either at their workplace, their school, or at a hospital. For the follow-up interview, the distribution of interview locations was fairly similar, with the exception that one interview had to be conducted over the telephone as the participant was spending the winter months in Florida.

3.3 Data Collection Methods: Overview

Data was collected from participants using an assortment of methods that were administered within the overall framework of two sessions spaced approximately four to six months apart. Initial interviews were conducted with 34 participants from July through November 2010. During this initial session, a brief initial demographic questionnaire was administered, followed by a semi-structured interview and then administration of a health condition questionnaire and several card-sorting exercises.

Approximately four to six months later (during the months of December 2010 through April 2011), each of the 34 participants was re-contacted by phone, e-mail, and/or mail to participate in a follow-up interview. Although all 34 participants agreed to a follow-up interview, one participant passed away before her follow-up interview could be conducted and one follow-up interview turned out to be unusable because the participant was quite ill at the time. Each follow-up session began with a semi-structured interview, followed by elicitation of a timeline and then re-administration of the health condition questionnaire and card-sorting exercises that were administered during the initial session. A visual depiction of the overall data collection process for this study is shown in Figure 13 on the following page.

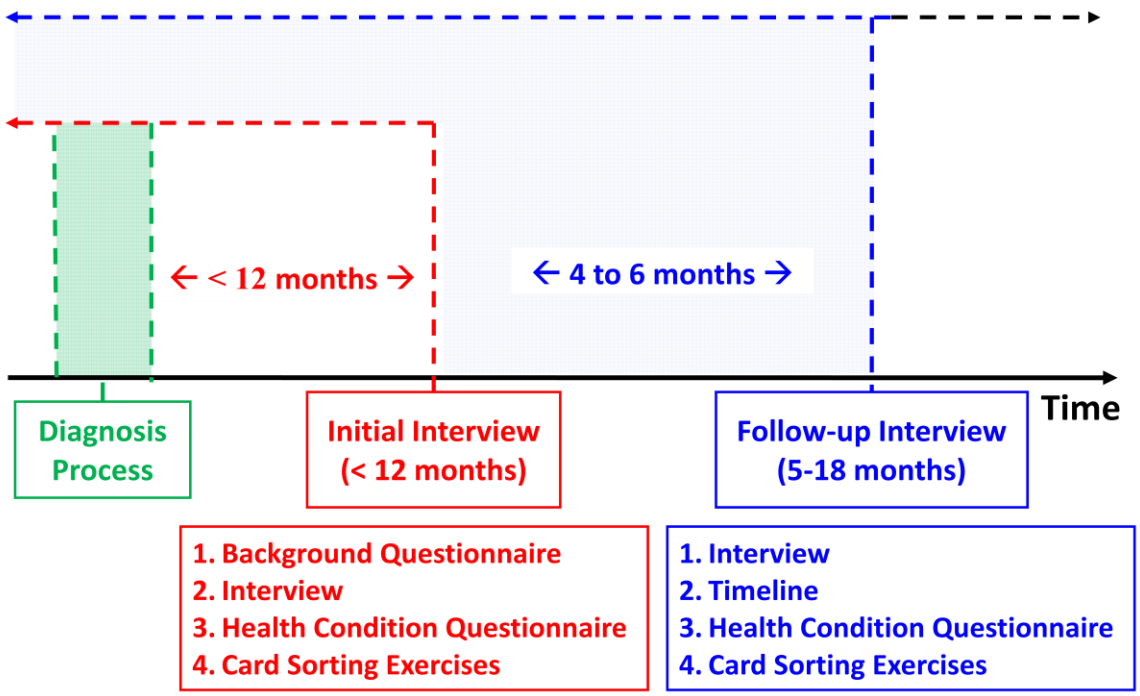


Figure 13: Data Collection Process

3.3.1 Data Collection Methods: Initial Interview

The initial interview session with each participant began with administration of both the informed consent form (Appendix C) and a brief background questionnaire (Appendix D). The informed consent form let participants know that they would be paid $40 for the initial session and an additional $50 for the follow-up session. It also requested participants provide their contact information (first name, phone number, and e-mail address) if they were interested in participating in a follow-up session. The informed consent form solicited participants' consent to participate, to have their interview session audio-recorded, to have photos taken of their diabetes-related items and information, and to be re-contacted within four to six months for a follow-up session.

The background questionnaire (Appendix D), which was administered directly following the informed consent form, collected some basic personal information, as well as information about the participant's computer/Internet experience and experience with type 2 diabetes. In addition to collecting standard demographic information about each participant's gender, age, marital status, educational attainment, and occupation, the

background questionnaire also asked participants whether they had home Internet access, whether they ever used the Internet from any other locations, and how many hours, on average, they spend using the Internet per day. Additional questions collected information about when each participant was first diagnosed with type 2 diabetes and about any diabetes-related classes and/or support groups he/she had ever attended.

Following the administration of the background questionnaire, the interview was conducted. The protocol (Appendix E) for the initial interview was based on the fundamental idea behind Dervin's (2003) Micro-Moment Time-Line Interview technique. This technique was chosen because this method "allows respondents to define, in their own terms, their situations, gaps, how they bridged their gaps, and the ways in which they put new sense to use" (pp. 256-257). One of the very important benefits of this method is that it allows respondents "to create their own context and to fully inform the interviewer about their worlds" (p. 257). The interview was semi-structured, starting out with some opening questions that asked interviewees to describe when they were first diagnosed with diabetes, how they first knew that something was wrong, how diabetes affects their day-to-day life, whether they know anyone else who has diabetes, and what they would tell a family member or friend who told them that they were recently diagnosed with diabetes. During the rest of the interview, the focus was on participants' information needs, seeking, and use during the pre-diagnosis period, the diagnosis process itself, and the post-diagnosis period. One of the questions participants were asked about the diagnosis process itself is a form of what Dervin (2003) calls a "magic wand" question. This question asked interviewees if, looking back at this period in their life, there was anything they know now that they wished they had known then. A final section of the interview addressed issues that crossed the boundaries of the pre-diagnosis, diagnosis, and post-diagnosis periods.

Following the interview portion of the initial session, a health condition questionnaire (Appendix F) was administered. This questionnaire gathered data about participants' recent experiences with their health condition and with information sources related to their health condition. Participants were asked to answer questions about their health condition, their feelings about their health condition, and their relevant information behavior using a series of five-point Likert scales. Three of these questions were adapted

from existing instruments. The first question was adapted from the CDC HRQOL-14, which is the Centers for Disease Control and Prevention Health-Related Quality-of-Life 14-Item Measure (Centers for Disease Control and Prevention, 2005). Question numbers 2 and 12 were adapted from the WHOQOL-BREF, which is a shorter version of the World Health Organization Quality of Life instrument (World Health Organization, 2004). Participants were asked to think aloud as they completed the health condition questionnaire so that the data captured would include not only their answers to the questions on the form, but also their reasoning behind their responses.

Following the health condition questionnaire, participants were asked to participate in five different card-sorting exercises (Appendix G). Figure 14 is a photo depicting an example of the first card-sorting exercise (i.e., people).

Figure 14: Photo of First Card-Sorting Exercise (People)

For each card-sorting exercise, Excel's random number generator function was used to randomize the order of the cards in each deck prior to each interview. The first four of these exercises had to do with participants' perceptions about the usefulness of various types of information sources in helping them to learn about diabetes. Each of the decks for these exercises represented a different type of information source [i.e., (1) People; (2) Media types; (3) Internet site types; and (4) Content types]. For each of these four exercises, participants were given a deck of cards and asked to first remove any cards representing sources with which they had had no experience (in relation to diabetes) and to then place each of the remaining cards into one of five different piles – very useful, somewhat useful, neutral, somewhat not useful, or not at all useful. After participants completed each deck, they were asked to identify the most useful source of all the ones they had placed into the "very useful" category.

For the final card-sorting exercise, participants were given a deck of cards that included many different reasons that they may have had for looking for diabetes-related information. Participants were asked to place each of these cards into a category (often, sometimes, or never) based on how often the particular goal listed on the card had prompted them to look for diabetes-related information. If a participant placed the cards "Prepare for doctor appointment" and "Find out more following a doctor appointment" into the same category, they were asked to discuss which one of these they tend to do more often and why. Participants' relative responses to both of these cards were sought in order to ascertain how each participant viewed doctors and doctor-provided information within the context of their overall information behavior landscape.

Following the card-sorting exercises, the session was wrapped up with a couple of closing questions. Participants were asked whether they would like to add anything to the interview. They were also asked if they had any questions that they would like to ask the interviewer. Also, alternate contact information was obtained from participants just in case any difficulty arose when trying to contact them later for a follow-up interview.

3.3.2 Data Collection Methods: Follow-up Interview

Approximately four to six months after their initial interview session, participants were contacted by phone, e-mail, and/or mail to set up a follow-up session. This session began with a follow-up interview – see Appendix H for the protocol for this interview.

Although many questions were asked at both the initial and follow-up interviews in order to gather data that would permit across-time analysis, several additional questions were asked at the follow-up interview. The interview began with a few opening questions asking participants to talk about how they had been and about whether/how their experience with diabetes had changed since we last met. Participants were then asked to discuss how diabetes affects their day-to-day life and what they would say to a family member or friend if that person told them that they had recently been diagnosed with diabetes. The remainder of the interview included questions about participants' diabetes-related information needs, seeking, and use. Some of the questions specifically added for the follow-up interview included a question asking participants to describe the characteristics that make information useful to them and another one asking participants to talk about the three most important things someone needs to know in order to be able to successfully manage their diabetes. Participants were also asked to describe any piece of information or source of information that had been especially influential to them in terms of how they understand and/or deal with having diabetes.

Following these interview questions, each participant was asked to draw a timeline depicting the important points along their journey with type 2 diabetes. They were told that they could include anything that they felt was an important part of their diabetes-related journey. A list of some possible things to include was provided. This list suggested including any test results they received back, any important events that had occurred, any decisions they had made, any setbacks they had encountered, and any turning points they had experienced. Other suggestions included any questions they had, tried to get answers for, and/or got answered and any help they needed, sought, and/or received. The list also specifically mentioned that they should include anything else that they felt is important. Participants were asked to talk aloud as they were drawing this timeline, describing what they were doing and why. Figure 15 shows a compact version of the timeline form that was provided to participants. The dates of their diagnosis and their initial interview, as well as the current date, were already filled in for them. See Appendix I for the actual timeline form that was provided to participants.

Timeline

Instructions: Using the timeline on the following page, please indicate any important points along your journey with diabetes. Please include about 10 different events or factors, placing positive ones above the line and negative ones below the line. As you draw this timeline, please describe for me what you are doing and why. Include things such as:

- Test Results
- Events
- Setbacks
- Decisions
- Turning Points
- Questions you had, questions you tried to get answers for, and/or questions you got answered
- Help you needed, sought, and/or received
- Anything else that you feel is important

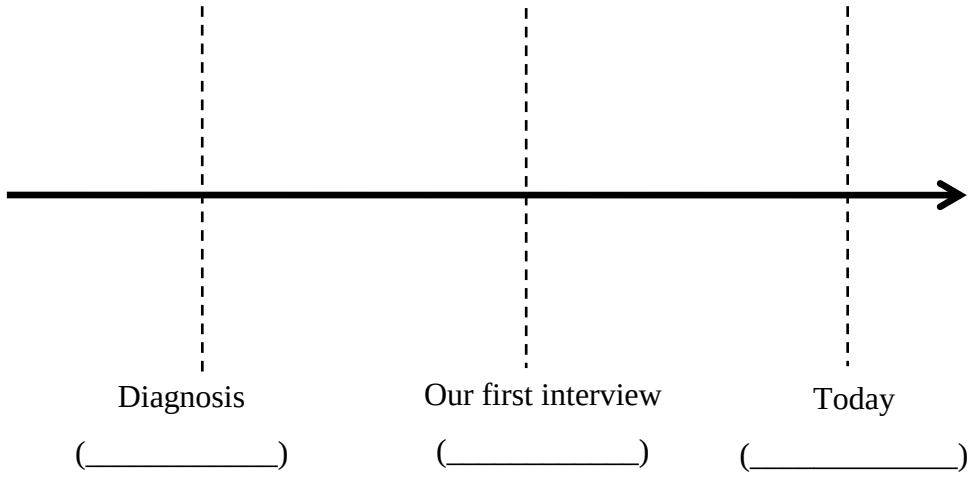


Figure 15: Timeline Form

The session then continued with another administration of the health condition questionnaire (Appendix F) and the card-sorting exercises (Appendix G) that participants completed during the first session. Then, the session was wrapped up with some closing questions. One of these questions asked participants whether they felt that participating in this study had influenced (or would influence) their behavior in any way. Participants'

responses to this question were probed in order to identify any potential impacts that this study may have had (or may be likely to have) in participants' lives.

3.3.3 Data Collected

The 34 initial interview sessions that were conducted with participants lasted an average of 101 minutes, ranging between 50 and 213 minutes. This phase of the study resulted in over 57 hours of taped interview data and over 1,500 transcript pages. Additional data gathered during the initial sessions included results from participants' background questionnaires, health condition questionnaires, and the card-sorting exercises.

The 32 follow-up interview sessions lasted an average of 105 minutes, ranging between 48 and 160 minutes. Follow-up interviews resulted in 56 hours of taped interview data and over 1,500 transcript pages. Additional data gathered during the follow-up sessions included the timelines sketched by participants, as well as the results from their health condition questionnaires and card-sorting exercises. Figure 16 shows the percentages of participants by the durations of their interviews (in minutes).

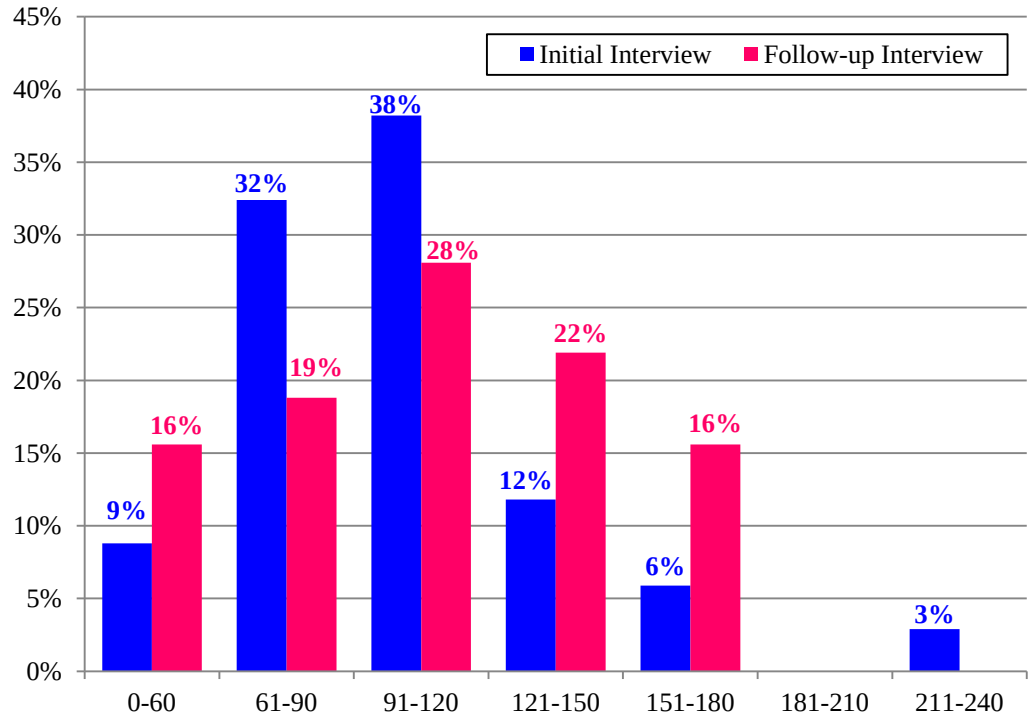


Figure 16: Percentages of Participants by Durations of Interviews (in minutes)

Figure 16 (above) shows that 21% (n=7) of the initial interviews lasted more than two hours and that this figure jumped to 38% (n=12) for the follow-up interviews.

In total, this study included 66 interviews, which yielded over 113 hours of taped interview data and over 3,000 transcript pages. In addition to interview data, 34 participants completed background questionnaires and 32 participants provided timelines depicting their journeys with type 2 diabetes. Also, 32 participants completed health condition questionnaires and card-sorting exercises at both the initial and follow-up sessions.

3.4 Data Analysis Methods

Data analysis proceeded both simultaneously with, and subsequent to, data collection. Data from background questionnaires, health condition questionnaires, and card-sorting exercises were entered into Excel and imported into SPSS for quantitative analysis. Statistical analyses run on this data included Pearson correlation coefficients, paired-sample t-tests, and regression analysis. Audio-recordings of interview sessions (including timeline think-aloud segments) were transcribed in preparation for qualitative analysis. Qualitative data analysis was carried out using NVivo 9. Three coding schemes were devised. Two structural codebooks (Appendix J and Appendix K) were derived deductively from the structure of each of the interview sessions, along with all of the protocols used during each of these sessions. A thematic codebook (Appendix L) was derived both deductively (from the literature review and the interview protocols themselves) and inductively based on participants' background questionnaires, interview transcripts, health condition questionnaires, card-sorting exercises, and timelines. The thematic codebook was developed and iteratively revised as data collection and data analysis proceeded. The sections of the thematic codebook within the information behavior categories of information needs, information seeking, information sources, and information use are shown as Table 3 below. For the entire thematic codebook, see Appendix L. The version in Appendix L includes columns which show the number of transcripts and the number of text passages to which each of the thematic codes was assigned across all 66 (initial and follow-up) interview transcripts.

Table 3: Sections of Thematic Codebook pertaining to Information Needs, Information Sources, Information Seeking, and Information Use

Code	Subcode	Sample Quotes
Information Needs	Information needs	"I just mostly want to find out about what to eat, how often to eat, what I cannot eat, which is an absolute no-no." (I26); "They've got to know how to properly control their diet, what to eat, what not to eat, how much to eat. They need to control their weight through diet and exercise. And they need to know how to monitor their blood sugar properly to make sure that the first two things are working right." (I16)
	Information wish list	"I'd like to see more in-print books on diabetes in large print. You don't find them." (I04); "It really would be nice if, like I said, there were some sort of package that they gave you, like a box with all the knowledge that you need to have for that…. Like a knowledge starter kit and then the advanced one… Like how to live with diabetes, a reference package." (I34)
	Information-related preferences	"I' tired of people trying to scare me. Just tell me… Me, it' got to be informational and you just need to tell me how it works." (I20); "My attention span is not really good right now, my eyesight is not really good, I'd rather watch it than read it." (I22)
	Not knowing what I don't know	"I didn't know I needed to know until I found out something." (I32); "At first, I feared the diabetes, now I fear what I don't know about the diabetes. It's kind of a shift. And that's I think why I'm motivated to read information about it and learn about it because there maybe something I don't know." (I06)
	Sufficient or insufficient information	"I feel like I know enough to stay out of hot water but there's always more I could be learning and will find out as I go down the road." (I14); "I think we in the medical profession… have a lot to learn about diabetes… I think the biggest problem is not knowledge that we have… Our biggest problem is education, education to the general public…. Tailor-made… to every individual, not cookie-cutter." (I33)
Information Sources	Doctor's orders	"That was one of the things that I learned initially was, you really have to be your own advocate. You have to take an active part in this disease. It's not like if you have some things you just have to do what the doctor says." (I25); "[My doctor] just handed [me] this diet on a piece of paper and said, 'Here, do this'… no information, no books, no… nothing." (I27)
	Internet and search engines	"And the Internet, like I said, it's up-to-date information and it's easily accessible. That's really important." (I12); "I hate going to the Internet because you never really know... You never know which sites to believe." (I24)
	Learning from one's own body and experiences	"I'm trying to figure out about… the role of exercise and the diabetes management… I've definitely looked for a lot of information on that. And then I sort of read my body and think about all the stuff that I'm taking in and think about what feels safe and healthy." (I09); "The journals help me step aside and see myself, see what I'm doing… Just objectively see how my behaviors are and how they could be impacting my diabetes." (I12)
	Learning from others' experiences (including narratives)	"I think it's always good to see how other people deal with situations, you know? And if suddenly you find yourself in that situation, then you're more comfortable with it because someone else got through it." (I14); "Stories, personal experiences, that helps me, that motivates me." (I20)

Code	Subcode	Sample Quotes
Information Sources (Cont'd.)	Libraries and librarians	"As soon as I realized from the Googling… what it was, I immediately hit the library for books on recipes and stuff. And that's where I found that Magic Menus book and I kept it out for the full extent that I could." (I10); "I know when I was first diagnosed, I got every book I could on diabetes out of the library." (I25)
	Referral	"So [my doctor] sent me to the diabetes educator, to the endocrinologist. And so the endocrinologist kind of took over his stuff." (I20); "[My doctor] referred me to that nutrition class… I used the information from the classes I was sent to, to get a first step, a fresh start on what I should be or shouldn't be doing." (I35)
	Vetting	"[The dietician] went through the whole book with me and put those smiling faces and wrote notes and...[put] sad faces if they're not [good for you]." (I02); "Well, this was just stuff he had suggested, the doctor did, and it was a book he had told me about, too. It was called the Smart Diet." (I35)
Information Seeking	Cross-verification; Use of multiple sources	"[WebMD] gives you information that you can actually research on your own, and I like to do that because I like to make sure myself. So if they tell me one thing, I will research it on several different other sites, and if all that information matches up there, then I feel I could trust it." (I04); "I will just do that, when I go to the doctor's office and they tell me, I go right home and get on the Internet. I go get my book or go to the library and I start researching and looking for myself." (I31)
	Information seeking plans	"I'm going to continue going to my classes more. I just purchased, it's Bob Greene's book – he's the guy who was Oprah's trainer – and he has a book on diabetes and pre-diabetes. I just received it, and so I'm going to work my way through that. And, I have other books that are working their way to me through the library." (I09); "I'll probably talk to my doctor some more and maybe get some pamphlets or maybe ask him some more questions about like my A1C, how to lower it because I really need to learn how to lower my A1C." (I18)
	Information seeking practices	"I got diabetes information initially… I mentioned my supervisor. I mentioned the diabetes education. I also had at least one provider who was diabetic who gave me some very good information... The reading that I have done. The support groups I've been in, and I've been in a couple. The diabetes care workshops that I've been to… I try to be able to pick up, out of any particular place… thing, at least one new piece of knowledge." (I25); "if I wanted to know something, I called the doctor and found out or I got a book and found out or I asked somebody and found out." (I05)
	Joint information seeking	"My son and I were on the Internet and we looked back, we thought perhaps [my neuropathy-related symptoms] might have something to do with me having a stroke. Maybe I was stroking out… some of things that was happening with me looked like it could have been a stroke." (I20); "I think the classes that my son and I took together, and at that time my boyfriend, you know, learned how to shoot insulin into me, were great." (I27)
	Passive information seeking	"Whatever [my doctor] wants me to know, he'll tell me." (I05); "it wasn't the fact that the information wasn't there, that my doctors and everything wouldn't provide that. It was my curiosity didn't go beyond what they were giving me as a part of the routine of treatment." (I29)
	Proxy information seeking	"My daughter went on the Internet, my daughter who had the computer, my oldest daughter. She went on the Internet to see what she could find out for me. She didn't really find out much for me." (I01); "I don't have to look for it. People are always giving you information… It's in the paper, my wife's friends. I get more information that I don't need." (I32)

Code	Subcode	Sample Quotes
Information Use	Difference finding out makes	"I probably wouldn't be here if I hadn't taken the time to educate myself." (I25); "Once you know better, then you do better, but if you don't know better you don't do any better." (I31)
	Information management practices	"If there's something that's really got my interest and I have a question about it, I print it out…I keep everything in a folder and when I go see my endocrinologist, I'll take it with me. If I go and see my ophthalmologist, I'll take that folder with me. That way if I have information or need something, it's right there in front of me." (I04); "We have the diabetic cookbooks, the diabetic pamphlets, on that little... In the hallway there where we keep our books, there's a little bookcase… Anything that's given to us, we do not throw it away." (I05)
	Information use	"My doctor has told me… that I should exercise more. So, that was useful… Somewhat [useful]… It's not like I take her advice." (I26); "Well, as far as knowing that I can fix it, or make it a little bit better, I feel somewhat optimistic. And in a way, I don't feel optimistic because I don't know if I have the ambition to do it, I guess." (I34)

Chapter 4

Results

This chapter consists of seven main sections. The first section provides an overview of the group of people who participated in this study. The second section presents the results from participants' health condition questionnaires. In the third through fifth sections, relevant findings are presented for each of this study's three research questions: (1) What are the factors that motivate or impede information seeking and use by people diagnosed with a chronic serious health condition and how do these factors and the nature of their influences transform across time?; (2) What are people's information needs and information seeking and use practices in relation to their health condition, and how do they change as their knowledge about, and experience with, their health condition change across time?; and (3) What sources and types of information do people with a chronic serious health condition find useful and how do these perceptions change as their knowledge about, and their experience with, their health condition change across time? The sixth section presents participants' viewpoints about the impacts of participating in this study. The final section provides a summary of the findings presented in this chapter.

4.1 Participants

4.1.1 Overview

Table 4 and Table 5 provide some background information about each of the 34 people who participated in the study. The data in these tables is from the background questionnaires that participants completed during the initial interview. Table 4 shows basic demographic information about each participant, including their gender, age, educational attainment, and employment status. This table also indicates whether each participant has Internet access from home and the average number of hours he/she spends on the Internet per day. Regarding the latter, some participants did not provide a specific

number in answer to this question, and instead provided a daily, weekly, or monthly range. These figures were converted to daily figures and the midpoint of the range was calculated.

Table 4: Participants' Demographic and Internet Access/Use Data

	Demographic Information				Internet Access/Use	
	(1)	(2)	(3)	(4)	(5)	(6)
#	Gender	Age	Educational Attainment	Employment Status	Home Internet Access	Average Number of Hours on the Internet per Day
I01	F	64	High school graduate	Retired	Y	0.50
I02	F	52	Some college	Retired	Y	2.00
I03	F	52	Some college	Employed	Y	2.00
I04	F	44	College degree	Retired	Y	4.00
I05	F	62	Some high school	Unemployed	Y	0.00
I06	M	51	GED	Disabled	N	0.00
I08	F	63	Some college	Retired	Y	5.00
I09	F	48	Graduate or professional degree	Employed	Y	2.00
I10	M	39	Some college	Employed	Y	15.00
I11	F	48	Graduate or professional degree	Disabled	Y	1.00
I12	F	44	Some college	Disabled	Y	2.00
I13	F	68	Some graduate or professional school	Retired	Y	3.00
I14	M	52	Graduate or professional degree	Unemployed	Y	3.50
I15	F	32	Some high school	Unemployed	N	0.00
I16	M	56	College degree	Unemployed	Y	6.00
I17	F	61	Some college	Employed	Y	0.00
I18	M	35	Some college	Disabled	N	0.20
I19	M	46	Graduate or professional degree	Employed	Y	3.00
I20	F	53	Some graduate or professional school	Disabled	Y	3.00
I21	M	50	Some college	Disabled	N	0.00
I22	F	47	High school graduate	Disabled	N	0.20
I23	M	81	Graduate or professional degree	Retired	Y	1.00
I24	M	45	Graduate or professional degree	Employed	Y	1.00
I25	F	72	Graduate or professional degree	Retired	N	0.00
I26	F	63	College degree	Retired	N	0.00
I27	F	57	Graduate or professional degree	Disabled	Y[2]	0.00
I28	M	57	Some high school	Employed	N	0.00

[2] Although I27 has home Internet access, she does not use it. Her husband is the only one that uses it.

	Demographic Information				Internet Access/Use	
	(1)	(2)	(3)	(4)	(5)	(6)
#	Gender	Age	Educational Attainment	Employment Status	Home Internet Access	Average Number of Hours on the Internet per Day
I29	M	67	Graduate or professional degree	Employed	Y	1.00
I30	M	50	Some college	Disabled	Y	1.00
I31	F	58	Some college	Employed	Y	0.60
I32	M	60	Graduate or professional degree	Employed	Y	1.00
I33	M	51	College degree	Disabled	Y	3.00
I34	F	40	Some college	Employed	Y	1.25
I35	F	46	College degree	Employed	Y	0.80

Table 5 shows some information about each participant's experience with type 2 diabetes, including their initial date of diagnosis, the date they started on insulin (if applicable), their self-reported A1C as of their initial interview, their self-reported A1C as of their follow-up interview, and the change in their A1C's between the two interviews.

Table 5: Participants' Diabetes-Related Data

	(1)	(2)	(3)	(4)	(5)
#	Date Diagnosed with Diabetes	Date Began Insulin (if applicable)	A1C as of Initial Interview	A1C as of Follow-up Interview	Change in A1C
I01	2001	1/2010	**7.0**		
I02	9/2009	n/a	**6.5**	**6.0**	**-0.5**
I03	9/2009	n/a	**6.2-6.4**	**6.2-6.4**	**0.0**
I04	1982	Summer 2000	**6.2**	**13.8**	**+7.6**
I05	1995	1998	**7.6**	**7.3**	**-0.3**
I06	12/2009	6/2010	**7.2**	**7.1**	**-0.1**
I08	2/2009	n/a	**6.0**	**6.0**	**0.0**
I09	7/2010	n/a	**14.0**	**8.2**	**-5.8**
I10	9/2009	n/a	**6.3**	**6.3**	**0.0**
I11	9/2009	n/a	**5.6**	**5.7**	**+0.1**
I12	10/2000	10/2000	**6.3**	**5.7**	**-0.6**
I13	8/2010	n/a		**6.1**	
I14	2/2000	2/2000	**7 or 8**	**High 6**	
I15	7/2010	7/2010			
I16	3/2008	n/a	**6.8**	**6.2**	**-0.6**
I17	9/2005	n/a	**7.4**	**7.1**	**-0.3**
I18	3/2009	n/a		**5.5**	
I19	9/2009	n/a	**7.5**	**5.8**	**-1.7**
I20	6/1993	2001 or 2003	**11.5**	**14**	**+2.5**
I21	5/2007	5/2007	**8.9**	**8.9**	**0.0**

#	(1) Date Diagnosed with Diabetes	(2) Date Began Insulin (if applicable)	(3) A1C as of Initial Interview	(4) A1C as of Follow-up Interview	(5) Change in A1C
I22	1/ or 2/2003	2004	**8.6**	**8.1**	**-0.5**
I23	1980	n/a	**6.3**	**6.5**	**+0.2**
I24	2/2010	n/a			
I25	6/2005	1984	**8.0**	**7.7**	**-0.3**
I26	9/2003	n/a	**399 [?]**	**[Deceased]**	
I27	9/1980	1994	**6.8**	**8.2**	**+1.4**
I28	5/2009	4/2010	**8.5?**	**7–9**	
I29	1985	2004 or 2005	**7.5**	**7.2?**	**-0.3**
I30	10/2009	n/a	**6.1**	**6.0**	**-0.1**
I31	3/2009	[Was: 3/2009 - 5/2009]	**Low 7?**	**7.x**	
I32	1/2010	8/2010	**11.3**	**8.0**	**-3.3**
I33	11/2009	9/2010	**11.7**	**6.7**	**-5.0**
I34	10/2009	9/2010	**8.0**	**7.5**	**-0.5**
I35	10/2009	10/2009	**6.4**	**5.8**	**-0.6**

Note. Green shading = Good (5.0 – 5.9). Blue = Nominal (6.0 – 6.9). Yellow = Slightly high (7.0 – 7.9). Orange = High (8.0 – 8.9). Red = Very high (9.0 and up). (Healthy-ojas.com, 2010)

In Table 5, the cells in columns (3) and (4) – participants' self-reported A1C values – have been shaded (wherever possible) to show their severity. The green and the blue shading indicate better blood glucose control, while the orange and red shading indicate poor blood glucose control. More specifically, the green shading indicates good A1C values (between 5.0 and 5.9), the blue shading indicates nominal A1C values (between 6.0 and 6.9), the yellow shading indicates slightly high A1C values (between 7.0 and 7.9), the orange shading indicates high A1C values (between 8.0 and 8.9), and the red shading indicates very high A1C values (9.0 and up). Whenever participants provided a range rather than a specific A1C value, the midpoint of the range was used to determine the shading. The final column in Table 5, column (5), shows the change in each participant's A1C between the time of his/her initial interview and the time of his/her follow-up interview four to six months later. Changes shown in green font represent decreases, while those shown in red font represent increases.

4.1.2 Demographic Information

Thirty-four people from seven different counties and nearly 20 different cities/towns within the state of Michigan participated in initial interviews. Table 6 provides some summary statistics regarding participants' demographic information. The

data in this table is from participants' background questionnaires, which they completed at the time of their initial interviews.

Table 6: Breakdowns of Participants by Demographic Factors

Variable	Breakdown
Gender	Male: 14 (41%) Female: 20 (59%)
Age	30-39: 3 (9%) 40-49: 9 (26%) 50-59: 12 (35%) 60-69: 8 (24%) 70-79: 1 (3%) 80-89: 1 (3%)
Educational attainment	Some high school: 3 (9%) High school graduate: 2 (6%) GED: 1 (3%) Some college: 11 (32%) College degree (including Associate's): 5 (15%) Some graduate or professional school: 2 (6%) Graduate or professional degree: 10 (29%)
Employment status	Employed: 12 (35%) Unemployed: 4 (12%) Disabled: 10 (29%) Retired: 8 (24%)
Marital status	Married/Living with partner: 16 (47%) Divorced/Widowed: 13 (38%) Separated: 1 (3%) Never married: 4 (12%)

Participants were fairly diverse in terms of several different basic demographic variables. For example, 14 (41%) men and 20 (59%) women participated. Ages of participants ranged from 32 to 81, with an average age of 53.4 and a median age of 52. Educational attainment across participants was also diverse. Nearly one-third of the participants (n=10; 29%) had a graduate or professional degree and one-half of the participants (n=17; 50%) had at least an Associate's degree. Roughly one-third (n=11; 32%) of the participants had completed some college but had not obtained a degree. Three participants (9%) had a high school diploma or GED and another three participants (9%) had completed some high school but had not received a diploma or GED. A few participants (n=3; 9%) reported that they were currently pursuing a certificate or a degree.

Participants also represented several different employment statuses and occupations. Just over one-third (n=12; 35%) of the participants were employed at the

time of the initial interview. Nearly one-third (n=10; 29%) were disabled. Eight (24%) were retired and four (12%) were unemployed. Participants' current/most recent occupations covered quite a wide range, including assembly worker at an automobile manufacturing plant, cashier, Certified Nursing Assistant, construction laborer, head collector for fraudulent checks, housekeeper, instructor, juvenile detention parole officer, pediatric surgeon, professor, real estate attorney, secretary, social worker, and systems administrator.

Participants also varied in terms of marital status. Nearly half (16; 47%) of the participants were married or living with a partner at the time of their interview. Ten (29%) were divorced and four (12%) had never married. The remaining four (12%) participants were either separated or widowed. Fourteen (41%) participants reported that they lived alone. Of the 20 participants who did not live alone, seven (21%) still had one or more child (defined as someone under age 18) living at home with them.

4.1.3 Computer/Internet Access and Use

Table 7 provides some summary statistics regarding participants' Internet access and use. The data depicted in this table is from participants' background questionnaires, which they completed at their initial interviews. Over 75% (n=26) of the participants had a computer at home and were able to access the Internet from home. Nearly all of these participants had broadband or cable Internet; just two participants reported that they had dial-up access. Fourteen of the 26 participants who had Internet access from home also use the Internet from other places. Of the eight participants who do not have Internet access from home, four visit other locations in order to be able to use the Internet. So, in total, over one-half (n=18; 53%) of the participants reported that they also access the Internet from places other than their home. The other locations from which participants reported using the Internet included libraries (n=13; 37%), work (n=7; 20%), school (n=5; 14%), other people's houses (n=3; 9%), and coffee shops/cafés (n=2; 6%). Hotels, hospitals, iPads/laptops, phones, and cars were also mentioned, however, only by one participant each. Just five participants (15%) reported that they do not use the Internet at all.

Table 7: Breakdowns of Participants by Internet Access and Use Factors

Variable	Breakdown
Location(s) of Internet use	Use Internet from home only: 11 (32%) Use Internet from home and other locations: 14 (41%) Use Internet only from locations other than home: 4 (12%) Do not use Internet at all: 5 (15%)
Average hours of Internet use per day	1.9
Counts of participants by average number of hours of Internet use per day	0 hours: 9 (26%) $0 < x \leq 1$ hours: 11 (32%) $1 < x \leq 2$ hours: 5 (15%) $2 < x \leq 3$ hours: 4 (12%) $3 < x \leq 4$ hours: 2 (6%) More than 4 hours: 3 (9%)
Average hours of Internet use per day by age bracket	30-39 (n=3): 5.07 40-49 (n=9): 1.70 50-59 (n=12): 1.76 60-69 (n=8): 1.31 70-79 (n=1): 0.00 80-89 (n=1): 1.00

On average, participants reported spending 1.9 hours on the Internet per day[3]. However, nine (26%) participants reported spending 0 hours while another nine (26%) participants reported spending more than two hours per day on the Internet. Not surprisingly, the numbers of hours of Internet use per day tended to be higher among younger participants. Internet use, however, did not necessarily mean that participants used the Internet in relation to diabetes. In fact, nearly half (n=15; 44%) of the participants reported at the initial interview that they had not used the Internet in relation to diabetes to a sufficient extent to enable them to complete the third card-sorting exercise (i.e., Internet site types). Figure 17 below shows for each age bracket the percentages of participants who indicated at the time of their initial interviews that they had Internet access from home, that they had used the Internet from any location, and that they had used the Internet in relation to diabetes. Although 16 of the 20 participants between the ages of 50 and 69 reported that they use the Internet, just half of them (n=8; 40%) had used the Internet in relation to their diabetes.

[3] When asked how many hours they spend using the Internet per day on average, some participants provided a daily, weekly, or monthly range. These figures were converted to daily figures and the midpoint of the range they provided was used to determine their appropriate bracket and to then calculate the average figure across participants.

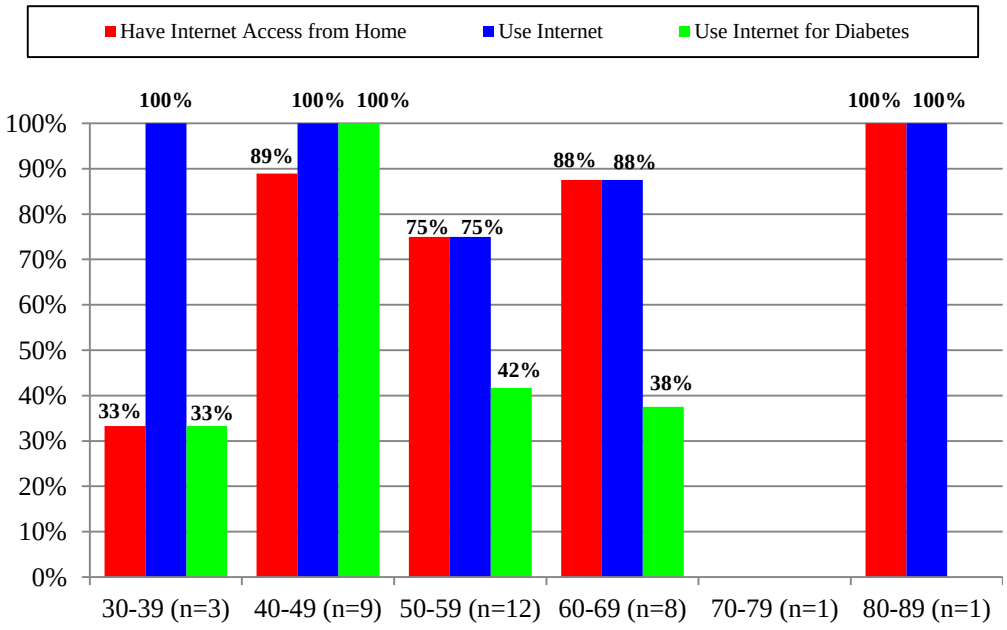


Figure 17: Internet Access and Use

4.1.4 Experience with Type 2 Diabetes

In order to qualify to participate in this study, participants had to have received their initial diagnosis of type 2 diabetes within the past year or had to have experienced some type of exacerbation in relation to their diabetes within the past year. Fifteen (44%) participants had received their initial type 2 diabetes diagnosis within the past year. Seventeen (50%) participants had developed one or more diabetes-related complications, such as neuropathy, vision impairment, kidney disease, and heart failure, within the past year. Three (9%) participants had gone on insulin for their type 2 diabetes within the past year. One participant had been put on an additional medicine for her type 2 diabetes. These numbers add up to greater than 34 (100%) because two participants fit more than one of the study criteria – they had received their initial diagnosis and been put on insulin within the past year.

Participants' initial dates of diagnosis ranged from 1980 to 2010. Although five (15%) participants were initially diagnosed with type 2 diabetes back in the 1980's, the majority of the participants (n=19; 56%) were diagnosed some time during 2009 or 2010.

On average, participants had had type 2 diabetes for just over 7 years (86.7 months) at the time of their initial interview. However, one-half of the participants (n=17) had had diabetes for 18 months or less at the time of the initial interview. Table 8 provides summary statistics for participants in relation to diabetes-related variables.

Table 8: Breakdowns of Participants by Diabetes-Related Factors

	Breakdown	
Variable	As of Initial Interview	As of Follow-up Interview
Date of diagnosis	1980's: 5 (15%) 1990's: 2 (6%) 2000-2005: 6 (18%) 2006-2008: 2 (6%) 2009: 14 (41%) 2010: 5 (15%)	
Number of months with diabetes	≤ 6 months: 1 (3%) 7-12 months: 8 (24%) 13-18 months: 8 (24%) 19-24 months: 2 (6%) 25-36 months: 1 (3%) 37-48 months: 1 (3%) 49-60 months: 1 (3%) More than 60 months: 12 (35%)	
Most recent A1C test result	No A1C test yet: 1 (3%) No idea/Unsure: 4 (12%) Good (5.0-5.9): 1 (3%) Nominal (6.0-6.9): 11 (32%) Slightly high (7.0-7.9): 8 (24%) High (8.0-8.9): 5 (15%) Very high (9.0 and up): 4 (12%)	No A1C test yet: 0 (0%) No idea/Unsure: 3 (9%) Good (5.0-5.9): 5 (15%) Nominal (6.0-6.9): 10 (29%) Slightly high (7.0-7.9): 7 (21%) High (8.0-8.9): 5 (15%) Very high (9.0 and up): 2 (6%)
On insulin?	Yes: 18 (53%) No: 16 (47%)	Yes: 16 (50%) No: 16 (50%)
Date began on insulin	Not on insulin: 16 (47%) 1980's: 1 (3%) 1990's: 2 (6%) 2000-2005: 6 (18%) 2006-2008: 1 (3%) 2009: 1 (3%) 2010: 7 (21%)	

Note. n = 34 for initial interview. n = 32 for follow-up interview.

At the initial interview, nearly all participants (n=31; 91%) reported that they had had an A1C test done within the past year. Participants' most recent A1C values ranged between 5.6 and 14.0, with an average of 7.8[4]. At the time of the follow-up interview, the

[4] Some participants were only able to provide a range when asked for their most recent A1C test result. When this occurred, the midpoint of the range they provided was used when calculating an average across participants.

range of A1C's had not changed much (5.5 to 14.0), but the average A1C had come down to 7.3. On average, the A1C scores of participants who participated in both interviews dropped by nearly one-half of a point over the course of this study. As of the time of the initial interview, just one participant had an A1C of less than 6.0, but by the time of the follow-up interview four to six months later, this count had increased to 5. A couple of participants, however, did see dramatic increases in their A1C's. I04's A1C went from 6.2 to 13.8 and I20's went from 11.5 to 14.0. However, several participants saw quite the reverse, registering dramatic decreases in their A1C's. For example, I09's A1C went from 14.0 to 8.2, I33's A1C went from 11.7 to 6.7, I32's A1C went from 11.3 to 8.0, and I19's A1C went from 7.5 to 5.8.

Figure 18 shows counts and percentages of participants by the change in their A1C between the initial interview and the follow-up interview.

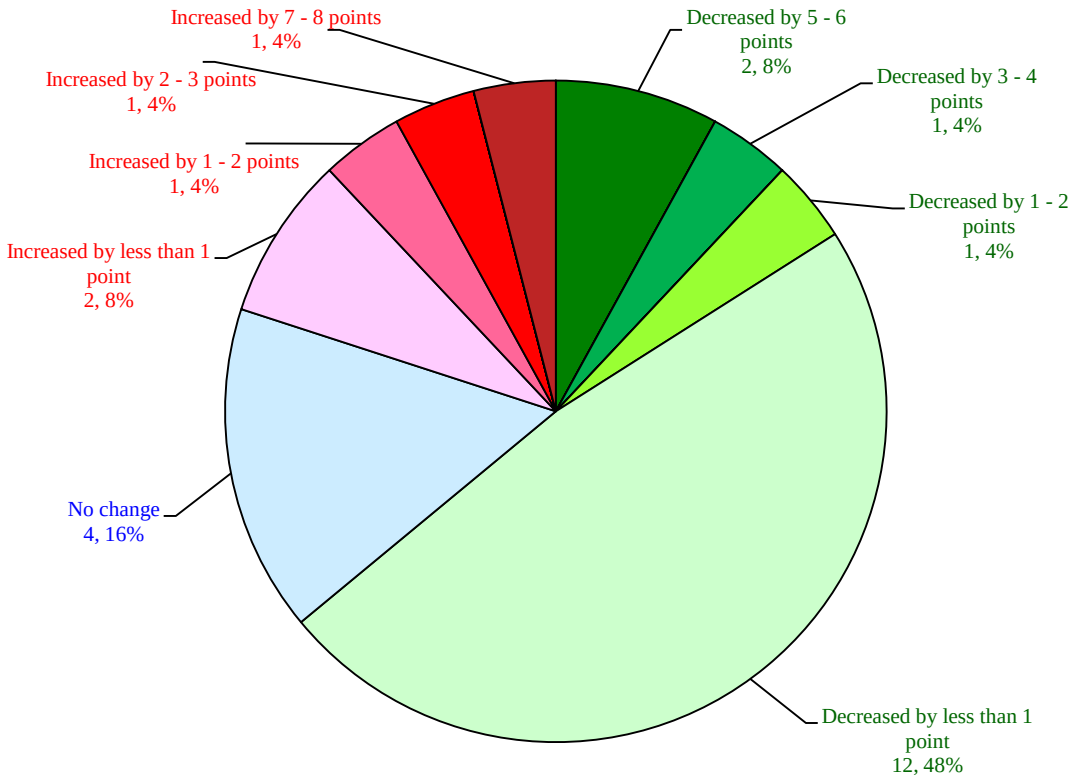


Figure 18: Participants by Change in A1C between Initial and Follow-up Interview

Figure 18 shows that for the 25 participants who provided A1C's at both interviews, the A1C's of 16 (64%) participants dropped, the A1C's of 4 (16%) participants exhibited no change, and the A1C's of the remaining 5 (20%) participants increased.

Just over one-half (n=18; 52.9%) of the participants were taking insulin as of the date of the initial interview. This stayed steady across the study period, except that one participant (I34) who had been taking insulin discontinued taking it. She had been taking insulin because she was trying to get pregnant; however, it turned out that she had other medical problems that would prevent her from becoming pregnant, so her doctor switched her from insulin to Metformin and Glyburide. About half of the participants on insulin (8; 24%) had first been put on insulin within the past year. The remaining participants on insulin had started it sometime between 1980 and 2007.

4.2 Health Condition Questionnaire Results

Thirty-two participants completed the Health Condition Questionnaire (Appendix F) at both their initial and follow-up interviews. In this section, the results from these questionnaires will be presented. For reporting purposes, the health condition questionnaire has been separated into four sections: (1) Health/physical condition measures; (2) Cognitive and information behavior measures; (3) Perceptions about availability of information; and (4) Affective measures. In each of the subsections below, the overall results on each health condition questionnaire measure as of the time of the initial and follow-up interviews are reported, followed by any statistically significant relationships between demographic factors and health condition questionnaire measures or between multiple measures on the health condition questionnaire that participants completed at the initial interview. Each subsection then closes with a discussion of any changes that took place in participants' responses to the health condition questionnaire measures between the time of their initial interview and the time of their follow-up interview.

4.2.1 Health/Physical Condition Measures

Overall, participants provided fairly positive ratings on all of the health/physical condition measures. Participants rated their general health as fair-to-good. They indicated that physical pain prevents them from doing what they need to do just a moderate amount

to a little. Participants rated the severity of their diabetes-related symptoms between neutral and not very severe. They indicated that their diabetes-related symptoms had gotten somewhat better over the past few months. Table 9 shows participants' average ratings on each of the health/physical condition measures. The values shown in blue font are the average ratings based on the initial interviews, while the values shown in red font are the average ratings based on the follow-up interviews.

Table 9: Participants' Average Ratings on Health/Physical Condition Measures

Measure	Scale with **Average based on Initial Interviews** and **Average based on Follow-up Interviews**
General health	1.....2.....3.....4.....5 Poor ← → Excellent **2.72** **2.83**
Prevented from doing things by physical pain	1.....2.....3.....4.....5 Extreme amount ← → Not at all **3.47** **3.69**
Severity of diabetes-related symptoms	1.....2.....3.....4.....5 Very severe ← → Not at all severe **3.38** **3.47**
Change in diabetes-related symptoms	1.....2.....3.....4.....5 Much worse ← → Much better **3.56** **3.63**

There was a statistically significant positive correlation between participants' responses on the scale measuring the extent to which they felt like they were impeded by their physical pain and their educational levels ($r(32) = .36$, $p = .046$), indicating that participants who were more highly educated were less likely to report being impeded by physical pain. Also, the longer a participant had had diabetes for, the lower their responses tended to be on the scale measuring whether their diabetes-related symptoms had gotten worse or better over the past few months ($r(31) = -.43$, $p = .017$). So participants who had had diabetes for longer were more likely to indicate that their diabetes-related symptoms had worsened over the past few months.

Overall, participants' responses on all of the measures relating to their health/physical condition increased slightly over the course of the study, indicating an overall improvement in their perceived levels of health. Figure 19 shows, for both the initial and follow-up interviews, the percentages of participants who selected one of the highest (i.e., best possible) ratings – either a '4' or a '5' – on each of these scales.

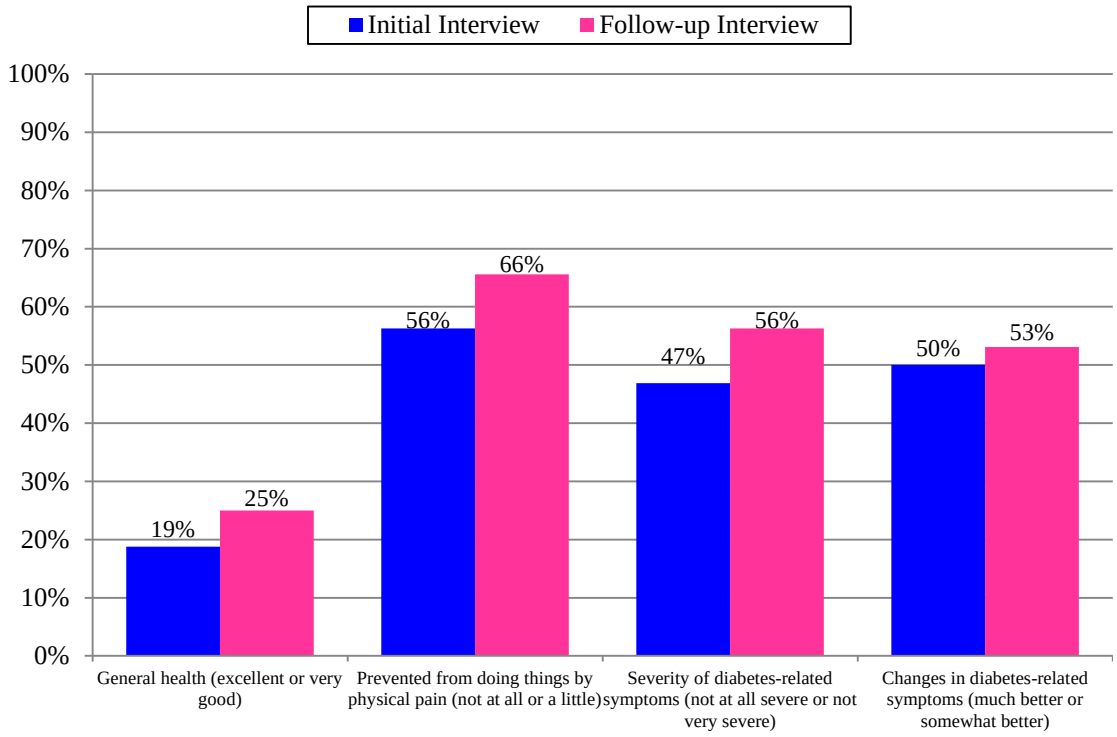


Figure 19: Health Condition Questionnaire: Health/Physical Condition Measures: Percentages of Participants Selecting One of Two Top Responses

The first set of bars in Figure 19 shows that at the time of the initial interview, 19% (n=6) of the participants indicated that their health was either excellent or very good. This figure increased to 25% (n=8) by the time of the follow-up interview. The second set of bars shows that 56% (n=18) of the participants indicated that physical pain prevented them from doing what they needed to do not at all or just a little at the time of their initial interview. For the follow-up interview, this percentage increased to 66% (n=21). The third set of bars shows that 47% (n=15) of the participants indicated at their initial interviews that their diabetes-related symptoms had been either not at all severe or not very severe. This figure increased to 56% (n=18) by the time of the follow-up interview.

The last set of bars shows that half (n=16) of the participants indicated at their initial interview that their diabetes-related symptoms had gotten much better or somewhat better over the past few months. By the time of the follow-up interview, this percentage increased slightly to 53% (n=17).

4.2.2 Cognitive and Information Behavior Measures

On average, the 32 participants who completed the full study indicated that diabetes was somewhat on their mind. They rated their understanding of diabetes as somewhat adequate and the importance of learning more about diabetes quite highly. However, they rated the importance of participating in decisions related to their healthcare even more highly than the importance of learning more about diabetes.

Regarding information behavior measures, participants indicated that they had been slightly more than somewhat active about trying to find out about diabetes as of the time of their initial interviews. Further, they tended to look for information about diabetes between a few times per month and a few times per week (average of 2.58 on the following scale: '1 – Never', '2 – A few times per month', '3 – A few times per week', '4 – Nearly every day', and '5 – Every day'). Table 10 shows participants' average ratings on each of the cognitive and information behavior measures. The values shown in blue font are the average ratings based on the initial interviews, while the values shown in red font are the average ratings based on the follow-up interviews.

Table 10: Participants' Average Ratings on Cognitive and Information Behavior Measures

Measure	Scale with **Average based on Initial Interviews** and **Average based on Follow-up Interviews**
Extent to which diabetes is on your mind	1.....2.....3.....4.....5 Very much so ← → Very little **2.16** **2.42**
Adequacy of current understanding	1.....2.....3.....4.....5 Very inadequate ← → Very adequate **4.23** **4.23**
Importance of learning more about diabetes	1.....2.....3.....4.....5 Very unimportant ← → Very important **4.38** **4.48**

Measure	Scale with **Average based on Initial Interviews** and **Average based on Follow-up Interviews**
Importance of participating in healthcare-related decisions	1.....2.....3.....4.....5 Very unimportant ← → Very important **4.78** **4.77**
Active in finding out about diabetes	1.....2.....3.....4.....5 Very inactive ← → Very active **4.22** **3.81**
How often look for diabetes-related information	1.....2.....3.....4.....5 Never ← Few/Month Few/Week Nearly every day → Every day **2.58** **2.58**

Participants' ratings on the scale measuring their perceptions about the importance of learning more about diabetes were negatively correlated with their educational levels ($r(32) = -.40$, $p = .023$). In other words, participants with lower educational attainment levels were likely to provide higher ratings when asked how important it was to them to learn more about diabetes. Also, there were statistically significant negative correlations between a participant's rating on the scale measuring their perceptions about the importance of participating in decisions related to their healthcare and both his/her age ($r(32) = -.38$, $p = .034$) and the number of months that they had had diabetes ($r(32) = -.36$, $p = .044$). This means that participants who were younger and participants who had had diabetes for a shorter period of time were likely to provide higher ratings when asked how important it was to them to participate in making decisions related to their healthcare.

As far as changes across the duration of the study, participants indicated that diabetes became less on their mind (average went from 2.16 to 2.42) and that they became less active about trying to find out about diabetes (average went from 4.22 to 3.81). However, paired-samples t-tests revealed that just the latter showed a statistically significant difference between the two interviews ($t(31) = 2.35$, $p = .025$, $d = 0.41$). Figure 20 shows the differences in participants' responses to the question about how active they had been about trying to find out about diabetes. As of the initial interviews, 14 participants (44%) said that they had been very active about finding out about

diabetes. By the time of the follow-up interviews, this figure had dropped to just seven participants (22%).

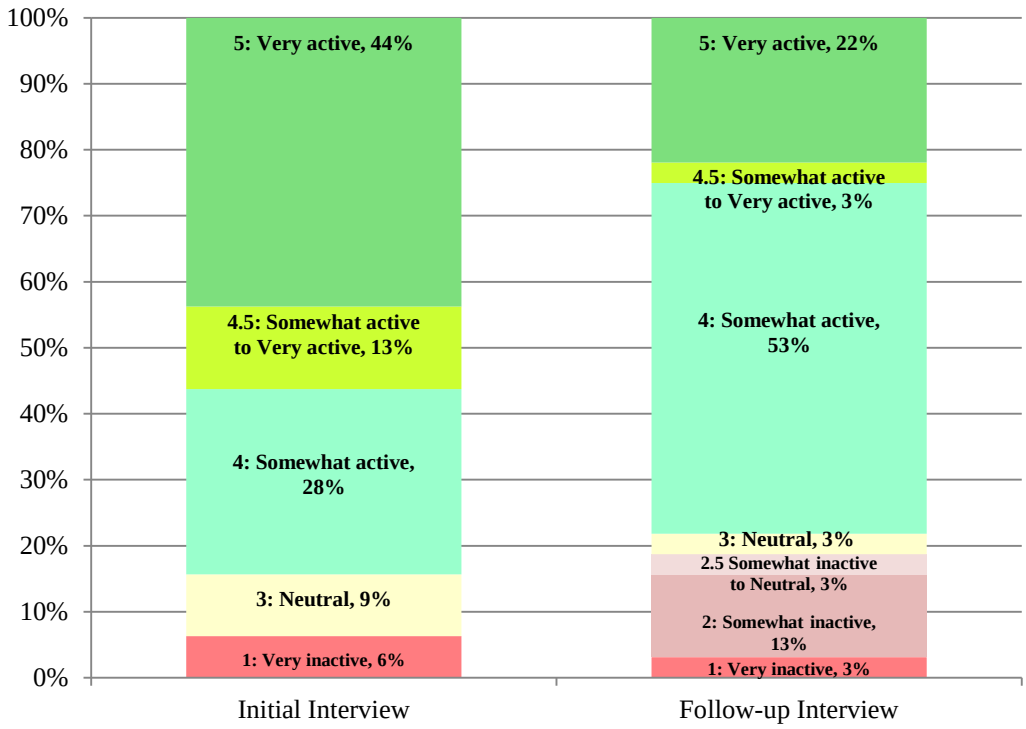


Figure 20: Health Condition Questionnaire: How active have you been about finding out about diabetes?

4.2.3 Perceptions about Availability of Information

Participants indicated that they were somewhat satisfied with getting answers to their questions about diabetes. They felt that the diabetes-related information that they needed in their day-to-day life was mostly available to them. Participants generally found it quite easy to get hold of any diabetes-related information that they needed. Table 11 shows participants' average ratings on each of the scales related to participants' perceptions about the availability of diabetes-related information. The values shown in blue font are the average ratings based on the initial interviews, while the values shown in red font are the average ratings based on the follow-up interviews.

Table 11: Participants' Average Ratings on Measures related to Perceptions regarding Availability of Diabetes-Related Information

Measure	Scale with **Average based on Initial Interviews** and **Average based on Follow-up Interviews**
Satisfaction with getting diabetes-related questions answered	1.....2.....3.....4.....5 Very unsatisfied ← → Very satisfied **4.19** **4.34**
Availability of diabetes-related information	1.....2.....3.....4.....5 Not at all ← → Completely **4.34** **3.92**
Difficulty of getting hold of diabetes-related information	1.....2.....3.....4.....5 Very difficult ← → Very easy **4.59** **4.39**

Participants who rated the availability of diabetes-related information higher tended to report less severe diabetes-related symptoms ($r(31) = .42$, $p = .020$). Participants who said that getting hold of diabetes-related information was easy tended to report less severe diabetes-related symptoms ($r(32) = .35$, $p = .049$).

Although participants' ratings as to their satisfaction with getting their questions answered increased over time (average went from 4.19 to 4.34), they provided decreased ratings as to the availability of diabetes-related information (average went from 4.34 to 3.92) and as to the difficulty of getting hold of diabetes-related information (average went from 4.59 to 4.39). However, paired-samples t-tests revealed that just the differences in participants' ratings regarding the availability of information were statistically significant ($t(30) = 2.89$, $p = .007$, $d = 0.52$). Figure 21 shows the changes in participants' responses[5] to the question asking how available the diabetes-related information they need in their day-to-day life is. While 14 participants (45%) answered 'completely' at the time of their initial interview, just eight participants (26%) gave this same response four to six months later at the time of their follow-up interview. Interestingly, three participants (10%) who had selected 'moderately' or 'mostly' at the time of their initial interview subsequently

[5] Just 31 of the 32 participants who had participated in both interviews provided a response to this question at both interviews. Therefore, only the data from these 31 participants was used for the calculations on this measure.

selected ‘not at all’ or ‘a little’ at the time of their follow-up interview. This suggests that participants’ perceptions about the availability of diabetes-related information worsened over time.

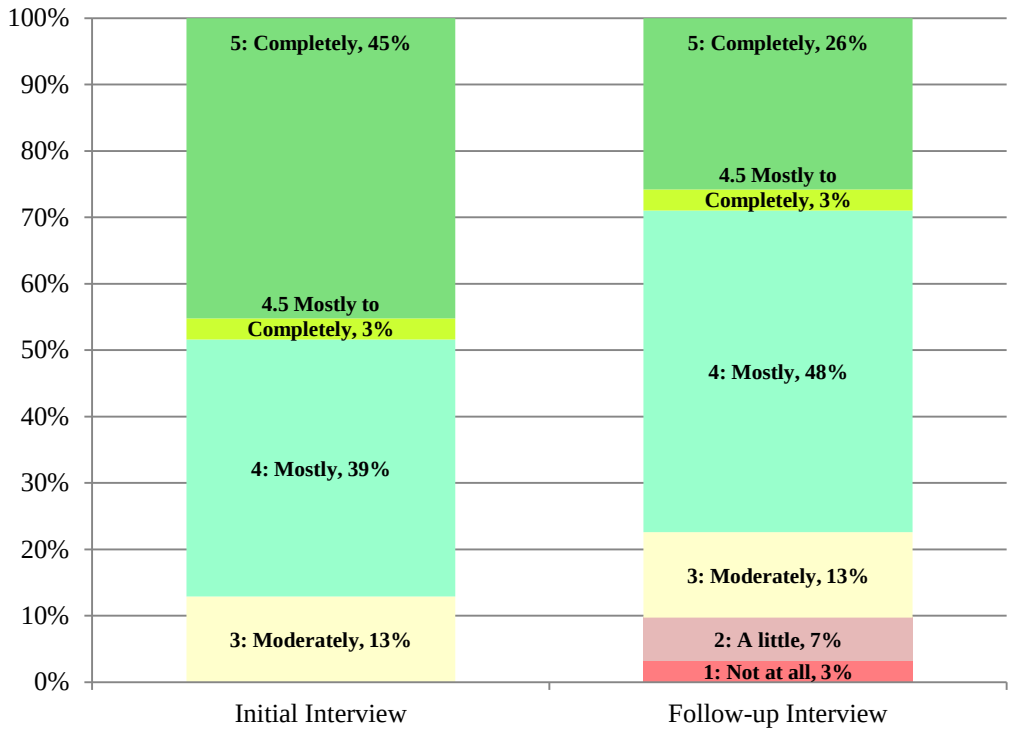


Figure 21: Health Condition Questionnaire: How available is the diabetes-related information you need in your day-to-day life?

4.2.4 Affective Measures

Participants were quite interested in their experience with diabetes. They felt somewhat certain about their experience with diabetes. They also felt somewhat clear and somewhat optimistic about their experience with diabetes. Participants indicated that they felt somewhat not alone regarding their experience with diabetes. They indicated that they felt somewhat in control regarding their experience with diabetes. Overall, participants felt that they were coping somewhat well with having diabetes. Table 12 shows participants’ average ratings on each of the affective measures. The values shown in blue font are the average ratings based on the initial interviews, while the values shown in red font are the average ratings based on the follow-up interviews.

Table 12: Participants' Average Ratings on Affective Measures

Measure	Scale with **Average based on Initial Interviews** and **Average based on Follow-up Interviews**
Interest in experience with diabetes	1.....2.....3.....4.....5 Very uninterested ← → Very interested **4.64** **4.61**
Feel certain/uncertain about experience with diabetes	1.....2.....3.....4.....5 Very uncertain ← → Very certain **3.78** **3.78**
Feel confused/clear about experience with diabetes	1.....2.....3.....4.....5 Very confused ← → Very clear **4.19** **4.42**
Feel pessimistic/ optimistic about experience with diabetes	1.....2.....3.....4.....5 Very pessimistic ← → Very optimistic **3.72** **4.02**
Feel alone regarding experience with diabetes	1.....2.....3.....4.....5 Very alone ← → Not at all alone **3.60** **4.03**
Feel in control regarding experience with diabetes	1.....2.....3.....4.....5 Not at all in control ← → Very in control **3.73** **4.05**
Feel like one is coping well with having diabetes	1.....2.....3.....4.....5 Not coping well at all ← → Coping very well **3.86** **4.22**

There was a highly statistically significant positive correlation between participants' ratings on the pessimism/optimism scale and the mildness of their diabetes-related symptoms ($r(32) = .48$, $p = .006$). So participants who reported feeling more optimistic rated their diabetes-related symptoms as less severe. There was another statistically significant positive correlation between participants' responses on the scale measuring how alone they felt about their experience with diabetes and their responses on the scale pertaining to the degree to which they felt physical pain prevented them from doing what they need to do ($r(31) = .49$, $p = .005$). So, in other words, feeling less alone

tended to go together with feeling less like physical pain was preventing them from doing things they needed to do. Another statistically significant positive correlation was found between participants' responses on the scale measuring how in control they felt of their experience with diabetes and both participants' educational levels ($r(32) = .37$, $p = .036$) and participants' responses on the scale having to do with the degree to which they felt physical pain prevented them from doing what they needed to do ($r(32) = .41$, $p = .020$). In other words, participants who were more highly educated and who reported feeling less impeded by physical pain tended to report feeling more in control of their experience with diabetes. One last statistically significant positive correlation was found between participants' ratings as to how in control they felt of their experience with diabetes and the average number of hours they reported spending on the Internet per day ($r(32) = .35$, $p = .049$). That is, participants who reported spending more time on the Internet tended to indicate that they felt more in control of their experience with diabetes.

As far as changes across time on these affective measures, participants indicated that they felt more clear (average went from 4.19 to 4.42), more optimistic (average went from 3.72 to 4.02), less alone (average went from 3.60 to 4.03), and more in control (average went from 3.73 to 4.05). They also indicated that they felt that they were coping with diabetes better (average went from 3.86 to 4.22). In fact, a paired-samples t-test revealed that the differences between participants' ratings as to how well they were coping with diabetes were statistically significant ($t(31) = -2.66$, $p = .012$, $d = 0.47$).

Figure 22 shows the percentages of respondents selecting one of the two highest possible responses (i.e., '4' or '5') on each of these measures. This chart shows the numbers of participants selecting the top two responses increased on all measures except uncertainty. The largest change occurred on the coping measure. At the initial interviews, 23 (72%) participants indicated that they were coping somewhat well or coping very well. At the follow-up interviews, this figure increased to 30 participants (94%).

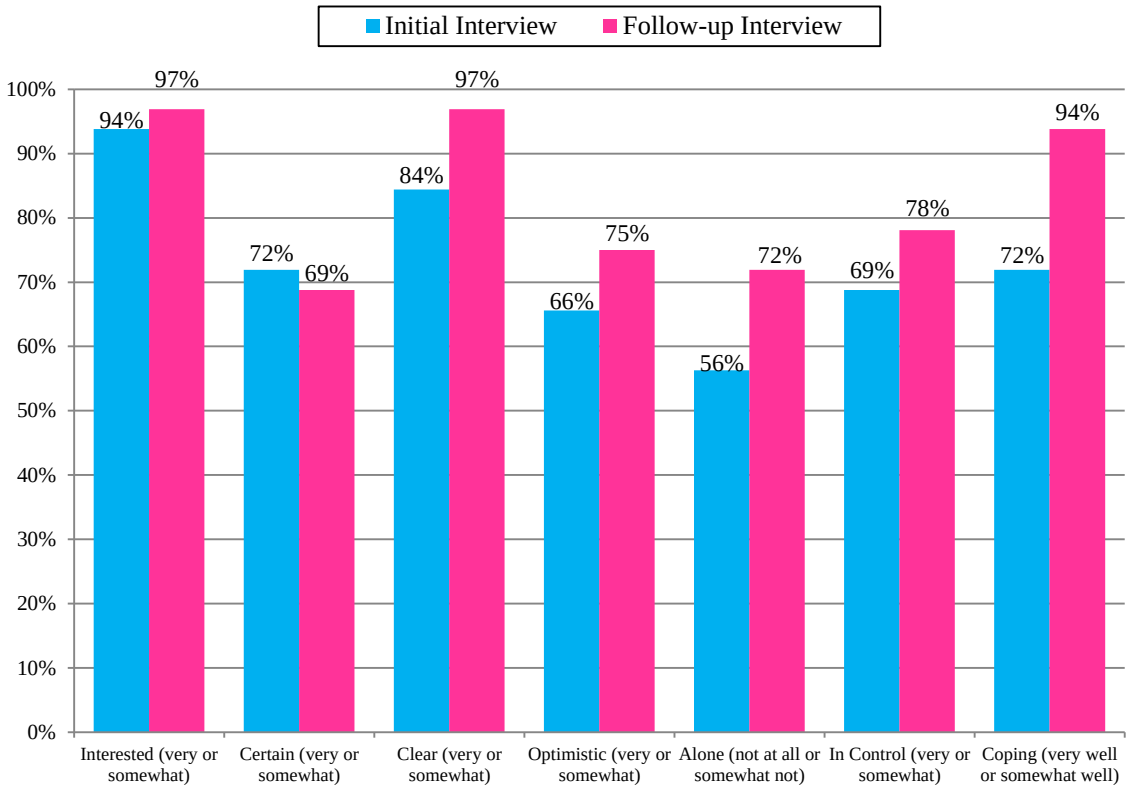


Figure 22: Health Condition Questionnaire: Affective Measures: Percentages of Participants Selecting One of Two Top Responses

4.2.5 Statistically Significant Correlations involving Information Behavior Measures

Several correlations involving information behavior measures from the Health Condition Questionnaire participants completed at the initial interviews showed statistical significance. These are summarized in Table 13 below.

Table 13: Physical, Cognitive, and Affective Correlates of Information Behavior Measures

	Information Behavior Measures			
Correlates	Active about finding out about diabetes	Satisfaction with getting diabetes-related questions answered	Availability of diabetes-related information	Difficulty of getting needed diabetes-related information
Severity of diabetes-related symptoms	-.22	.29	**.42***	**.35***
Feeling certain about one's experience with diabetes	**.38***	**.60****	.30	.18

Feeling clear (not confused) about one's experience with diabetes	**.41***	**.76****	**.45***	.07
Feeling optimistic about one's experience with diabetes	.14	**.47***	**.42***	-.01
Feeling less alone regarding one's experience with diabetes	-.21	-.22	-.14	**.44*†**
Feeling in control of one's experience with diabetes	-.10	**.41***	.12	.07
Feeling like one is coping well with having diabetes	.23	**.50***	.32	.17
n	32	32	31	32

Note. ***p* < .05. ****p* < .01. †*n* = 31.

The statistically significant correlations reported in Table 13 provide evidence of a link between information and information behavior on the one hand, and the sense that one is coping better physically, cognitively, and emotionally with having diabetes on the other. For example, participants who rated themselves as more active in finding out about diabetes indicated that they felt more certain and more clear about their experience with diabetes. Similarly, participants who provided higher ratings when asked how satisfied they were with getting their diabetes-related questions answered indicated that they felt more certain, more clear, more optimistic, more in control, and like they were coping better with having diabetes. Participants who rated the availability of diabetes-related information higher indicated that their diabetes-related symptoms were less severe. These participants also indicated that they were more clear and more optimistic about their experience with diabetes. Participants who rated the difficulty involved in getting hold of diabetes-related information lower indicated that their diabetes-related symptoms were less severe and that they felt less alone regarding their experience with diabetes. The strongest correlations of the ones shown in Table 13 were between satisfaction with getting one's diabetes-related questions answered, on the one hand, and feeling certain and clear about one's experience with diabetes, on the other.

Many of these correlates of information behavior measures, including being satisfied with getting answers to one's diabetes-related questions, feeling certain about one's experience with diabetes, and feeling clear about one's experience with diabetes were also found to be positively correlated with feeling in control of one's experience with diabetes and feeling like one is coping well with having diabetes. See Table 14. Not

surprisingly, there was also a highly statistically significant positive correlation between feeling in control and feeling like one is coping well with having diabetes ($r(32) = .55$, $p = .001$).

Table 14: Demographic, Physical, Cognitive, and Affective Correlates of Feeling in Control and Feeling like one is Coping Well with Diabetes

Measure	Feeling in Control	Coping Well
Educational attainment	**.37***	.23
Average hours per day on the Internet	.26	**.35***
Not impeded by physical pain	**.41***	.33
Current understanding of diabetes	.33	**.53***
Satisfaction with getting answers to diabetes-related questions	**.41***	**.50***
Feeling certain about one's experience with diabetes	**.52***	**.58***
Feeling clear (not confused) about one's experience with diabetes	**.35***	**.63****
Feeling optimistic about one's experience with diabetes	.25	**.48***
Feeling less alone regarding one's experience with diabetes	**.37*†**	.12
n	32	32

Note. ***p* < .05. ****p* < .01. †*n* = 31.

Table 14 shows that participants felt more in control if they were better educated, if they felt less impeded by their physical pain, if they felt more satisfied with getting answers to their diabetes-related questions, and if they felt more certain, more clear, and less alone regarding their experience with diabetes. Similarly, they were more likely to feel like they were coping well with having diabetes if they tended to spend more hours per day on the Internet on average, if they felt like they had a more adequate understanding of diabetes, if they felt more satisfied with getting their diabetes-related questions answered, and if they felt more certain, more clear, and more optimistic about their experience with diabetes. The strongest correlations of the ones shown in Table 14 were between feeling clear and feeling like one is coping well, feeling certain and feeling like one is coping well, feeling like one has a sufficient understanding of diabetes and feeling like one is coping well, and between feeling certain and feeling like one is in control.

4.2.6 Summary: Health Condition Questionnaire Results

Overall, participants' responses on the Health Condition Questionnaires indicate that they, on average, feel like they are doing fairly well physically, cognitively, and emotionally. Comparing their responses across time, participants indicated that they were doing better across nearly all factors at the time of their follow-up interview. However, participants also indicated that they had become less active about trying to find out about diabetes and that the diabetes-related information they needed in their day-to-day life had become less available to them.

The many statistically significant correlations that were identified based on participants' responses to the background questionnaire and to the initial Health Condition Questionnaire provide evidence that information and information behavior are linked to positive outcomes for participants, such as feeling like one is physically, cognitively, and emotionally coping better with having diabetes. For example, the results indicated that participants who rated the availability of diabetes-related information higher and participants who indicated that it was easy to get hold of the diabetes-related information that they needed tended to report less severe diabetes-related symptoms. Also, participants who rated themselves as more active about finding out about diabetes indicated that they felt more certain and more clear about their experience with diabetes. Participants who felt more satisfied with getting their diabetes-related questions answered indicated that they felt not only more certain and more clear, but also more optimistic, more in control, and like they were coping better with having diabetes. Similarly, participants who rated the availability of diabetes-related information higher indicated that they felt more clear and more optimistic about their experience. Also, participants who said that it was easier to get hold of the diabetes-related information they needed indicated that they felt less alone about their experience with diabetes.

Most strikingly, the participants who indicated that they felt more in control of their experience with diabetes were the ones who felt more satisfied with getting their diabetes-related questions answered. Similarly, the participants who rated themselves as coping better with having diabetes were the ones who provided higher ratings regarding the adequacy of their understanding of diabetes and who provided higher ratings as to their satisfaction with getting their diabetes-related questions answered. Thus, these

results provide strong evidence that information and information behavior are linked with a wide array of positive outcomes, including the sense that one is in control of his/her experience with diabetes and that one is coping well with having the disease.

4.3 Factors Motivating or Impeding Information Seeking and Use

This section presents results pertaining to this study's first research question: What are the factors that motivate or impede information seeking and use by people diagnosed with a chronic serious health condition and how do these factors and the nature of their influences transform across time? During both the initial and follow-up interviews, participants were asked to talk about what has made them want to try to find out more about diabetes, what has made them *not* want to learn about diabetes, and what has kept them from being able to find answers to their diabetes-related questions. Participants' responses revealed that a variety of physical, social, cognitive, and affective factors propel, dampen, and hinder their diabetes-related information seeking and use.

4.3.1 Factors Motivating Information Seeking and Use

Many different factors were found to have motivated participants' diabetes-related information seeking and use. These factors have been classified into the following four categories: (1) Physical; (2) Social; (3) Cognitive; and (4) Affective. Factors categorized as physical include those that pertain to the body, as well as those that pertain to the availability and accessibility of resources in the physical environment. Social factors are ones that pertain to any type of interpersonal process, whether between the participant and other people with diabetes, between the participant and his/her healthcare providers, or between the participant and society at large (as in the case of stigma, for example). Factors categorized as cognitive include those that pertain to participants' perceptions, thought processes, and/or knowledge. Affective factors are ones pertaining to participants' emotions.

Some factors were found to cross multiple categories; however, for the purpose of this discussion, they were placed into the category that seemed to be the most fitting. Also, one additional type of factor, time, was found to often underlie each of these other four types. In the sections that follow, the specific factors identified within each of these five categories will be listed and examples will be provided. This section will then close

with a discussion of the results from the card-sorting exercise that pertained to the factors that motivate participants' diabetes-related information seeking.

4.3.1.1 Physical Factors Motivating Information Seeking and Use

Physical factors were, by far, the most commonly mentioned motivators of information seeking and use. At both the initial and the follow-up interviews, nearly every participant mentioned at least one physical factor that motivated their diabetes-related information seeking and/or use. Factors included in this category have to do with the participants' physical state, including their current physical state, their feared future physical state, and their desired future physical state. In the last subsection, some factors pertaining to the availability and accessibility of resources within each participant's physical environment are discussed.

a. Current physical state

Many participants pointed out that simply being diagnosed motivated them to look for diabetes-related information. For example, when asked what makes him want to try to find diabetes-related information, I33 simply stated, "Just being sick with it, I guess… Just being diagnosed with it." I30 similarly responded, "Just knowing me having diabetes… It makes me want to know." These quotes illustrate that simply having the knowledge that one has diabetes is enough to propel one to look for diabetes-related information.

Another very commonly mentioned motivating factor in this category is the experiencing of symptoms or some type of bodily change that was (or was believed to be) related to the diabetes. As I29 explained, "Once the retinopathy showed up and more erectile dysfunction, I began to take it more seriously… Information collection, in my way of doing things, is stimulated by a… change in my body." I25, who was experiencing retinopathy and who had 75 to 80% loss of kidney function, similarly emphasized, "The medical issues that I have gotten have been enough of a wake-up call to me that I've, 'You better do a better job of taking care of yourself and learning more about what's going on.'" Note that for both of these participants, physical symptoms were the harbinger of their nascent information needs.

Several participants pointed out that while they were having no symptoms now, a future change in this regard would spur them on to engage in additional information seeking. I05, for example, stated, "I've got a pretty good grip on what things are happening today at this particular time. Should something change on me, yeah, I would definitely… go on finding out what it's all about." I29 similarly stated, "If and when I start developing any of the classic symptoms like neuropathy… then I think I will want to know more about what's going on with me… and what I can do about it." I04 explained, "I have gone through the learning curve and as long as… everything stays in control, I am happy with the situation. If it gets out of control, then I will do some more learning or I'll reinvestigate." These quotes illustrate that these participants were consciously choosing to let their physical symptoms be the primary driver of their information seeking. Unfortunately, this choice is potentially shortsighted, as the development of symptoms may occur at a point in time when it is too late for information to be of maximal (or any) use.

b. Feared future physical state

Concern about developing diabetes-related complications and/or dying was one of the most commonly mentioned factors motivating participants to look for and use diabetes-related information. I06 explained, "Fear of amputation, fear of death, fear of liver/kidney failure… fear of going blind… There's just massive motivation once you're diagnosed… Fear motivated me." I13 similarly stated, "The real motivation is long-term… That blindness and… what happens to your circulation, your feet."

Several participants mentioned a fear of death when asked what motivates their diabetes-related information seeking and use. I05 pointed out, "There's not much more than wanting to stay alive a little bit longer to motivate you." Several participants took this fear of death even further, stressing that they wanted to die without losing any of their body parts. As I17 explained, "My goal, hardly educational, is to die with all my body parts. I want all my body parts. I want my own teeth when I die." So for these participants, just a fear of developing physical complications and dying was sufficient to motivate them to look for and use diabetes-related information.

c. Desired future physical state

Many participants were motivated to look for and/or use diabetes-related information because of their desires for their own future physical health. While a few participants hoped that looking for diabetes-related information would help them to get rid of diabetes, many others hoped that it would enable them to achieve more attainable goals, such as avoiding or getting off diabetes-related medications and/or insulin and maintaining or improving their health and/or quality of life.

For a few participants, diabetes-related information seeking was driven by a desire to not have diabetes. I22 stated, "The most useful was not wanting to have it… It makes you want to get rid of it right away… So you're like, 'What can I do to get rid of it?'" I34 similarly stated, "I don't want to be a diabetic anymore… Maybe if I just do the right things, it won't stick, you know?" Although wish-fulfilling fantasy has been found to be a less adaptive strategy than information seeking within the context of a chronic illness (Felton and Revenson, 1984), for these participants, wish-fulfilling fantasy actually drove their information seeking.

Several participants mentioned they were motivated to seek and/or use diabetes-related information because of their desire to avoid going on a diabetes-related medication (or insulin) or to get off a diabetes-related medication (or insulin). I04 stated, "I tried to get all kinds of information I could. I was trying to do everything I could because my doctor had warned me if I couldn't keep it down, they were going to put me on insulin." I12 explained, "I think I want to learn more because I found out there's a possibility I might give up insulin."

Participants frequently mentioned that their information seeking/use was motivated by a desire to improve their health and/or quality of life. I09 explained, "I'm in the middle of a lot of things and I want to have a lot of vitality to be doing them… I enjoy my work, I love doing exercisy sort of things and… I want to keep going." I28 explained that he looks for diabetes-related information "Because I have it… And it will affect the quality of life that I have. Even though I have it, I could still have a decent quality of life if I maintain my blood sugar." These participants clearly recognized that having information and implementing it in their lives would lead to a better outcome for them.

One participant (I32) made an interesting distinction between being motivated by the desire to maintain one's current (healthy) physical state versus the desire to avoid a future (ill) physical state. This participant took his health for granted until it started to decline. The decline in his health then motivated him to look for and use health-related information in an effort to halt the decline. He explained:

> I like to know what's happening to me, the knowledge factor. It's not so much the health factor, to stay healthy. Obviously, I wouldn't have gotten to this situation if I believed in staying healthy… but I am very serious about not getting sick, the opposite. You know what I'm saying? It wasn't a positive thing – "Do this and you'll stay healthy." It's now like, "Do this and you won't get worse… Cause you to pass away earlier than you should be."

d. Availability/Accessibility of Resources

Participants were also motivated to look for diabetes-related information by the convenient accessibility of information within the context of their everyday life activities. For example, several participants mentioned picking up brochures or watching videos while waiting in the doctor's office. I02 described, "Like even waiting in a doctor's office… You see the little films they have there… The people there are overweight and how they got to exercise, and I know I got to exercise." I22 stated, "I think the magazines [are the most useful] because I'm always reading them because I'm always at the doctor's… I tend to read more when I'm in the doctor's." I06 similarly stated, "When I go to my diabetic appointment, the whole lobby is full of all kinds of pamphlets and so I'm going to sit there for half an hour waiting anyway, so I start reading stuff." The common thread across all of these participants' comments is that they are motivated to view or read diabetes-related information simply because of having to be in a context where that information is made readily available to them.

A few participants pointed out that although they do not actively look for diabetes-related information, they would read it if they happened to come across it. For example, I15 stated, "I don't really go looking for [diabetes-related information]… [but] like say I'm in a store and I see a little brochure… then I like to start reading it and see if it's something I want to know about." I20 similarly explained, "If it [information about diabetes-related drugs] comes into my track, maybe I will jump on it and try to see what's going on to see what [of] this stuff should be incorporated." All of these comments underscore the importance of making diabetes-related information readily available

within people's everyday contexts. This can help to increase the chance that people with diabetes who are more passive information seekers will come across the information they need.

4.3.1.2 Social Factors Motivating Information Seeking and Use

Another type of motivating factor commonly mentioned by participants was social factors. Two major categories of social factors were mentioned by participants – inbound and outbound. Inbound factors were ones concerning the influences of outside social forces on participants. Outbound factors concerned participants' influence on, and interactions with, other people in their lives. More specifically, the inbound category included: (1) Watching or hearing about the experiences of other people with diabetes and (2) Receiving (or not receiving) social support from other people in their lives, including family members, friends, and doctors. The outbound category included: (1) Wanting to learn how to manage their diabetes and utilize this information so they would be able to live and be there for other people (usually their children or grandchildren); and (2) Wanting to help other people who have (or are at risk of developing) diabetes.

a. Inbound Social Factors Motivating Information Seeking and Use

Many participants talked about learning from the experiences of other people with diabetes. This took many different forms. They frequently mentioned being motivated to learn about diabetes and implement this information in their lives because of observing or hearing about people with diabetes-related complications. Far less frequently, they mentioned that they were motivated to learn about diabetes and implement this information because of observing, hearing about, or talking with people with diabetes who are successfully managing it.

Many participants told horror stories about people (often their relatives) developing diabetes-related complications and dying. As I04 explained, "I know somebody, he's passed away since and was a diabetic and he was slowly coming apart because of gangrene. And I don't want that to happen." Some participants specifically mentioned that observing the effects of diabetes on other people in their lives has motivated them to do better than they did at managing their diabetes. I09, for example, described being motivated by "watching my relatives' lack of compliance and their whole

complications." She went on to explain, "From the very beginning, I just knew I was not going to walk down the road they did because I've seen what can happen to you."I24 described his motivation to look for and use diabetes-related information in this way: "Seeing the impact on people around me. That obviously motivates you to control your diet when you see people who've lost their eyesight and basically died early because of diabetes." Although it was certainly painful for these participants to watch their loved ones develop diabetes-related complications, this was also beneficial in a way because it made them more aware of the crucial importance of information seeking and use. These participants did not have to wait to look for and use diabetes-related information until they, themselves, developed physical symptoms, as they already had vicarious knowledge of what could happen down the road.

A few participants said that they were motivated to learn about diabetes by other people with diabetes who were managing it well. I12 described having both an aunt who was a bad example and her dad who was a good example. She stated, "My aunt… She's had glaucoma… kidney failure and a kidney transplant… because of poor control… We [participant and her dad] kind of compete as far as our A1C and going to the gym and things like that." However, the people mentioned by participants were not always relatives – sometimes they were celebrities or complete strangers. I04, for example, described being inspired by reading about Halle Berry and about a couple who did the Tour de France. This participant explained, "They [diabetes-related magazines] give these kinds of stories that says, 'Just because you got it don't mean you can't do it'… And I like that." I20 similarly described, "Reading about others' experiences [with diabetes]… Testimonials give me hope… Not their bad experiences, but their good ones." Thus, some participants were motivated to manage their diabetes by the inspiration and hope engendered by stories about other people who were successful at this endeavor.

Several participants described being motivated to look for and use diabetes-related information as a result of the support they received from other people. I20 described switching from doctors who she felt were condescending, who told her what to do, and who were trying to sell her drugs that she didn't want to take to a particular doctor who she really liked. She said of this doctor: "He did not treat me like I was stupid. He treated me like I was part of the team, and we have a wager going." This

doctor agreed that if she can bring down her A1C, he would decrease her medication. She stated, "That was just the most motivating thing in the world because he did not make my thought process invalid. He gave value to what I had to say about my body." She said that she returns home after visiting this doctor feeling challenged to figure out how to beat him. I06 described being motivated by the positive reinforcement provided to him by his doctor. He stated:

> When the doctor told me one day at an appointment, he said, "You know, I really appreciate your diligence and your dedication to your recovery… You're meticulous on your recording… You're checking your blood sugar… You're really working hard… I appreciate your effort." That made me feel good… I'm just one of the people that need a slap on the back once in a while to keep me motivated.

Some participants mentioned being motivated by how they were treated by people other than doctors. I31, for example, explained that someone at her church told her that she can reverse her diabetes. This participant stated, "And when she said that I was like 'Okay, I'll get on that street. I'm on the wrong street. Let me get on the… 'I can reverse it' street. So I backed my car up and I got under 'I can reverse it'… That was a shot in the arm for me." Clearly, the extent and types of social support which participants receive can have a profound impact on their self-efficacy and on their motivation to look for and use diabetes-related information.

b. Outbound Social Factors Motivating Information Seeking and Use

Several participants talked about wanting to manage their diabetes so that they would be around for other people, often their children or grandchildren. I02 explained, "Someday I'll have grandkids maybe, and I would like to be around for them and to enjoy them and take them camping and do fun stuff." I26 explained, "My kids want me to get more educated about it because… It's already been a hardship on them losing their daddy, so they really want me to eat better so I won't be joining him anytime soon." This particular participant was also motivated by her granddaughter, who wanted her to be able to run and ride bikes with her. Another participant (I15) expressed a fear of going into a diabetic coma and leaving her two small daughters. She worried:

> I keep being told I could go into a diabetic coma and that makes me think about my girls a lot. I don't want them to be without someone… That's not fair to them for me to put them here and… not take care of myself to the best of my ability.

These participants were motivated to look for and use diabetes-related information by their concern for the welfare of other people in their lives.

Some participants mentioned that they were motivated to look for diabetes-related information because they were trying to help someone else who has diabetes or because they were trying to help prevent someone from getting it." I15, for example, stated, "Helping take care of like my fiancée's grandmom made me want to learn about it too, so I knew what to do if stuff went wrong." I34 similarly described trying to help a co-worker: "She's so bad about taking care of herself… In order to prove things to her, I will find information and present it to her… to make her feel guilty about not doing what she's supposed to do." Another participant (I22) explained that her husband getting diagnosed with diabetes four years after she had been diagnosed motivated her to learn about diabetes in order to "set a better standard for him" and to be "a better mentor for him."

A few participants expressed that their information seeking was sometimes motivated by concern about their children and/or grandchildren later developing diabetes. As I04 described, "Diabetes runs on both sides of my family. I've got two young nephews who… are very prone to it… So if I can find out as much as I can find out, maybe they won't ever get it." So concern for other people motivated participants to look for diabetes-related information in order to be able to help them by either passing the information on to them or by using the information on their behalf.

4.3.1.3 Cognitive Factors Motivating Information Seeking and Use

Participants mentioned several cognitive factors that motivated their diabetes-related information seeking and use. These factors pertained to their thought processes and their knowledge about diabetes. More specifically, these factors included realizing that it was their own responsibility to learn how to manage their diabetes, wanting to keep up to date, wanting to educate themselves about diabetes, and needing to confirm information they already had.

a. Taking responsibility

Participants were motivated simply by their understanding that that they are the ones who are ultimately responsible for learning how to manage their diabetes and then

putting this information to use. For example, I32 explained, “It’s not like anybody’s teaching you how to manage it… I’m like doing it on my own. I need to know the issues so I can decide and I’m not putting my fate in somebody else’s hands to decide.” I22 specifically mentioned herself when asked about what sources she has used to obtain diabetes-related information. She stated, “Myself, I’d give myself a ‘2’ [somewhat useful] because I’m the one that’s doing all the research. If you want it, you’ve got to do it yourself… I think we are our best educator. It’s up to us.”

Participants emphasized that the person with diabetes is the one who is ultimately responsible for gathering the necessary health-related information. I31, for example, stressed, “Try to gain all of the information that you possibly can and don’t just say, ‘Well, the doctor said this and that’s it.’ Research and find out.” I32 similarly recommended, “Try to find the best way for you to solve the problem, because you have to solve the problem.”

One participant (I15) pointed out that just knowing that she needs to know something is enough to motivate her to look for diabetes-related information. Another participant (I06), however, eloquently described his dawning realization that he may not be aware of all the diabetes-related information that he does not know, but needs to know. He explained:

> At first, I feared the diabetes, now I fear what I don’t know about the diabetes. It’s kind of a shift. And that’s, I think, why I’m motivated to read information about it and learn about it, because there may be something I don’t know. And the reason I feel that way is because I’m finding there are a lot of things I don’t know… What else is out there I don’t know?

b. Keeping up to date

Many participants were motivated to look for diabetes-related information because they wanted to keep up to date with any new developments. They wanted to be sure that they remained aware of any new research findings or any new products that would help them to manage their diabetes. I22 explained, “[I’m] always [looking for information] to keep up with it… Because new and better stuff, if it comes out, I want to know about it. I don’t want to be left in the dark.” I29 similarly stated, “I like to stay current and that’s on a foundation of the basics… I mean, keeping up to speed… is important to me.” For some participants, hearing that there was some new development

that might be potentially relevant to them provided the impetus to look for information. I16, for example, stated, "I haven't actively looked for new information on diabetes but if I hear that there might be new information about diabetes, I would definitely research it."

c. Educating oneself

Participants frequently mentioned looking for diabetes-related information in order to educate themselves, often in order to prepare for or to follow up on an appointment with their doctor. Preparation for a doctor appointment frequently involved getting one's own information and questions together while following up on a doctor appointment frequently involved confirming something the doctor said or letting the information from the doctor inform and guide their future information seeking.

Participants prepared for their doctor appointments by gathering their own personal records together and by preparing lists of questions that they would like to discuss with the doctor. I09 described educating herself so that she's prepared to have a discussion with the doctor. She stated, "I write down questions. Yeah, definitely. It gets confusing in there. You have to have your script." Some participants emphasized that by preparing for their doctor appointments, they were able to get the most out of the limited time they spent with their doctor. I06 explained, "There are certain things I need to do to prepare so that I can get the maximum benefit… I don't want to waste a minute I'm there. I want to get as much out of it as I can." I28 similarly pointed out, "The more information I can gather and let him know, the better information I can get about what to do or what not to do."

Sometimes participants looked up information following a doctor appointment because they felt like the appointment prepared them to do a better job of looking for relevant information. I10 explained that he tends to look for information following a doctor appointment "because by then I already know what they're thinking is wrong… And that gives me more direction to point into… Look for more information."I14 explained that he looks for information after a doctor appointment using "buzzwords" that the doctor has given him. He explained, "Now I feel packed with a little more information… I'll Google maybe something I heard her say or… Well, it certainly gives me a little more focused direction." In contrast, some participants looked for information following a doctor appointment in order to confirm the information that their doctor had

given them. I03 explained, “I guess when I come home from a doctor’s office, I’m more curious about it or if he didn’t say something or if he did say something, I want to see what other people are saying about it.” I14 stated, “Find out more following a doctor appointment, often. I don’t tell them, but I often second-guess the doctor.”

d. Needing to confirm information

Another factor that motivated participants’ diabetes-related information seeking was a need to confirm the veracity of some information they already had. I22, for example, described re-reading papers, pamphlets, and newspaper articles “especially when I think I’m right and I’m not. I want to make sure I’m right… Maybe I misread that or maybe I heard wrong.” I31 described coming home from the doctor’s office and getting on the Internet to look up what her doctor had told her. She explained, “If you come home and you find out that what your doctor had said is on the computer, then you know you can put your confidence in the doctor.” One participant (I17) looked for diabetes-related information because it comforted her if the information she found matched with the strategies she was using to manage her diabetes. She explained, “I think what I like about information… is it affirms what I’m doing. It tells me I’m doing the right thing… I go, ‘I’m doing that… I could do that better, but I’m doing that. I’m okay.’”

4.3.1.4 Affective Factors Motivating Information Seeking and Use

Although many of the other types of motivating factors (i.e., physical, social, and cognitive) are also infused with affect, there were a few factors which seemed primarily affective in nature. These factors were ones which primarily had to do with the participants’ emotions. More specifically, these factors included a desire to feel in control, a desire to decrease anxiety or uncertainty, and a desire to rise to the challenge posed by diabetes.

Some participants described being motivated to look for and use diabetes-related information by the desire to feel in control. As I11 explained, “I started to find I want to be in control… The more information you have, the more control you feel… You always think of things as gonna be worse… And you can sort of combat that with information.” Some participants were motivated to use diabetes-related information by their sense that

they can control their experience with diabetes. I35, for example, said, "I care more about my health even more now… because you have control… This way, I can control, like I'm really taking care of myself."

Feelings of anxiety or uncertainty were also common motivators of information seeking. They emphasized that information plays a key role in combating their anxiety. I09, for example, said that her diabetes-related information gathering is about "coping, dealing with anxiety and uncertainty, feeling like the more information I have… the less stressed out I am." I06 similarly pointed out, "You immediately panic, but then when you get more information… Information is key. It really is."

A few participants mentioned being motivated to look for and use information by a desire to meet the challenge posed by diabetes. One participant (I28) pointed out that being diagnosed with diabetes gave him the opportunity to "put [up] a good fight." I34 said that she is motivated to look for diabetes-related information in order to stay healthy and because "it's kind of like a challenge, I guess, to see how much I can improve… I guess I kind of look at it like a job in a sense… Of having to save my own life." While these two participants emphasized the life-or-death aspect of the challenge posed by diabetes, one participant (I17) placed more emphasis on her enjoyment of striving to meet this challenge. She explained, "The challenge… Yeah, I'm up for it… I've always been up for it. I've never not been up to the challenge of managing that disease. I find it infinitely interesting… The challenge of it, I really enjoy that."

4.3.1.5 Time-related Factors Motivating Information Seeking

As mentioned above, the dimension of time was found to be a significant force underlying the various types of factors motivating participants' diabetes-related information seeking. Some participants mentioned that their diabetes-related information seeking was motivated by processes that unfolded across time, such as learning to adapt to diabetes, changing life circumstances and priorities as one gets older, and the influence of past success or failure in managing diabetes on the present.

Several participants emphasized that they have learned to adapt to diabetes over time. For example, I06 explained, "But I'm learning, you know… You adjust. You kind of realize how important it is, that your life's at stake and you just kind of accept it." This adaptation process, however, often led participants to decrease their diabetes-related

information seeking over time. I31, who had had diabetes for approximately 18 months at the time of her initial interview, characterized her diabetes-related information seeking as "Nearly every day. Not every day. I used to be consumed with it like that." I04, who had had diabetes for nearly 30 years and who had been on insulin for the past 10 years, explained, "I just check for updates is all… I don't look for more information because I really don't think there's more… I've had experience… There's not a lot of questions… that I [haven't] gotten answered."

The diabetes-related information seeking and use of some participants was motivated by changes in their life circumstances and associated changes in their priorities. One of the relatively older participants, I29, eloquently explained, "Once I began to understand the time-bound quality of diabetes and once the retinopathy showed up and more erectile dysfunction, I began to take it more seriously." For this participant, the evolution in his understanding of the seriousness of diabetes and the onset of his diabetes-related symptoms both occurred at the same time as he began to lessen his involvement in his company. He pointed out, "The fact that I retired, semi-retired, was circumstantial but it facilitated rigor."

A couple of participants emphasized the importance of the past in influencing the future. For these participants, past success tended to motivate them to do better in the present, while past failure tended to dampen their motivation to do better in the present. One participant (I31) who was on insulin but had quickly become able to control her diabetes with just dietary changes explained, "How I was able to come out of it… That really motivated me."I12 similarly explained:

> I feel my world is all cyclical because if I'm doing well, then I want to learn more, to continue doing well… When I was doing poorly… You kind of just get into a funk and you don't want to know, you just want to pretend like it doesn't exist.

4.3.1.6 Results from Card-Sorting Exercise: Factors Motivating Diabetes-Related Information Seeking

During one of the card-sorting exercises, participants provided ratings indicating how often various goals prompt them to look for diabetes-related information. The top two motivators for diabetes-related information seeking at the time of both the initial interviews and the follow-up interviews were: (1) Learn how to manage diabetes and (2)

Learn what I can do to improve my health and/or prevent disease. A theme of 'what can I do?' pervaded both the initial and follow-up interviews. Overall, participants were very interested in learning what they could do to manage their diabetes. The bottom two motivators as of the time of both interviews were: (1) Find/select health provider and (2) Decide whether to take or stop taking a medication. Many participants indicated that they were all set with doctors and had no need to find another one. Many participants also emphasized that they do not decide (on their own) to take or stop taking a medication. As I05 put it:

> I don't decide that, no. I stay right [with] what the doctor tells me. Sometimes I have to use a little more, sometimes I have to use a little less, that's what the sliding scale is all about. That's still doctor's stuff.

Table 15 shows the 32 participants' average ratings for each of the different goals that may have motivated them to look for diabetes-related information. For the purpose of statistical calculations, participants' responses of never, sometimes, or often were coded as follows: 1=Never; 2=Sometimes; and 3=Often. The numbers in the columns labeled 'n' show how many of the 32 participants responded either 'sometimes' or 'often' regarding that particular factor.

Table 15: Participants' Ratings of Factors Motivating their Diabetes-Related Information Seeking

	Initial Interview					Follow-up Interview					Changes			
Factor	n	M	SD	m	ř	n	M	SD	m	ř	n	M	m	ř
Learn how to manage diabetes	29	2.48	0.69	3	1	31	2.75	0.51	3	1	2	0.27	0	0
Learn what I can do to improve my health and/or prevent disease	30	2.47	0.62	3	2	30	2.44	0.62	3	2	0	-0.03	0	0
Learn about the side effects of a medication	28	2.34	0.70	2	3	29	2.34	0.65	2	3	1	0.00	0	0
Learn how to prepare meals	25	2.31	0.82	3	4	27	2.33	0.76	3	6	2	0.02	0	-2
Learn about potential diabetes-related complications	28	2.28	0.68	2	5	26	1.97	0.59	2	19	-2	-0.31	0	-14
Share information about my experience with other people	27	2.22	0.72	2	6	26	2.19	0.74	2	11	-1	-0.03	0	-5

	Initial Interview					Follow-up Interview					Changes			
Factor	n	M	SD	m	ř	n	M	SD	m	ř	n	M	m	ř
Gather information just because I'm curious	27	2.17	0.70	2	7	28	2.34	0.70	2	3	1	0.17	0	4
Find out more following a doctor appointment	24	2.16	0.81	2	8	27	2.19	0.70	2	11	3	0.03	0	-3
Learn about potential interactions between medications	25	2.13	0.75	2	9	28	2.08	0.60	2	15	3	-0.05	0	-6
Read about others' experience with diabetes	24	2.13	0.79	2	9	20	1.78	0.71	2	23	-4	-0.35	0	-14
Keep up to date on new discoveries, treatments, etc.	23	2.06	0.80	2	11	27	2.25	0.72	2	9	4	0.19	0	2
Learn about possible treatment options	23	2.06	0.80	2	11	29	2.30	0.66	2	7	6	0.24	0	4
Learn what to expect from a particular procedure or treatment	23	2.06	0.80	2	11	28	2.27	0.70	2	8	5	0.21	0	3
Make decisions about purchasing vitamins, supplements, or anything else that may help to improve my health	23	2.06	0.80	2	11	21	1.88	0.75	2	21	-2	-0.18	0	-10
Prepare for doctor appointment	24	2.06	0.76	2	11	27	2.34	0.75	3	3	3	0.28	1	8
Sort out conflicting information	25	2.06	0.72	2	11	26	2.06	0.67	2	16	1	0.00	0	-5
Learn about the causes of diabetes	24	2.02	0.75	2	17	26	1.95	0.60	2	20	2	-0.07	0	-3
Learn about the signs/ symptoms of diabetes	24	2.00	0.72	2	18	25	2.13	0.75	2	14	1	0.13	0	4
Decide when/ whether to get treatment	22	1.92	0.76	2	19	25	2.16	0.77	2	13	3	0.24	0	6

	Initial Interview					Follow-up Interview					Changes			
Factor	n	M	SD	m	ř	n	M	SD	m	ř	n	M	m	ř
Decide when/ whether to go to the doctor	22	1.89	0.74	2	20	25	2.25	0.80	2	9	3	0.36	0	11
Gain and/or maintain hope	20	1.88	0.79	2	21	24	2.05	0.74	2	17	4	0.17	0	4
For self-diagnosis	18	1.81	0.82	2	22	18	1.69	0.69	2	25	0	-0.12	0	-3
Learn how to help someone else who has diabetes	19	1.81	0.78	2	22	21	1.84	0.76	2	22	2	0.03	0	0
Deal with my emotions about diabetes	20	1.75	0.67	2	24	19	1.77	0.75	2	24	-1	0.02	0	0
Reduce uncertainty or anxiety	18	1.70	0.71	2	25	24	2.00	0.72	2	18	6	0.30	0	7
Decide whether to take or stop taking a medication	14	1.61	0.77	1	26	16	1.66	0.75	2	26	2	0.05	1	0
Find/ Select Health Provider	9	1.33	0.59	1	27	14	1.66	0.83	1	26	5	0.33	0	1
All		2.03					2.10					0.07		

Note. n = number of participants. M = mean. SD = standard deviation. m = median. ř = rank (based on means).

Looking at changes in these factors across time yields some interesting findings. Several of the factors that participants indicated were more frequently motivating their diabetes-related information seeking at the time of their follow-up interviews had to do with interactions with doctors. Paired-samples t-tests revealed that participants' ratings on the following two factors increased between the time of their initial interview and the time of their follow-up interview and that these differences were statistically significant at the $p < .05$ level: (1) Decide when/whether to go to the doctor and (2) Find/select health provider. Participants also increasingly looked for information in order to learn how to manage their diabetes. On the flip side, participants' ratings on the following two factors decreased and these differences were statistically significant at the $p < .05$ level: (1) Read about others' experience with diabetes and (2) Learn about potential diabetes-related complications Table 16 shows the means and standard deviations for each of these factors at both interviews, along with the specific results of the t-tests that showed statistical significance at the $p < .05$ level.

Table 16: Participants' Ratings of Factors Motivating their Diabetes-Related Information Seeking: Statistically Significant Changes Across Time

		Initial Interview	Follow-up Interview	t-test results		
Factor	*n*	*M (SD)*	*M (SD)*	*t*	*p*	*d*
Decide when/whether to go to the doctor	31	1.89 (0.74)	2.25 (0.80)	-2.31	.028	0.41
Find/select health provider	31	1.33 (0.59)	1.66 (0.83)	-2.12	.042	0.37
Learn how to manage diabetes	31	2.48 (0.69)	2.75 (0.51)	-2.16	.039	0.38
Read about others' experience with diabetes	31	2.12 (0.79)	1.78 (0.71)	3.23	.003	0.57
Learn about potential diabetes-related complications	31	2.28 (0.68)	1.97 (0.59)	2.06	.048	0.36

4.3.2 Factors Demotivating Information Seeking and Use

When asked if there had ever been anything that decreased their desire to find out more about diabetes, many participants responded, often emphatically, in the negative. I08, for example, responded, "No, I'm never that way... I don't like to live in denial… I think it's polluted… snakes in the grass there." I05 similarly responded, "No, absolutely not… I can't think of anything that would cause a person to say, 'Nah, I don't want to know about sugar'… I mean, if you're diabetic, you want to know about this stuff."

On the other hand, however, most participants described at least one factor that made them not want to learn about diabetes during at least some point in time in their journeys with diabetes. For reporting purposes, these factors have been classified into four categories: (1) Physical; (2) Social; (3) Cognitive; and (4) Affective.

4.3.2.1 Physical Factors Demotivating Information Seeking

Interestingly, both a lack of symptoms and an abundance of symptoms were mentioned as factors that made participants not want to learn about diabetes. While participants with no diabetes-related symptoms felt no impetus to look for diabetes-related information, those with many diabetes-related symptoms also felt no desire to look for diabetes-related information.

Some participants did not want to look for diabetes-related information because they felt there was no need since they didn't have any symptoms. I19 explained, "I guess

if… I had issues with sight or anything like that, then maybe I would be more interested in looking at things. But I haven't had a big issue overall with it, so there's been no driving factor." I21 similarly explained, "If I did all of a sudden [experience symptoms], then I would want to know what's going on."

On the other hand, some participants who were experiencing some serious diabetes-related complication(s) said that these physical symptoms sometimes make them not want to learn any more about diabetes. I22, for example, explained why she doesn't want to learn any more about diabetes:

> When it doesn't work… When none of it works and you're taking your insulin, you're following your diet, and you're doing what you're supposed to be doing and your sugar's just going up and your symptoms are getting worse and your neuropathy is getting worse. And yet, you're following the rules, you're playing the game out to the fullest and you're winning but you're losing… It's just like it gets to be too much… I've even told the doctors, "I don't want to know after this. After what I'm dealing with now with my stomach shutting down, I do not want to know anymore. What good is it going to do me to know any more? I don't need any more. I've got a full boat. You give me any more and I'm just going to shut down and quit. I'm going to give up… You're going to overwhelm me so much that I'm going to give up."

Another participant (I32) indicated that he would not want to know about diabetes if something similar ever happens to him. He stated:

> It hasn't happened yet, but if it ever gets to the point where I am not satisfied with the way things are going and I get to thinking… "It doesn't matter what I do, it's not going to help"… I'm not thinking like that. I don't want to think like that, but I eventually believe it will probably happen.

4.3.2.2 Social Factors Demotivating Information Seeking

Some participants felt that the stigma surrounding diabetes or a lack of constructive social support made them not want to learn any more about it. When asked to describe any factors that make her not want to learn about diabetes, I27 responded, "The attitudes of family and people in the community… Cancer has more support… than… diabetes… There's more a rallying… by the community… It's your fault if you get lung cancer but other kinds… it's not considered your fault." This participant further stated, "You got it [diabetes], you don't have much support for having it, and so why bother?"

Some participants were ashamed to admit that they had diabetes because they felt like they had done something to cause it. I17 talked about how she felt when she was first diagnosed: “I felt like it was almost like a venereal disease… I can’t even justify that thought but I was so ashamed of having diabetes, I really didn’t want anyone to know… I did something to cause this, you know?” I03 mentioned that she seldom shares information about her diabetes-related experience with other people because it’s “Almost a stigma still for me to have it and an embarrassment or whatever… I feel like I caused it… myself. I should have done things differently and I wouldn’t have it.”

Not receiving sufficient social support or receiving perhaps well-intended but destructive social support demotivated some participants. I27 stated, “I got [diabetes] in '80… My family thought it was my fault and I must have done some things or whatever to get that. And they were not supportive.” This participant described, “You’d go to a family dinner, and there they’d have 10 tons of sugar…. They’d say there’s nothing… else in the room to eat except what we're having.” I09 similarly described, “At Thanksgiving, I mean, everybody at the table knows that I’m diabetic and there are people who are going, ‘Well, maybe you should just have two pieces of pie.’ ‘No! Thank you for being so helpful!’”

Sometimes participants sought out help for their diabetes, but the help turned out to be more destructive than constructive. I31, for example, described attending diabetes-related support group meetings that were not at all helpful to her. She stated:

> That support group didn’t help me… because the people that I was in there with, they kept saying to me, “Girl, you know what? You gonna be like this for the rest of your life. Girl, you can’t eat this, you can’t eat that.”… I quit going… It was very depressing to me… When I got through with them, I had no hope… All of the negative things that the people were saying… The times that they were saying it was the wrong time, especially for me, because I was trying to get on a road to recovery.

4.3.2.3 Cognitive Factors Demotivating Information Seeking

One of the most commonly mentioned cognitive demotivating factors was denial and a hope that the diabetes would just go away; however, participants often described this as a stage that they moved through. As I03 explained, “The block I put up about it initially… I didn’t want to know, didn’t want to deal with at first… I didn’t want to find out more… I would just find out more stuff I didn’t want to know.” I18 similarly

described, “In the beginning… I didn’t want to learn nothing about it. I didn’t want it to affect me… I really didn’t. I just wanted it to go away, like ‘Leave me alone. I don’t believe you’re real.’”

I10, a young participant who was very successful at getting his diabetes under control within months of his diagnosis, made an important point about the importance of the timing of the transition from denial to acceptance. He stated:

> I guess I am just abnormal when it comes to dealing with these things… I want to know what to do to stop it, whereas most people they [doctors] end up dealing with are the exact opposite: “That’s nice. You go away with your news. I don’t need it, go away. I have enough issues.” “Yeah, well you’d have less issues if you’d actually listen, especially health-related issues that progress. They told you here. Now you’re deciding here, you should have decided here… Your kidneys are failing because you have diabetes. You should have listened back here. You’re on complete dialysis now. You should have listened back here.”

Another cognitive demotivating factor mentioned by participants was their attitudes toward the behaviors necessary to manage diabetes. For example, when I26 was asked if there had ever been anything that made him not want to learn about diabetes responded, “My addiction for ice cream.” I13 similarly responded, “Yeah, my chocoholism. Oh yeah. That’s easy.”

Participants’ attitudes toward the necessary health behaviors sometimes drove them to not do what they need to do to manage their diabetes. I08, for example, stated that she would rather be dead than have to live in a way that she doesn’t want to live. I26, who passed away before her follow-up interview could be conducted, said, “In the meantime, I’m still eating unhealthy. [chuckle] But I feel like we all got to go some time, so I might as well enjoy what I eat before I leave here.” I05 similarly stated:

> I feel like this. I’m 63. I’m not going to live forever. If I want a chocolate cookie, I’m going to eat the damn thing and I’ll take some more insulin for it. [laughter] It don’t help the A1C, but I’m going to eat it anyway… We all got to go some time. I’d just as well go with a chocolate cookie in my mouth. [laughter]

In contrast, however, one participant (I06) pointed out, “It’s like people say, ‘Well, everybody’s got to die some time.’ Yeah, that’s true but the smart ones try to postpone this when possible.”

4.3.2.4 Affective Factors Demotivating Information Seeking

Several different types of affective factors, including fear, depression, and anger, made some participants not want to know more about diabetes.

Frequently, participants mentioned that they did not like hearing about potential diabetes-related complications. I25, for example, stated, "When I was first getting diabetes… they often were talking about ulcers, sores that would not heal and I had no particular desire to learn about that." When I14 was asked if anything had ever made him not want to learn about diabetes, he stated, "I still don't like hearing about amputees… I don't like to hear about those tragedies." One participant (I20) pointed out that the fear engendered by hearing about diabetes-related complications is destructive. She stated:

> Diabetes, they go talking about amputation and kidney dialysis and all this other stuff... They feed people with all that fear and fear doesn't do anything but paralyze people... Hope is the thing that makes people get up and want to live and live healthily and do things.

Depression was also mentioned by some participants as a demotivating factor. However, participants varied as to when they became depressed. For some participants, they became depressed when they were first diagnosed. For others, they became depressed somewhat later. I20, for example, became depressed upon being diagnosed. She stated, "I don't think I even wanted to know [about diabetes]… Because I remember when I was first diagnosed… I went into depression." I12, in contrast, described how depression set in as the newness of the diagnosis faded: "When I first got diagnosed, I was really gung-ho into learning a lot. And then, as it wore off already, I wasn't that interested. I didn't want to… The depression set in that I had diabetes."

A few participants mentioned that anger had, at some point, made them not want to learn about diabetes. One participant (I08) was angry at her doctor because she felt that she wouldn't have gotten diabetes if he had listened to her. She recounted saying to her friend, "I am so freaking mad because I feel that I was let down by the medical community… I don't even want to think about it." Another participant (I22) was angry (just in general) that she had gotten diabetes and was angry with her doctor for promising her that she could get rid of diabetes by losing weight. She stated, "Before… I wasn't dealing with it… I was so mad. I had a lot of anger… Mad that I have it, mad that I got it, and mad that I couldn't get rid of it." This participant was also angry because her doctor

had told her that if she lost weight she would no longer have diabetes. She stated, "Well, I lost weight and the diabetes didn't go away anywhere."

4.3.3 Factors Impeding Information Seeking and Use

Unfortunately, participants encountered many different types of barriers when trying to look for and use diabetes-related information. Again, for presentation purposes, these barriers have been classified into four categories: (1) Physical; (2) Social; (3) Cognitive; and (4) Affective.

4.3.3.1 Physical Factors Impeding Information Seeking and Use

The physical barriers participants mentioned encompassed both factors relating to their physical condition and factors relating to their life situation. Some participants had physical and/or financial issues that limited their ability to look for and/or use diabetes-related information. Several participants had co-existing conditions along with the diabetes that complicated their health-related information needs, seeking, and use. Many participants mentioned having insufficient time to engage in diabetes-related information seeking.

a. Physical Problems

Physical problems, such as neuropathy and vision problems, hindered some participants in their attempts to look for or manage diabetes-related information. One fairly common example of this was an inability to read small print. I13, for example, lamented, "I wish I did this more often but I don't learn about the side effects. I try to read the label, but God, it's small print!" Another participant who had vision problems, including both cataracts and glaucoma, wanted information to be able to prove to her doctor that being ill causes your sugars to go up. When asked if she might do some research on this, she replied, "If my eyes get real well where I can read more, I probably will." For one participant (I22), developing neuropathy in her hands took away her ability to keep a logbook in which she had been recording her blood glucose levels. This participant also mentioned having cognitive difficulties as well. She pointed out that her physical and cognitive problems have changed the primary way in which she seeks diabetes-related health information. Basically, she went from being an active information seeker to a more passive one. She explained:

> I like to pick up health tips and I'm not much of a reader anymore because my eyes are bothering me and I shake and I can't concentrate or remember what I read. I hate that crap. So that's the way to do it for me, just listen, keep my ears open.

b. Comorbidities

Having multiple health problems complicated the health-related information seeking and use of several participants. Some of the comorbidities reported by participants included congestive heart failure, breast cancer, kidney disease, bipolar disorder, and depression. I27, who had both diabetes and bipolar disorder, described the difficulties she had in finding a doctor that could treat both of these together. She explained:

> It took years to… get a shrink that would talk to the primary care doctor and work together and it makes all the difference in the world. And you're healthier on both fronts… But finding somebody who would do that… was a real struggle… [Somebody who would] treat the whole person with all the illnesses they have.

This participant now has kidney disease and is searching for a doctor that can deal with both the diabetes and the kidney disease. She pointed out, "The kidney doctor has some information, but then his specialty isn't diabetes, you know?"

Some participants mentioned that they, at times, have put one of their conditions on hold while they try to deal with the other one. I35, for example, had gone for a mammogram and they had found a lump in one of her breasts. She described, "I was just like 'Let me deal with one thing at a time. Let me deal with this diabetes stuff… And I'll deal with that [breast lump] later, since I don't feel nothing.'" A few participants with depression or bipolar disorder explained that these illnesses, at times, caused them to not care about having diabetes. As I03 explained, "If I was really depressed, I could care less about having diabetes."

c. Resource Issues

Lack of money, transportation, insurance, and computers/Internet access were also mentioned as impeding factors. I24, for example, spoke of his diabetic brother: "He's going through some tough times so he's financially disadvantaged… being financially disadvantaged motivates him not to do what he probably should be doing." I26 recounted, "[My doctor] tried to send me to… [diabetes-related] classes. They were

like once a week, I think, but I didn't have the transportation or the gas money to go that far… every week."

Not having a computer and/or Internet access were also viewed as impeding factors by some participants. I26, for example, asked, "How do I find out about diabetes without having a computer?" When asked how available diabetes-related information is to him in his day-to-day life, I28 responded, "I would say mostly, it ain't completely… If I had a computer, it would be more available… It would be complete then because I could just go online and do certain things." This participant goes to the local branch of his public library to use one of their computers to access the Internet. He rated the Internet 'somewhat useful,' qualifying his response with "if I can ever get on that." Another participant (I18) who uses the Internet from his public library said that he uses Wikipedia simply because "it's easiest for me at this point and I only get an hour." This suggests that having limited access to the Internet may have a profound influence on how people look for information and on which sources they tend to turn to.

d. Lack of Time

Lack of time to devote to activities related to looking for information about diabetes was another frequently mentioned impeding factor. I06, for example, stated, "My doctor wants me to attend a diabetic support group… and I'm going to be looking into that, but right now, I've got so many things going on I just don't have the time." I15, the youngest participant in this study at 32-years-old, stated:

> My whole finger is completely numb now. I mean it's more number than what it was… I should be worrying about or... trying to figure that stuff out… I've been [so] busy with the babies that I don't start to think about [it]… I'm constantly going.

4.3.3.2 Social Factors Impeding Information Seeking and Use

The main impeding social factors related to logistical problems with getting appointments with their doctor and dissatisfaction with how they were treated by doctors and other healthcare professionals. Participants were frustrated when they were unable to see their own doctors and when they could only get appointments that were far into the future. They also felt impeded when their doctors and other healthcare providers did not spend sufficient time with them, did not listen to them, did not explain things sufficiently

to them, treated them in a cookie-cutter fashion, behaved in an authoritarian fashion toward them, and failed to follow up with them.

a. Logistical Problems with Getting Appointments with their Doctors

Participants described problems that they encountered when trying to make appointments with their doctors. Sometimes they were unable to make an appointment with the specific doctor that they wanted to see and sometimes they were only able to get appointments that were quite far into the future. I09 lamented, "I almost never get to see the doctors that I want to see. So it's like whoever is available in that little practice." Another participant (I35) whose doctor was finishing up his residency and then moving on stated, "I don't want no other doctor… You have to get used to a person. Oh, no! I don't know what I'm going to do… I don't even want to deal with nobody else. I really don't." For this participant, losing her doctor could result in less personalized, and perhaps lower quality, healthcare. Another participant, I04, stated, "It takes so long to get to see my endocrinologist that it's best to find [answers to her diabetes-related questions] on the Internet." Note that for this participant, this impeding factor actually has an influence on her information seeking practices.

b. Insufficient Time with Doctors and Other Healthcare Professionals

Participants commonly mentioned that they felt that doctors and other healthcare professionals did not spend sufficient time with them. I21 complained, "Nurses and doctors… They're busy all the time and every time you try to ask them, they're in the middle of something… They're running here, running there… It's not like you get to sit down and have a chat." Some participants described how this situation resulted in them not getting sufficient information from their doctor. I24, for example, stated:

> I wouldn't say that I got a lot of information from the doctor… If I bring him a question, he'll answer it, but it's not like they sit down and did a two- or three-hour session with me to help me understand the disease. I had to go learn it myself.

Some participants described strategies that they use in order to minimize the potential negative impact of having such limited time with their healthcare providers. I17, for example, described, "I usually have a piece of paper with a list… So I ask questions and he'll… It's not a huge list because they only spend so much time with you."

c. Doctors not Listening

Not feeling listened to by one's doctor was another commonly mentioned impeding factor. I25, for example, stated, "I think I'd really like [doctors] to pay more attention to what I'm trying to tell them." She pointed out the negative impact this had on her:

> I sometimes feel that when I say things to [my General Practitioner] about concerns I have, I don't feel I get good answers… [She] doesn't seem to listen, doesn't seem to really hear what I'm saying… You know, if you don't listen to a person, you're not going to give them a good answer.

d. Doctors not Providing Sufficient Explanation

Some participants felt that doctors were not very clear, comprehensive, and/or direct in communicating with them. I21, for example, stated, "I'm not saying that the doctors are lying to you, but they give it to you sometimes in such a way that you don't understand it real crystal clear." I06 mentioned that he has had problems with his family doctor just assuming that he already knows things. He stated, "I didn't know… But the doctor acts like that's common knowledge and what am I, a stupid ass because I didn't know that?" Another participant, I32, felt that the meaning of the A1C test was never really explained effectively to him. This participant also recounted a conversation he had had with his doctors at the hospital: "You're not giving me the whole picture here. You're only giving me this one little element of it. I want to know about this, this, and this." This participant also asserted:

> Nurses… speak candidly. Doctors appear to me to be always couched in subtleties… They're trying to be nice in saying what they have to say… "What am I supposed to infer from what you're telling me?'… They seem to me to shield the direct information.

e. Cookie-Cutter Treatment by Doctors and other Healthcare Professionals

Some participants felt like doctors did not provide them with individualized treatment based on their own specific circumstances and that they did not value patients' expertise about their own bodies. I33, for example, complained: "I think that they just had a certain agenda that they wanted to do. They wanted facts. Fact was the A1C was 11.7… glucose was 484. 'Okay, so we got these numbers so we're going to treat these numbers.'" This participant, who was currently on disability but had been a nurse, went on to state: "You can't forget the emphasis of the whole individual… You can't cookie-

cutter… And that's what our diabetic education has emphasized, cookie-cutter type mentality, for years."

Some participants felt that information was not useful if it was just disseminated to them with no regard to their specific circumstances or questions. I29 stated, "When I was first diagnosed… there was a diabetes education program but it was… mostly, not all, but mostly a one-way information dissemination kind of process, rather than [an] interactive process based upon my particular circumstances." Another participant (I20) felt that her expertise about her own body was not valued by doctors. She eloquently explained:

> Those nurse educators and nutritionists and doctors, they are all experts, but what is their expertise? Their expertise is in everybody… They can give me the average African-American that's such-and-such, but I know I'm not average. I know me… Your plan is based on everybody else, not me…. They look at me, you know, "What does she know? She don't have no letters behind her name"… They assume that I have no information, but I have more information about me than anybody else does.

f. Authoritarianism

Being treated in an authoritarian manner was another impeding factor that was commonly mentioned. I35, for example, said "I don't mind like discussing stuff with him, but… I want to have some say-so and I don't feel like I do." Another participant (I17) expressed some doubt about whether her doctor would be willing to refer her to an endocrinologist. She explained, "Some doctors, I think they think whatever they're doing is entirely the right thing to do and how dare you ask to go see someone else." Another participant (I20) felt like doctors didn't like her because she asked them questions. She pointed out, "I want you to not just say 'This is this' and 'I want you to do that.' I want you to say, 'This is this' and 'This is how we came up to this conclusion'" She went on to explain that she wants more of a partnership-type relationship with her doctor. She described, "Based on the information you've given me, I can go look and see about my information, and we can put things together, I can put things together for myself."

One participant's (I27) endocrinologist simply dropped her as a patient because she was not compliant. This participant recounted:

> I had an endocrinologist who's a diabetes specialist who said, "You can't be compliant and so I'm not seeing you anymore." And I was devastated and I thought I was gonna die, you know, if I didn't have an endocrinologist and this

> guy was supposed to be, you know, renowned and done research and all this stuff… But not being compliant, hey, that's the name of the game, you know, in medical care, especially with something you're gonna have for 20, 30, 40 years. You aren't gonna be perfect all the time and if he can't take those kind of patients, I don't think he should be a doctor. But you need to reward people for what they do right, not say, "Well, I'll skip you. I'm not taking you."

Sometimes participants were upset with their doctor's insistence and sole reliance on medications. I26, who passed away before her follow-up interview could be conducted, described, "The doctor I had, he was a bit of a quack… He'd give you narcotics if you wanted that but he… He wasn't really off into really saving your life or nothing, you know?" I33 whose doctor just kept increasing his insulin dosage every time he saw this participant's blood sugar numbers, stated, "How much of this increasing are we going to [do]? We can't just keep on increasing and increasing without really addressing the issue." Another participant, I34, stated, "I wish there would have been more of a package that you got… 'Congratulations. Here's your diabetes starter information kit'… Something that had multiple parts to it, not just 'Here's a drug and we'll see you in three months.'"

A surprisingly large number of participants were dissatisfied with what they perceived to be their doctors' closed-mindedness toward vitamins/supplements and alternative types of treatments for diabetes and other health conditions. I01, for example, said, "I asked my doctor… He says, 'Oh, those vitamins aren't going to do a thing for you. You just do what I tell you.'" I17's dietician told her that supplements were "very expensive urine." This participant said, "I think the doctors are doing well in guiding me through the diabetes experience, but he doesn't like the supplements… So we're kind of at an impasse. It's kind of like 'Don't ask, don't tell'." I35 stated, "I don't really… feel like he'll let me take [vitamins]… I'm scared to take something without him saying I can 'cause I don't want to mess up the medicine." At her follow-up interview, this participant stated, "They say ask your doctor before you take any of this stuff, so… I take other medicines… That's the reason why I was asking because I didn't know if they'd interact…. He just wants you to take your medicine." These quotes suggest that a dangerous situation may exist in which people are unknowingly taking vitamins and supplements that are actually harmful for them.

Several participants mentioned that it was not motivating to them when anybody, whether the person was a doctor or not, told them that they *had* to do something. I03, whose husband was diagnosed with diabetes a couple of years before her, stated, "There were times when [my husband] was good about just talking about it as opposed to telling me, preaching to me… 'You got to do this and you got to do that', because that doesn't motivate me at all." I05 whose daughter (I04) was diagnosed with diabetes 13 years earlier than her, indicated that her daughter is her most useful source of diabetes-related information. She explained:

> Because she gets on the computer and tells me what's going on… She watches me and I watch her… When she gets something new on the computer, any kind of suggestions, something, she comes to me and says, "Well mom, what do you think?"… She doesn't say "Let's do this" or "Let's do that" or "You do this" or "You do that". She'd say, "What do you think?" That makes a big difference.

g. Doctor's Failure to Follow Up

Some participants were unhappy with their doctors because they did not follow up with them. I22, for example, stated, "My diabetic doctor and diabetic nurse… They're supposed to be checking on my diabetes every day and calling and monitoring. They haven't done crap in six months." This participant went on to say, "It's kind of disappointing when… you're fighting to get this under control and they're supposedly fighting with you but as soon as you leave their office, it's like you're just another patient." I33, a former nurse, pointed out that education will not do any good if there's no follow-through. He stated:

> When you teach Aunt Millie… this is the way to take care of your feet, this is the way you do your insulin, this is how you do your Accu-Chek's… Teach her that but then go out two weeks later. Say, "Okay, let me see your Accu-Chek forms"… That's where we fall out… And it's just not fair to them because the next thing you know six months later, you're going to see them down at the emergency room with an ulcer on their heel wondering how come… it just showed up.

4.3.3.3 Cognitive Factors Impeding Information Seeking and Use

Participants described encountering many different types of cognitive barriers when trying to look for and/or use diabetes-related information. These included experiencing what the researcher is terming here 'incognizance,' being unaware of potential sources of diabetes-related information, encountering cognitive limitations and

information overload, difficulties navigating through complex information, having to wade through advertisements, feeling distrustful towards doctors and/or the government, encountering misinformation, and a perceived lack of relevant information. Also, some participants did not look for diabetes-related information simply because they did not perceive diabetes to be their top priority at this time or at some other point in their lives.

a. Experiencing Incognizance

Incognizance – a term being used by the researcher here to denote a state of being unaware that there is something one does not know, but needs to know – was a frequently described state. I06, for example, described, "You don't understand the symptoms of high blood sugar or blurry eyes, going to the bathroom. You don't connect to that, you're not a doctor, you know?" He pointed out that although he had all these signs of diabetes, "Nobody knew to ask me. And I didn't think they were a big enough deal… It was just normal to me." I27 pointed out, "If [you] don't have the classes, you don't even understand why you need to have one… You don't understand the purpose of it." When asked if he had ever been unable to find the diabetes-related information he needed, I32 responded, "No, it's been the reverse. I didn't know I needed to know until I found out something." These quotes suggest that, at times, participants' information needs existed long before they were able to recognize them.

I08, a former Unit Clerk at a hospital, explained what she perceived to be a crucial difference between her and other people:

> I always know that I don't know everything… The minute you think you know it all, you stop learning… I don't know it all and I certainly don't know about something I didn't even know existed, and that's why I search, but I know of the existence of so many things that other people are not aware of.

This participant, in contrast to some of the other participants at some points in their lives, is not incognizant – she is very aware of the fact that she doesn't know what she doesn't know, and thus, of the need to continue to look for diabetes-related information.

For some participants, their (perhaps incorrect) assumptions contributed to their incognizance, as they prevented them from being able to realize that there was something they didn't know and, thus, kept them from looking for needed diabetes-related information. I06 who had had a diabetic stroke while he was sleeping and woke up

unable to use his legs stated, “I just assumed that I had laid on it wrong, I pinched a nerve… Diabetes was the last thing on my mind. I don’t know why – my mom had it, but I just never gave it a thought.” I32 mentioned, “I was naïve about it…. I thought it was just like… you take a pill, it solves the problem… So I didn’t have any need to know. I didn’t think I had a need to know.”

Some participants described current assumptions that may be keeping them from getting information that they need. I24, for example, stated, ‘I don’t need to learn right now about [diabetes] because I already know what I need to.” I31 similarly stated, “‘Learn about the signs and symptoms.’ I already know them so I never look at that because I already know what it is.”

b. Being Unaware of Potential Sources of Diabetes-Related Information

Several participants mentioned that they weren’t sure where to turn to when they needed diabetes-related information. I06 pointed out, “There’s no problem with motivation [to look for diabetes-related information], but it’s where to get the information.” I26 described trying to ask her diabetic brother-in-law about insulin and having him change the subject or leave the room. She stated, “Nobody wants to tell me the truth about diabetes. How do I find out about diabetes without having a computer? Who can I call?... It seems like you should be able to call a hotline.’” This participant also described not knowing what she should be eating. She talked about perhaps going over to her daughter’s house and asking her to look it up on her computer. She stated, “Maybe she could find out what I was really supposed to eat. There are all these people always saying to me, ‘You know, you’re supposed to eat healthy.’ Okay, what is healthy?”

c. Encountering Cognitive Limitations and/or Information Overload

Some participants described dealing with cognitive limitations and/or being overloaded with information when they were first diagnosed with diabetes. I26 described making lists of what’s going on with her to bring to the doctor and then forgetting to bring these lists to her appointment. Some participants were overwhelmed by the amount of information they were given when they were first diagnosed. I05 described, “There was just so much running through my mind, I couldn’t remember everything they told

me… I cannot say that [pamphlets she was given by her doctor] were [useful], no. It was more stuff than I wanted to do." I06 pointed out, "I mean, it's overwhelming. There's so much shit to learn. And you have to learn it so quick because it's affecting my eyes, my kidneys…" Note the difference in these two participants' reactions to information overload – I05's attitude was that she didn't want to do what she needed to do, while I06's attitude was that he better quickly learn what to do so that he didn't develop complications.

d. Difficulties Navigating through Complex Information

Having to wade through complex information was another impeding factor that was commonly mentioned. Some participants described problems with figuring out what one needs to do to get government benefits. I20, for example, stated, "Then you have to work with the government, which has you jumping through all kinds of hoops in order to get the benefits that you need… To be disabled, you've got to have a brain on you." Some participants talked about difficulties sorting through conflicting information. I32, for example, said, "Sort out conflicting information. That's a lot of work. I probably wouldn't go to that effort."

Some participants mentioned specific difficulties with navigating the Internet or specific Websites. Specific problems described included difficulties with technology, searching, and information overload. I22 explained, "To me, the Internet, having it is like the agency sometimes. It's 'Server busy. Sorry, try again later.' If you've been on for half an hour, you finally find your site, then it closes down on you… It's tough." When asked what she thought about the diabetes-related information on the Internet, I11 replied, "I had trouble finding the answer and I'm the queen of searching. Plus, I'm an MD and I still couldn't necessarily get the answer that was right…" This participant pointed out that the information on the American Diabetes Association is written "above the education level… of most people that would be searching." I24 stated, "I just hate it when I get like 20,000 hits on the same thing and I was trying to narrow it down." I34 summarized her thoughts about the Internet this way:

> If you think about the speed of the Internet and how fast we find the information that we're looking for or the heading that we're looking for, you want to find the information in that category as fast as you found the category… It's not like in the olden days where you had to go and look up the Dewey Decimal… And you don't

> want to have to read, like I said, someone's dissertation [laughter] or find the answer in the last paragraph.

Some participants found specific Websites difficult to navigate. I11, for example, stated, "Some of the Internet sites that you'd think would be better, I find very hard to negotiate, like the American Diabetes Association. Some of those are sort of hard to get around them." I14 stated, "Government agency Websites. I'm on Medicare now and there's nothing more convoluted than a government Website, but I had to go there." I34 stated, "Oddly enough, the University of Michigan's Website isn't all that fabulous. One of the hardest things is to search anything on those hospital ones. Horrible."

e. Having to Wade through Advertisements

The plethora of advertisements was also found to be an impediment to information seeking. This was particularly the case when the ads were interleaved within legitimate sources of information. I06, for example, said, "You have to wade through a bunch of garbage. There's a lot of commercials. Even at the diabetic clinic… maybe there's 10 pages on diabetes and one page actually addresses diabetes and the other nine pages are commercials." I29 similarly stated, "The commercialization of these information products is just a part of society, at least our culture. We commercialize everything we do. So I'm a little bit impatient with that, but I cope with it." When asked if there are any types of diabetes-related information that are not useful for him, I14 responded, "Spam and junk mail… There's always somebody trying to sell something… related to my diabetes and so you get a lot of junk mail."

f. Feeling Distrustful Toward Government and/or Doctors

Although mistrust toward the government and/or doctors was not specifically mentioned by participants as a factor that impeded their diabetes-related information seeking, it seems likely that these feelings of mistrust do, at times, impede participants' information seeking. I20, who was on disability, pointed out, "We can't really rely on the folks that is getting paid to help you because if they getting paid because you're disabled, they're not going to help you become… undisabled because that's their paycheck." I22 stated, "It's a multi-billion, trillion dollar disease. I don't know if the government would

want you to have a cure for diabetes. There is so much money, pharmaceutically, to be made on diabetics."

Several participants expressed mistrust toward doctors. I09, who had recently received a form letter from her doctor stating that she should go on a statin given her cholesterol level and the fact that she had just been diagnosed with type 2 diabetes, said, "I came to know like, 'Okay, my doctor is giving me kind of mainstream advice that's just influenced in part by the drug industry.'" I35 distrusted that doctors had actually found a lump in one of her breasts. She stated, "I figured because I had Medicaid – I'm lower income – maybe they just saying that just to be experimenting." I27 asserted, "A lot of people… don't take their medicine consistently on time… because they don't feel there's any consequences. And they don't believe the doctor that gives it to them. They don't trust them or believe in them." I08 advised:

> You cannot ever, ever, ever trust anything. There is no absolute anywhere in this world, and not in medicine. I have seen doctors say, "Yeah, that's the answer we've been looking for all these years"… And then you find that it's not the answer… You got to know what you got to know… You just have to make your best choices, go with prevailing opinion if you think that it has a good basis. You can't just look at the opinion, you have to look at how they arrived at it. It leads me to a lot of questions.

g. Encountering Misinformation

Receiving or coming information that they knew to be inaccurate and/or outdated was another impeding factor mentioned by participants. I06, for example, explained that the label on insulin says that you have to throw it away 90 days after you open it. However, when he asked his doctor about this, his doctor told him that this wasn't true and that the manufacturer was just trying to sell more insulin. This participant lamented, "You tend to read the label and believe what you read and that's not necessarily true." This participant also mentioned that his doctor told him that he can re-use his syringes for three or four days, even though they say on them that you can only use them once. He stated, "That was just something that they put on there just to sell more syringes." This participant summarized, "There's a lot of companies that… are trying to capitalize on this illness and they're sending out a lot of bad information." I25 complained about encountering outdated information. When she was first diagnosed back in the 1980's, she

went to the library and checked out books on diabetes. However, the books she could find were from the 1950's.

Some participants complained that some of the information they came across on the Internet was outdated or incorrect. I14, for example, pointed out, "I figure when I put it in that search engine, I'm more likely to get the most up-to-date, refreshed information… Not always the case… A lot of times you're led to stale Websites with old information." One participant (I22) who did not have Internet access and whose friend often looked things up on the Internet for her, stated, "I don't want her to get crap information that she read it on Google… 'cause anybody and their brother can put something on Google." I33, a former nurse, emphasized, "I think you have to be very careful in regard to what you're reading and you have to go to well-trusted sites." He pointed out, "If you're not a healthcare practitioner, you're just Johnny Joe Layman out there, I think there's too much out there. If you're reading too much, you can really get confused… And I think that's the danger about it."

h. Perceived Lack of Relevant Information

Some participants felt like they had not had access to clearly relevant information at the time when they needed it. Sometimes this was due to an inability to perceive the relevance of available information. For example, a few participants did not perceive any relevance when a family member or spouse was diagnosed with diabetes, often years before they, themselves, were diagnosed with diabetes. For example, one participant's (I23) mother had been diagnosed with diabetes years ago and this participant's wife stated, "We'd just kind of pass it off, you know, never thinking that he could get it… If he had been watching his weight, would he have not gotten it?" Similarly, I28 stated, "Even though my sisters had diabetes, I never took an interest in what they were going through… But it's… a different ballgame now." Although I06's mother had been diagnosed with diabetes years earlier, he did not deem this relevant. He explained, "I never gave it a thought because why should I? It was something that I didn't need to understand it, had no knowledge of, until it hit me… Then all of a sudden, 'Oh shit! I better learn about this.'"

Some participants complained that it was impossible to determine if information was relevant for you until you had already gone to the effort to read it. I26, for example,

said that she gets frustrated when she reads through pamphlets only to find out that they did not answer the specific questions that she had. I32 rated magazines just somewhat useful for diabetes-related information "because they write about it a lot and you never know when you're really going to find a good nugget of information, so you got to read the article." For some participants, the Internet was seen as a way around this problem. I34, for example, rated the Internet as more useful than books because:

> Very similar to a doctor, you can actually put stuff in and get an answer back and depending on what keywords you use or how you approach it, you can get different… You can kind of focus your questions down, whereas a book, you would have to scan through chapters of nonsense in order to get to your keyword.

For some participants, information may have been relevant but was not provided in a conducive situation. I21, for example, described, "Nobody sits down with you unless you're in the hospital, unless you're in a bed… Well, if you're in the bed, who gives a shit?"

Other participants pointed out that the relevance of information changes over time. I29, for example, pointed out the importance of keeping up-to-date: "I'm going to ask to go through [the diabetes education class] again because stuff changes. I mean, new research informs protocols for care. You know? And so I think it's important to have an ongoing education process." Another participant (I04) who had had diabetes for nearly 30 years explained:

> Seems like most of the support groups are for people who are just being diagnosed with diabetes. I haven't found one that's a continuing, you know, for somebody who's like me. I'm ten years on insulin. I haven't found a group like that… Just because we're not new diabetics anymore, it don't mean that we don't come into questions or need help or just want somebody to talk to… It doesn't work like that.

I27 described the opposite experience. She attended a support group that included people who had had diabetes for longer than her and who had developed serious complications. She described:

> In one way, [the support group] was very helpful. In another way, it was very scary because there were people there who were going blind… people with severe, severe diabetes illnesses…It wasn't so much a group of people who just got it, you know, how do you deal with it.

i. Not Prioritizing Diabetes

Some participants very honestly admitted that diabetes simply is not their priority at this point or at some other time in their lives. I08 explained, "I've got enough on my plate right now. I don't need this." At her follow-up interview, this participant stated, "I probably should be more interested [in diabetes] but I have so many intervening factors in my life right now that are screaming 'I'm the priority' that I'm putting myself in the backseat. And I know I shouldn't." I14 similarly talked about the initial period after he was diagnosed with diabetes: "I had what I thought were more important things to do than to deal with this… I mean, I've got people to see and places to go." There was a gradual transition from classifying diabetes as a low priority to classifying it as high priority that was evident in the stories of some participants. One participant (I29) who had had diabetes for over 25 years and who had recently gone into semi-retirement described a transition in his priorities over time:

> The work that I do is entrepreneurial. You have to get projects to support yourself. So which is more important, supporting yourself or worrying about diabetes?... The first one… drove out the second… As time goes along and I don't have to put as much effort into [work]… that's [diabetes] one of the things that I care about… The care accumulates as time has.

4.3.3.4 Affective Factors Impeding Information Seeking and Use

Participants also mentioned various affective factors that impeded their diabetes-related information seeking and use. For one participant (I17), being emotional because of the diabetes diagnosis had a negative influence on her ability to manage diabetes. She stated, "I wish I would have been more serious about it quicker… not so emotional, just more serious about it. You're very emotional when you're diagnosed. That really clouds your vision."

Some participants mentioned experiencing specific emotional reactions that sometimes impeded their diabetes-related information seeking. For example, they reported feeling scared, worried, and depressed when they were first diagnosed with diabetes. I06 stated, "When you're first diagnosed, it scares the shit out of you. You think you're going to die. And it's just because you don't have any knowledge." I26, who passed away just before her follow-up interview, explained that she was not checking her blood sugar levels because of fear. She stated, "I just think I would get upset if I took it

because it would probably be high and I'd think, 'Oh God, is this it? Is this going to be the day?'… I'm afraid to take it." I31, however, explained that she was unable to get better until after she was able to calm down. She stated, "When they first told me, I almost worried myself to death… When I stopped worrying about it… that's when the recovery began to set in… Recovery could not come in because I was so worried about what I had." For I20, depression impeded her ability to manage her diabetes. She stated, "When you first get diagnosed, you go through the depression, 'Oh, I'm diabetic. That means I'm going to die soon. And if I'm going to die soon, I might as well eat what I want to eat… And then that just kind of fuels the fire of your disease."

4.3.3.5 Time-Related Factors Impeding Information Seeking

Several participants mentioned that the presence, extent, and/or influence of impeding factors, along with the potential usefulness of information, tended to change over time. I06, for example, stated, "I guess that it gets easier with time, but it's an adjustment. It's a major adjustment having to be aware of so many different areas all the time. I'm assuming it gets easier as time goes by."

Some participants emphasized that the potential usefulness of diabetes-related information changes over time. I14, for example, stated, "Learn about the signs and symptoms of diabetes. It's a little late for the signs and symptoms with what I've got going." I29 stated, "The kind of diabetes education program that was available to me because of… taking insulin for the first time, if that had happened much earlier in the process, it would have had a stronger impact on my behavior." This participant explained that he became more and more conscious of diabetes as he began to develop diabetes-related complications. He pointed out, "That's what is so insidious about diabetes because when you have symptoms, for some people, it's kind of like too far down the road." This was certainly the case for many of this study's participants who were not diagnosed with diabetes until they experienced some major diabetes-related complication, such as having a stroke (I6 and I11), going into a diabetic coma (I28), or developing congestive heart failure (I33).

4.3.4 Summary: Factors Motivating or Impeding Information Seeking and Use

Table 17 summarizes this study's findings regarding the second research question; that is, the factors that motivate, demotivate, and impede participants' diabetes-related information seeking and use.

Table 17: Factors Motivating, Demotivating, and Impeding Participants' Diabetes-Related Information Seeking and Use

Dimension	Motivating Factors	Demotivating Factors	Impeding Factors
Physical	Concerns about current physical state (e.g., being diagnosed; experiencing symptoms)	Unconcern due to absence of physical symptoms (thus, no impetus to look for diabetes-related information)	Barriers posed by physical problems (e.g., physical disabilities, such as vision impairment or severe neuropathy; comorbidities)
	Feared future physical state (e.g., diabetes-related complications; death)	Overwhelm due to seemingly uncontrollable physical symptoms (thus, no desire to look for diabetes-related information)	Barriers posed by lack of resources (e.g., money; transportation; insurance; computer/Internet access
	Desired future physical state (e.g., get rid of diabetes; get off medication; improve one's health and/or quality of life)		Lack of time to devote to managing diabetes
	Increased information seeking due to ready accessibility of information within people's everyday life contexts		
Social	Watching or hearing about the experiences of other people with diabetes (e.g., people experiencing complications or people who are successfully managing their diabetes)	Stigma (e.g., feeling blamed by society for developing diabetes; feeling ashamed of having diabetes)	Problems getting doctor appointments (e.g., can't see the doctor one wants to see; can't get an appointment with him/her soon enough)
	Receiving social support (e.g., respect and positive reinforcement from one's doctor; encouragement from other people in one's lives)	Lack of constructive social support (e.g., family members offering only foods participant cannot eat; support group meetings experienced as scary and depressing)	Feeling treated by doctors in unacceptable ways (e.g., doctors not spending enough time with them; doctors not listening to them; doctors not providing sufficient explanation; doctors providing cookie-cutter treatment; doctors behaving in an authoritarian manner towards them; doctors neglecting to follow up with them after appointments)

Dimension	Motivating Factors	Demotivating Factors	Impeding Factors
Social (Cont'd.)	Desire to learn to manage diabetes so that one would be there for other people (e.g., children or grandchildren)		Being told by doctors or other people in their lives that they *had* to do something
	Wanting to help other people who have diabetes or who are at risk of developing diabetes		
Cognitive	Realizing that it's up to them to manage their diabetes	Denial/wish that diabetes would go away	Experiencing incognizance (i.e., not being aware of one's information need(s); not knowing that one doesn't know something that one needs to know)
	Desire to keep up to date with any new developments	Attitudes toward behaviors necessary to manage diabetes (e.g., not wanting to change one's eating habits)	Being unaware of potential sources of diabetes-related information
	Desire to educate themselves, often in order to prepare for or follow up on a doctor appointment		Barriers posed by cognitive limitations and information overload (e.g., forgetting to ask doctors the questions one had thought of; inability to remember everything)
	Need to confirm information		Difficulties navigating through complex information (e.g., problems with getting government benefits; difficulties navigating the Internet or specific Websites)
			Need to wade through advertisements (especially when they're interleafed within legitimate sources of information)
			Encountering misinformation (e.g., biased information; outdated information)
			Feeling distrustful toward the government and/or doctors

Dimension	Motivating Factors	Demotivating Factors	Impeding Factors
Cognitive (Cont'd.)			Perceived lack of relevant information (e.g., not seeing the relevance when a family member of spouse had previously been diagnosed with diabetes; not being able to determine relevance unless one read an entire document; relevant information was not provided in a conducive situation or at the right time; what is relevant changes over time)
			Lack of prioritization of diabetes management
Affective	Desire to feel in control of their diabetes	Fear (e.g., fear engendered by hearing about diabetes-related complications)	Emotionality
	Desire to decrease feelings of anxiety or uncertainty	Depression	Specific emotional reactions (e.g., stress; fear; worry; depression; overwhelm)
	Desire to meet the challenge of managing diabetes	Anger (e.g., anger at doctor; anger at being diagnosed with diabetes)	
Time-Related	Decreased information seeking over time as participants learned to adapt to having diabetes		Present, extent, and/or influence of impeding factors change over time (e.g., may subside as participant adjusts to having diabetes)
	Increased or decreased information seeking over time as participants' life circumstances and/or priorities changed		Potential usefulness of information changes over time (e.g., diabetes education is more useful when one is first diagnosed and has not yet developed complications)
	Increased or decreased information seeking as participants succeed or fail in managing their diabetes (e.g., cyclicality)		

4.4 Information Needs and Information Seeking and Use Practices

In this section, results are presented that relate to this study's second research question: What are people's information needs and information seeking and use practices in relation to their health condition, and how do these change as their knowledge about, and experience with, their health condition change across time?

4.4.1 Information Needs

This section discusses the following themes pertaining to participants' information needs: (1) Incognizance, which is a term used here to refer to an unawareness of one's own information needs; (2) Fulfillment/non-fulfillment of information needs; (3) Types of information deemed most important to know; and (4) Information wish list, which includes the types of information participants would like to have available to them and/or to others in the future.

4.4.1.1 Incognizance

Many participants mentioned that they had information needs of which they had been unaware at the pertinent time. This incognizance was often due to a failure to recognize the relevance of information to their particular situation, often until it was too late. This failure to recognize relevance resulted in participants having unidentified information needs. At times, these unidentified, and thus unfulfilled, information needs resulted in dire consequences for participants. Incognizance occurred at various, and often multiple, times in participants' lives, including during their pre-diagnosis, diagnosis, and post-diagnosis time periods.

Many participants were unaware of the relevance of diabetes before they experienced any symptoms or received a diagnosis. I28 stated, "If I would have known… 10 years ago, that by eating all this sugar and eating all these starchy foods that I later on… may develop diabetes, I might not have ate all of that… pasta, rice, potatoes, bread." Even when relatives were diagnosed with diabetes years before diabetes became an issue in their own lives, participants did not see any relevance for them personally. I06, for example, explained, "I wish I would have taken my mom's diabetes more seriously. I wish I would have had information that explained to me that it's possibly hereditary and that I'm a good candidate for getting it. He further stated, "Had I had that information, I would have been monitoring myself a lot earlier and that stroke could have been prevented. It may not have even happened if I would have been ready." I24, whose wife had been diagnosed with diabetes years earlier, stated, "She took care of herself and she managed it… I didn't need to worry about it. I worried about it because I knew… my family had it, but I never really knew much about it or worried about it."

Some participants experienced symptoms before they were diagnosed with diabetes, but either had no idea what they meant or assumed that they were due to something else altogether. I23 stated, "I would say that I didn't have any distant early warning symptoms." I28, on the other hand, experienced many symptoms in the time leading up to his diabetic coma, including extreme thirst, balance problems, and difficulty staying awake. His girlfriend pointed out, "We didn't know that he had diabetes. It came on just like that but the signs was there and we didn't know nothing about diabetes. We didn't know what the signs were." I26 attributed her symptoms, including loss of appetite, weight loss, hair loss, frequent urination, and dizzy spells, to grief over having just lost her mother. Before I15 was diagnosed, she was feeling tired and sluggish and more thirsty than usual. When asked if she had tried to find out anything about her symptoms before she was diagnosed, she responded, "No… I thought I was going through like, I guess, like a cold maybe or something. I thought it would go away." This participant eventually learned that she had diabetes when she went to a clinic because she was pregnant. I17 astutely stated, "Diabetes is silent. You don't know you have diabetes until somebody tells you… I was 55 and I didn't know… I would go to the bathroom and urinate a lot, but I didn't find that unusual."

Participants described experiencing periods of incognizance even following their diagnosis. Often, this incognizance had to do with a lack of sufficient knowledge to be able to formulate any specific questions. When I29 was asked if he felt like he still had unanswered questions after he was diagnosed, he replied, "No, because I didn't know what the questions were." I16 explained, "I don't think I had any more specific thoughts about what I wanted to know… after the doctor first diagnosed me… I kind of just went into the class with just no mind about seeing what they could teach me." I06 pointed out, "It's a lot to learn, but you don't know what to ask until basically you go through the symptoms. And then you ask."

Some participants pointed out that specific people, such as healthcare providers and support group members, can help you to know what questions to ask. For example, I19 rated treatment facilities and/or providers as very useful in the card-sorting exercises because "I figured treatment facilities and providers is going to give you information on what information you need." I17 pointed out that support group members can also

provide this type of meta-information: “I find the older people in the support group… I like the questions they ask because some of them might be questions that I wouldn’t even ask.” I08, a former Unit Clerk at a hospital, provided this advice for people diagnosed with diabetes: “Take a class. Because when you don’t know about something, you are unaware of what you need to know. So you can’t go look up something that you don’t even know exists.”

4.4.1.2 Fulfillment/Non-fulfillment of Information Needs

When asked if there had ever been a time when they could not find out something they needed to know about diabetes, approximately two-thirds of the participants responded in the negative. Frequently, they would then list all of the sources that they felt they could turn to when they had a diabetes-related question. I05, for example, responded, “Not that I know of. There’s too many ways. You can go to the library and get a book on diabetes… Ask your doctor and she’ll make sure you know what you need to know. Get on the CB.” I12 responded, “No… I think I have a good support team, between my doctor, nutritionist, and then family and then the Internet.” I10 responded, “No. It’s kind of hard not to find information on the Net.”

One participant who had had diabetes since 2003 pointed out that the availability of diabetes-related information has increased over time:

> I think now it’s easier to get your questions answered and find out things. Before, people would just say, “I don’t know. Look it up.” Or something. Well, it’s not always that easy to look up. I think they’ve made it, the information and informing yourself about diabetes, a lot easier now that it’s become so popular.

About one-third of the participants, however, indicated that they have had difficulties with getting one or more of their diabetes-related questions answered. Often, these information needs pertained to some particular symptoms they were having or had to do with how to manage diabetes. When asked whether there had ever been times when she was unable to get her diabetes-related questions answered, I25 replied, “There sure have been times when I haven’t felt that I got what I wanted from a doctor… The tinnitus… And some of the neuropathies… I mentioned it… It just kind of got ignored…I got no treatment.” I15 replied, Oh yeah, quite a few… The main problem is how to count your carbs, you know? What helps to keep your sugar down? That would be the main

question that I couldn't answer." I31 replied, "I didn't know what I could do to lower [my blood glucose level]… I didn't know at first that I could eat everything, but in moderation… Had I known… I don't think it would've gone so hard with me."

Some participants pointed out that they haven't always had specific questions in mind. I03 pointed out, "Seems like I didn't have a lot of questions… I didn't really seem to have a lot of questions then." I29 pointed out, "It wasn't… that the information wasn't there, that my doctors and everything wouldn't provide that. It was my curiosity didn't go beyond what they were giving me as part of the routine of treatment." I32 responded to this question in this way: "No. It's been the reverse. I didn't know I needed to know until I found something out."

Many participants emphasized that their needs for diabetes-related information are ongoing. I28 recommended that people with diabetes attend diabetes-related classes, emphasizing that the need for these classes is ongoing: "I would recommend them to… anybody with diabetes. I don't care if they've had diabetes for one year or five years, [we] always [need] a refresher course because we as human beings tend to get lax sometimes." I29 explained:

> Because I've had this thing for so long, 25 years… that one shot doesn't do it for me… I don't know how endocrinologists and you guys might work this out but something that was periodic. I don't know whether that means, 5 years 10 years, I don't know what it means but it's not… The one shot idea doesn't work for me… I mean, different things are curiosities at one point than they are at others… I have been tempted, but I've never done it, to be in a support group because those things keep up in front of you, the thing that you've got a problem. And so, you know, I mean, it's more periodic than a one shot educational experience.

Some participants, however, felt that their needs for diabetes-related information are only ongoing if something changes. I16, for example, explained why he doesn't need a refresher course. He stated:

> Unless there is some whole new wealth of information that comes out… If [they] say this, "Oh, we've been doing this wrong all this time. We need to tell them to do this instead." Then maybe I'd go… I've been living it day-to-day, you know, so I don't really need a refresher.

4.4.1.3 Types of Information Deemed Most Important to Know

Participants provided a wide array of responses when asked what they felt were the three most important things someone needs to know in order to be able to

successfully manage their diabetes. Many of these responses had to do with gaining the necessary knowledge to be able to engage in appropriate health behaviors, such as watching what you eat (including what, when, and how much), losing any excess weight, exercising, checking your feet, taking your medicine(s) and following any other recommendations given to you by your doctor, regularly monitoring your blood glucose levels, keeping a log of your food intake and your blood glucose levels, going for regular visits to your doctor to get A1C tests done, and avoiding stress as much as possible. I20 stated, "Tell them about my ER's… Eat right, exercise regularly, and stay out of the emergency room." I25 explained, "Diabetes is like a three-legged stool. One leg is medication, one leg is diet, one leg is exercise. And you have to have them all in balance."

Some participants made recommendations related specifically to information seeking and/or use. I03, for example, recommended, "Try to find out as [much] information as they can, whether it's the doctor or Internet or books or pamphlets, whatever that might be." I12 similarly recommended that people get "information on a regular basis, up-to-date information." A few participants recommended talking with people who have had diabetes for some time. I03 pointed out, "Sometimes it's helpful to talk to other diabetics who might have had it for a while… I think when it's personal, it helps a lot." I31 emphasized the importance of implementing information. She stated, "You need to realize that there is a change in your life and you got to be willing to make that change… You have to be very disciplined. You have to do what is required… Don't slack off." I17 advised, "Never let your guard down, never forget, never forget. Never forget you have diabetes. Not one day, not one."

4.4.1.4 Information Wish List

Throughout both the initial and follow-up interviews, many participants mentioned information-related things that they would like to have, whether for themselves or others. Participants wanted improvements to their glucometers, improved communication with their doctors and other healthcare practitioners, hotlines that they could call with their diabetes-related questions, support groups that were targeted towards people at the same stage as them (e.g., 10 years on insulin) or people with the same complication as them (e.g., blindness or kidney disease), and for diabetes-related

information to be made more widely available to the public so that people might be more educated about signs or symptoms that they should be watching for.

Participants who had vision problems and/or neuropathy wanted glucometers that would be easier for them to use. I04, for example, stated, "I've got neuropathy in my hands and sometimes it's kind of hard… If the buttons were a little bigger, that would be great… The… little stuff across the top… I can't see." Additionally, a few participants mentioned that they would like their glucometers to maintain more than 30 days' worth of data. I04 stated, "I'd like to be able to go back and say, 'Okay, I was active on this day and I went too low. So I need to take less insulin,' that kind of thing. It would be extremely helpful." I34 stated, "I wish I had like a year. You know, where you could have it out over a graph or whatever… I'd like to see it for the entire time I've been doing it… Like an overall."

Some participants pointed out that they wished they could have, or could have had, better communication with their doctors. For some participants, this had to do with their methods of communicating, such as wanting to not get an answering machine when they call the office (I02) or wanting to be able to e-mail their doctor (I14). Other participants, however, wished that their doctors had been clearer with them about the importance of managing diabetes or that they had been willing to do some follow-up appointments with them to make sure that they were on the right track behaviorally. I13, for example, stated, "I would have liked my doctor to be a little more stern with me." I29 similarly wished that his doctor had been more clear with him about how serious diabetes is and what can happen if you don't pay attention to it. He also said that he wished there had been "some type of check-in, maybe until you begin to change your behavior… There's a difference [between] monitoring your A1C and monitoring your behavior and trying to figure out… I do much better if there's a personal kind of involvement." I33 also felt that doctors should have a follow-up appointment with each patient during which they look at the patient's records of their food intake and blood sugar readings over the past seven to ten days. He explained:

> Now I know there's one thing I feel a lot of doctors don't do… It's a lot of work and I know some patients don't want to do it but it's a good reference… That is for probably a week to 10-day period, do a daily food intake, a daily consumption… But I think what's happening is our health care practitioners are

> not sitting down and paying attention to... Like I said, we're treating symptoms, we're not getting to the cause of it... I know… your healthcare practitioners, your doctors, will not want to do that… They just don't have the time.

Several participants mentioned that they would like to have a hotline that they could call whenever they come across a need for diabetes-related information. I27, for example, said, "Now the classes sometimes teach them [sick-day diets], but you don't remember what they said in the classes. It's like when you have that problem, that's when you need to know. And that's where like ask-a-nurse… would really help." I26 stated:

> Nobody wants to tell me the truth about diabetes. How do I find out about diabetes without having a computer? Who can I call? I have these things shifting through my mind from time to time. It seems like you should be able to call a hotline, "Look, I have these questions about diabetes. Can you answer me?"

A few participants who had had diabetes for some time indicated that they would like to have a support group specifically aimed at their needs. I04 explained that she had been on insulin for 10 years and that she would like to participate in a support group for people at a similar stage in order to "see how they handle everything… maybe some of the foods that they cook, some of the exercise they do, vacations they take, how they handle family or a job or going to school." This participant stated, "I'd like to see how they handle it and maybe I can say, 'Hey, you know, I have a… problem with this, what do you suggest or what do you think?' And they can give me some helpful tips." I27 pointed out that libraries "could be great resources in how to deal with complications." She explained that libraries could have clubs that advertise for people based on the specific diabetes-related complication that they have, such as blindness or kidney disease. She suggested that these clubs be run by counselors who have the same complication. She explained:

> I think an information place could have… how do you get a handicap sticker? All kinds of little things and you could have the people who have the illness to be your authorities… Gather the people who've got the experience and make them feel good inside by having them be the speakers of this is how you do this.

This participant emphasized that she would like an information service like this to put out the message that there is hope and that "there's a way through the maze."

Several participants mentioned that they think the public needs to be made more aware of diabetes and the types of symptoms they should be watching out for. I16 stated,

"I could have used more pre-diagnosis information… It would have been helpful if I had had more information on diabetes symptoms to look out for or had bothered to look them up for myself." I06 emphasized:

> I think the one thing I'd want to get the message out to anybody is that this disease can affect anybody… People don't realize how prevalent this is becoming… I think maybe people need to… have some kind of a little education thing in schools or something to kind of prepare people to keep an eye out for it… so it doesn't come as such a shock or surprise when you get it… When you're first diagnosed, it scares the shit out of you. You think you're going to die. And it's just because you don't have any knowledge. So I think maybe some pre-knowledge before it hits might kind of help people at least look out for it or be aware of it.

4.4.2 Information Sources and Information Content Types

Participants described using a wide range of strategies for diabetes-related information seeking. They consulted many different kinds of sources, including people (e.g., doctors, nurses, diabetes educators, dieticians, pharmacists, family members and friends), media types (e.g., brochures/pamphlets, magazines, books, Internet, television), and types of Internet sites (e.g., medical Websites, lifestyle Websites, Wikipedia, blogs, forums). They looked for information covering a wide variety of content types, including diet, exercise, diagnostic tests/procedures, diabetes management, risk factors, and diabetes-related complications.

During the card-sorting exercises, participants rated various sources and types of information as to their usefulness. This section provides an analysis of the numbers of participants that consulted each source type and that looked for each type of content. Participants' usefulness ratings will be discussed later in section 4.5, which covers research question number three.

4.4.2.1 People

Participants consulted a wide range of people in order to fulfill their diabetes-related information needs. Table 18 shows the numbers of participants that reported consulting each type of person. Not surprisingly, all participants consulted doctors. And a majority of participants consulted nurses, diabetes educators, dieticians, pharmacists, and family members and friends. About one-half of the participants had attended diabetes-

related support groups. Relatively few participants consulted librarians and alternative health practitioners.

Table 18: Participants Consulting each Type of Person

	Initial Interview			Follow-up Interview			Changes		
Type of Person	n	%	Rank	n	%	Rank	n	%	Rank
Doctors	32	100.0%	1	32	100.0%	1	0	0.0%	0
Family members who do not have diabetes	27	84.4%	2	25	78.1%	5	-2	-6.3%	-3
Nurses	26	81.3%	3	26	81.3%	2	0	0.0%	1
Diabetes educators	25	78.1%	4	23	71.9%	6	-2	-6.2%	-2
Dieticians	24	75.0%	5	26	81.3%	2	2	6.3%	3
Pharmacists	23	71.9%	6	20	62.5%	8	-3	-9.4%	-2
Friends who do not have diabetes	23	71.9%	6	20	62.5%	8	-3	-9.4%	-2
Friends who have diabetes	22	68.8%	8	26	81.3%	2	4	12.5%	6
Family members who have diabetes	22	68.8%	8	21	65.6%	7	-1	-3.2%	1
Other people with diabetes (other than family members or friends)	21	65.6%	10	20	62.5%	8	-1	-3.1%	2
Support groups	16	50.0%	11	15	46.9%	11	-1	-3.1%	0
Counselors/therapists/ social workers	12	37.5%	12	12	37.5%	12	0	0.0%	0
Health store employees	12	37.5%	12	9	28.1%	13	-3	-9.4%	-1
Librarians	7	21.9%	14	3	9.4%	15	-4	-12.5%	-1
Alternative health practitioners (such as chiropractors or acupuncturists)	3	9.4%	15	6	18.8%	14	3	9.4%	1

During this card-sorting exercise, participants were provided with an "Other" card onto which they could write in and rate the usefulness of additional types of people that they consulted about diabetes. Participants indicated that they had also consulted co-workers (n=2), themselves (n=1), dentists (n=1), grocery store employees (n=1), and strangers (n=1).

4.4.2.2 Media Types

Participants were asked about their use of eight different types of media. Table 19 shows the numbers of participants that reported using each media type for diabetes-related information seeking. The most consulted types of media were brochures/pamphlets, magazines, Internet, and books. The least consulted were journals and various types of mass media, including radio, newspapers, and television.

Table 19: Participants Consulting each Type of Media

	Initial Interview			Follow-up Interview			Changes		
Type of Media	n	%	Rank	n	%	Rank	n	%	Rank
Brochures/Pamphlets	29	90.6%	1	30	93.8%	1	1	3.2%	0
Magazines	26	81.3%	2	24	75.0%	3	-2	-6.3%	-1
Internet	25	78.1%	3	26	81.3%	2	1	3.2%	1
Books	25	78.1%	3	21	65.6%	5	-4	-12.5%	-2
Television	16	50.0%	5	22	68.8%	4	6	18.8%	1
Newspapers	14	43.8%	6	16	50.0%	6	2	6.2%	0
Journals	12	37.5%	7	15	46.9%	7	3	9.4%	0
Radio	9	28.1%	8	8	25.0%	8	-1	-3.1%	0

Again, participants were provided with an "Other" card onto which they could write additional types of media they had consulted for diabetes-related information. Participants indicated that they had also referred to their own journals and logs (n=7), as well as their glucometers (n=2).

4.4.2.3 Internet Site Types

Participants used many different kinds of Websites for their diabetes-related information needs. As of the initial interview, 19 (59%) participants indicated that they had used at least one type of Website or a search engine. This figure rose to 22 (69%) by the time of the follow-up interviews. Table 20 shows the numbers of participants that used each type of Website to look up diabetes-related information. By far, the most commonly used types of Internet sites were Medical Websites and search engines. However, Wikipedia and lifestyle Websites were not far behind. Just under one-third of participants used forums, blogs, and government agency Websites. Relatively few

participants, however, used personal Websites, dictionary/encyclopedia Websites (other than Wikipedia), insurance Websites, and videos/YouTube.

Table 20: Participants Consulting each Type of Internet Site

	Initial Interview			Follow-up Interview			Changes		
Type of Website	n	%	Rank	n	%	Rank	n	%	Rank
Medical Websites	17	53.1%	1	20	62.5%	1	3	9.4%	0
Search Engines	15	46.9%	2	20	62.5%	1	5	15.6%	1
Wikipedia	11	34.4%	3	13	40.6%	3	2	6.2%	0
Lifestyle Websites	11	34.4%	3	11	34.4%	4	0	0.0%	-1
Forums	10	31.3%	5	8	25.0%	6	-2	-6.3%	-1
Blogs	10	31.3%	5	7	21.9%	8	-3	-9.4%	-3
Government agency Websites	9	28.1%	7	8	25.0%	6	-1	-3.1%	1
General news Websites – News articles	8	25.0%	8	10	31.3%	5	2	6.3%	3
Shopping Websites	8	25.0%	8	6	18.8%	9	-2	-6.2%	-1
General news Websites – Opinions	8	25.0%	8	4	12.5%	12	-4	-12.5%	-4
Personal Websites	8	25.0%	8	3	9.4%	13	-5	-15.6%	-5
Dictionary/Encyclopedia Websites (other than Wikipedia)	5	15.6%	12	6	18.8%	9	1	3.2%	3
Insurance Websites	5	15.6%	12	5	15.6%	11	0	0.0%	1
Videos/YouTube	4	12.5%	14	1	3.1%	14	-3	-9.4%	0

4.4.2.4 Content Types

Participants were asked about the usefulness of each of 20 different types of diabetes-related content. Table 21 shows the numbers of participants that reported using each type of content. Nearly all participants had looked for information about diet, diagnostic tests/procedures, diabetes management, risk factors, exercise, diabetes-related complications, signs/symptoms, cooking/recipes, product information, and medication options, side effects, and/or interactions. Relatively fewer participants had looked for information about home remedies and insurance information; however, these counts were still quite high. In fact, over one-half of the participants had looked for information about home remedies.

Table 21: Participants Using each Type of Content

	Initial Interview			Follow-up Interview			Changes		
Type of Content	n	%	Rank	n	%	Rank	n	%	Rank
Diet	31	96.9%	1	32	100.0%	1	1	3.1%	0
Diagnostic tests/procedures	31	96.9%	1	31	96.9%	2	0	0.0%	-1
Diabetes management	30	93.8%	3	31	96.9%	2	1	3.1%	1
Risk factors	30	93.8%	3	27	84.4%	9	-3	-9.4%	-6
Exercise	29	90.6%	5	31	96.9%	2	2	6.3%	3
Diabetes-related complications	29	90.6%	5	30	93.8%	5	1	3.2%	0
Signs/symptoms	29	90.6%	5	29	90.6%	7	0	0.0%	-2
Cooking/recipes	28	87.5%	8	30	93.8%	5	2	6.3%	3
Product information	28	87.5%	8	27	84.4%	9	-1	-3.1%	-1
Medication options, side effects, and/or interactions	28	87.5%	8	25	78.1%	13	-3	-9.4%	-5
Causes	27	84.4%	11	29	90.6%	7	2	6.2%	4
Medication warnings and/or allergies	27	84.4%	11	24	75.0%	15	-3	-9.4%	-4
Treatment options, costs, and/or impacts	25	78.1%	13	26	81.3%	12	1	3.2%	1
Diabetes-related emotions	25	78.1%	13	20	62.5%	17	-5	-15.6%	-4
Stories/personal experiences	24	75.0%	15	27	84.4%	9	3	9.4%	6
Treatment facilities and/or providers	24	75.0%	15	20	62.5%	17	-4	-12.5%	-2
Disease prevention	23	71.9%	17	25	78.1%	13	2	6.2%	4
Vitamins/supplements	23	71.9%	17	23	71.9%	16	0	0.0%	1
Home remedies	19	59.4%	19	16	50.0%	20	-3	-9.4%	-1
Insurance information	18	56.3%	20	20	62.5%	17	2	6.2%	3

4.4.3 Information Seeking

In this section, participants' diabetes-related information-seeking practices will be described The first and second subsections cover some specific types of information seeking, including passive information seeking and some more collaborative types of information seeking such as joint information seeking and proxy information seeking. The third subsection looks at the ways in which participants dealt with conflicting

information when they were looking for diabetes-related information. The fourth subsection discusses some of the changes that took place in participants' information seeking across time. The last subsection outlines participants' plans for future information seeking on the topic of diabetes.

4.4.3.1 Passive Information Seeking

Some participants described specific situations or time periods during which their diabetes-related information seeking consisted solely of passive information seeking. I05, for example, when asked if she looks for information in order to gain and/or maintain hope, responded, "I don't look for it, but when it's there, I take it. I use it." When she was asked if she looks for information following a doctor appointment, this same participant replied, "No. Whatever he wants me to know, he'll tell me." Another participant (I26) had this response when she was asked how useful she has found brochures and pamphlets to be: "I don't care to read… I have a hard time focusing… I drift off into another thought. But when I see something on TV, since I am a TV addict, I pay more attention to what they say."

A few participants seemed to rely solely on serendipity for diabetes-related information, at least during the present phase of their experience with diabetes. I32 explained, "I don't seek [information] out… I have kind of fallen into it… I have not been looking for stuff… It's been like I had to be someplace else and I saw it and I go, 'Oh, that's good!'" I15 similarly stated:

> I don't really go looking for [diabetes-related information]… I mean, I'll get a question every now and again but… Like, say I'm in a store and I see a little brochure that says, "Do you have diabetes?" and it asks questions and stuff. Then I like to start reading it and see if it's something I want to know about.

4.4.3.2 Collaborative Types of Information Seeking

Participants described engaging in some collaborative types of active information seeking, including proxy information seeking and information sharing, joint information seeking, and having information vetted, recommended, and/or clarified for them by another person or information source.

a. Proxy Information Seeking and Information Sharing

Family members and friends often looked for diabetes-related information on participants' behalf and/or saved this type of information for them if they happened upon it. Conversely, participants also described looking for diabetes-related information for family members and friends who were also diabetic and sharing information with them.

Some participants were given newspaper articles, magazines, and/or books by family members and friends. I02's husband saves newspaper articles about diabetes for her and her brother has sent her books and a subscription to a diabetes-related magazine. I34 indicated that her mom has bought diabetes-related books for her. I32 explained:

> My friends give me information. My wife gets it from… clubs where she hangs out, crochets… She talks to these people and these people give her information, real-life information, like "You better watch out for this, you better do this," all these old ladies she deals with. Then she brings home information and I go through it… Sometimes you run across nuggets and stuff.

Several participants who were not Internet users themselves had family members or friends who would use the Internet to look up diabetes-related information for them. I01 explained, "My daughter went on the Internet… to see what she could find out for me." I05 stated, "Anything [my daughter who also has diabetes (I04)] learns new on the computer, she brings that to me… She learned stuff that I would never know."

Not only did participants benefit from others' proxy information seeking, they also looked for information on other people's behalf. I02, for example, described using the Internet to try to find recipes for her diabetic sister. I24 talked about needing to find diabetes-related information for his wife and his brother who both have diabetes. He said, "I need to do some [investigating] for my brother and I'll probably end up doing something for my wife here real quick too 'cause she's having problems with [her medication]." I34 described looking up information for her co-worker: "She's so bad about taking care of herself. I think in order to prove things to her, I will find information and present it to her… to make her feel guilty about not doing what she's supposed to do."

A few participants mentioned having a reciprocal relationship with family members and/or friends in which they share diabetes-related information on an ongoing basis. I28 indicated that he and his diabetic sister share information. I31 described, "I

have friends… When they find something, they're going to shoot it to me and I shoot it to them [through e-mail], so we keep connected to each other… Sometimes we text each other, too." This participant also said that she and a friend of hers "share information that's been told to us by our same doctor."

b. Joint Information Seeking

Some participants have looked for, or plan to look for, diabetes-related information in conjunction with other people. I29's wife attended his diabetes-related classes with him. He explained, "The whole process, the education process, was with my spouse. Now she came along and was very much a part of that." I01, I02, and I20 described using the Internet with other people. I01 stated, "My daughters tell me I should go on the Internet, somewhere on the Internet, so I'll have them help me do that. My daughters are whizzes at that." I02 described saying to her sister (who also has diabetes), "Let's go on the computer and find out some recipes." I20 stated, "My son and I were on the Internet… [because] we thought perhaps… I was stroking out." One participant described attending a series of diabetes-related classes with her boyfriend and her son. She stated, "They were very helpful… [My son] knew then what I could eat without being the food police. You know what I mean?"

c. Vetting, Recommending, and Clarifying

Some participants described consulting information and/or information sources that had been vetted for them or recommended to them by other people or by other sources. I02, for example, described a book that her diabetes educator had given her: "She went through the whole [cookbook] with me and put those smiling faces and wrote notes and… [put] sad faces if they're not [good for you]." I06 took a book to his doctor to get his opinion on it. His doctor told him, "No… Don't listen to this guy. He's just trying to sell books."

Sometimes the sources that were recommended to them or that were upheld as good sources of diabetes-related information were particular Websites. I20 said that her cousin, who is both a nurse and diabetic, turned her on to a particular Website. I12 mentioned that her nutritionist has "kind of drummed that in, that [the American Diabetes Association Website is] a good source to use." I13 explained that she uses WebMD

because “I think it’s very reputable. From other sources that I’ve read in magazines and so forth, they always recommend WebMD as a reputable source.” I04 stated, “You hear about WebMD all the time on television, in the newspaper, on the radio. Even other Websites on the Internet will say, ‘Any more questions, check WebMD.’ So I trust it more than I would any other thing.”

Some participants also mentioned that people clarified information for them. For example, I02 mentioned that the nurses at her doctor’s office help her to understand what the doctor was saying. She explained, “You know, the doctor mentioned this and [the nurse] goes, ‘Oh honey, he meant this and that.’ And then I felt better, ‘Oh, okay. I understand now.’” I20 described her diabetic nurse cousin as “the person in our family everybody goes to because she’s a nurse, so she knows how to interpret what the doctor says.” This participant further explained, “Doctors give you all these big-old, long words about what’s wrong with you. She’s just going to break it down for you, ‘This means this’… For everybody, she’s the go-to person.”

4.4.3.3 Dealing with Conflicting Information

Approximately one-third of the participants in this study indicated that they have not tried to sort out conflicting information when looking for diabetes-related information. For most of these participants, this was because they had not come across any conflicting information. I29 explained, “I don’t do that [sort out conflicting information]… This is a fairly well-researched field. By and large, there’s consensus.” However, some participants simply indicated that they haven’t tried to sort out conflicting information. I03, for example, stated, “Sort out conflicting information. Oh, that was the one that I said I needed to do, but haven’t done.” I32 stated, “Sort out conflicting information. That’s a lot of work. I probably wouldn’t go to that effort.” Quite a few participants, however, described one or more specific strategies that they tend to use or that they would use when they encounter conflicting information about diabetes. These strategies included consulting a healthcare professional, looking into the source(s) of the information, and cross-verifying using multiple online and/or offline sources.

a. Consulting a Healthcare Professional

Turning to one's doctor or other healthcare professional was a common strategy that participants used when they encountered conflicting information. I26 stated, "I go to the professional and ask her. I don't listen to the street thing, you know?... Street knowledge isn't always going to get you there, you know?" I32 similarly stated, "I would go for an expert. I don't want to waste time if I can talk directly to the expert." I19 stated, "I'll ask the doctor his opinion… You can't believe everything you read [on the Internet]… Sometimes it has to be interpreted as to what my condition is and what they're saying and maybe it doesn't really apply to me." Note that this last quote makes the important point that although information may be factually correct, it may not actually be relevant for a particular person given his/her situation.

b. Looking into the Source(s) of the Information

Another strategy participants used to sort out conflicting information was to look into the sources of particular pieces of information. I15, for example, stated, "I would… go by… who would be the… probably the most right in the situation… If one's a nurse and one's a friend… I'd go with the nurse information." I22 pointed out, "I can be reading a book and then I find out the guy doesn't even have diabetes or he's not even a doctor and at the end of the book I'm like, 'No wonder this guy's full of crap.'"

Some participants talked about looking into the sources of diabetes-related information that they've come across on the Internet. I04 described, "A lot of times when you find something [on the Internet], they will have footnotes where they find the information. I'll hit the footnote, pull it up, and see if their footnotes are matching. And I always double-check, triple-check." I34 stated, "I just keep going until I find… I guess [what in] my mind would be the most reputable source and has the best supporting information behind it." I08 said that she just knows which Websites are reliable. When asked how she knows this, she replied, "Experience… I noticed that… [the] doctor says like, 'Well, you can't rely on the Internet.' And I'll tell him, 'I'll correct you on that. If you're inexperienced and stupid, you can't rely on the Internet'."

c. Cross-Verifying

Participants quite commonly mentioned that they compare and weigh information from various sources, including their own knowledge of themselves, when trying to deal with conflicting information that they've encountered. When asked how she goes about sorting out conflicting information, I09 replied, "I look for more information, I weigh… You know, some of it goes with what seems sensible. Some of it is knowing things about myself and weighing that against the other sources of information." This participant further stated, "I've definitely looked for a lot of information on [the effect of exercise on blood sugar levels]. And then I… read my body and think about all the stuff that I'm taking in and what feels safe and healthy." I18 stated, "If I'm having conflicting… If one person tells me and the other person tells me, I would probably… ask a third source… some neutral source… I always have a third person… You can never rely on two people only."

Some participants used multiple Internet sites to cross-verify information. I10, for example, stated, "I do a lot of comparison and everything, just pulling up multiple sites, setting them pretty much side by side, reading through one of them, reading through the other, and then trying to compare bits and pieces." When asked what he does if the information from two different sites conflicts, he replied, "Find a third, fourth, or fifth. See which one is more accurate… And if neither one of them are, go somewhere else." I12 explained that she uses the Internet when she's trying to sort out conflicting information. When asked how she decides what she's going to believe, I12 replied, "Kind of two out of three sort of thinking." One participant (I04) expressed the opinion that conflicting information is actually one of the advantages of the Internet. She explained, "It has different viewpoints. You know, you get one person might say one thing, somebody else will say something different about the same thing, and you can compare the two to see which one makes more sense."

4.4.3.4 Changes in Information Seeking across Time

Some participants described at least one way in which their diabetes-related information-seeking practices have changed over time. Most participants reported engaging in less information seeking as time went on; however, a few participants described increases in their information seeking. Many participants pointed out that

learning about diabetes is a process that unfolds over time. Some participants also talked about transitions in the ways that they look for information or in the specific information sources that they tend to consult.

a. Decreased Information Seeking over Time

Many participants indicated that they have decreased their diabetes-related information seeking over time. I16, for example, said, "How active are you trying to find out about diabetes? Now, I'm kind of neutral on it, as opposed to when I first got diagnosed. Then it was, 'Oh, I want to learn. I want to learn.'" I23 similarly stated, "I feel like I know enough about it that I'm not really searching for more information." I31, when asked how often she tends to look for information about diabetes, replied, "Nearly every day. Not every day. I used to be consumed with it like that." This participant explained that this transition took place as she began to feel better.

Some participants' diabetes-related information seeking decreased specifically in relation to certain topics. I34, for example, stated, "I don't look up recipes and stuff that much anymore… Basically, I don't feel like cooking. Or the things that I've found, I'm not as interested in cooking." I29 indicated that he no longer looks for information about the side-effects of medications. He stated, "I have been taking the same things for so long that the insulin and the Glucophage which I take are just… I don't look for information anymore about those." I14 stated:

> Learn about signs and symptoms of diabetes. Well, I know I have it, so as far as symptoms of diabetes, I'm just going to say sometimes because I don't need to look for symptoms that I have diabetes anymore…. It's a foregone conclusion.

b. Increased Information Seeking over Time

Just a few participants mentioned that their diabetes-related information seeking increased over time. These participants tended to be ones who had been diagnosed within the past year. I13, who had just been diagnosed three weeks prior to her initial interview, stated, "Trying to find out about diabetes, very inactive… But soon to change." I34, who had been diagnosed just less than one year before her initial interview, indicated that she has become more active in terms of looking for diabetes-related information. She explained what drove this transition: "When the denial starts to change a little bit and

then the reality of… the other things that you want to do in your life and how the diabetes affects the other plans that you have."

c. Learning as Process

Many participants talked about how learning about diabetes was a process. I18 explained, "I really didn't know what to like expect at first. I'd say it took me a good six months to understand what diabetes was... I still… drank pop. I thought, 'Oh, it's not that bad. I just got diagnosed.'" This participant further stated, "I'm still learning to deal with it… I feel like I'm in the infantile stage of it, as they say." I06, who had been diagnosed eight months prior to his initial interview, stated, "I'm learning, you know? And it's not that bad as I get going through it. You adjust. You kind of realize how important it is, that your life's at stake and you just kind of accept it." I20 mentioned that there were phases in learning to deal with diabetes. She explained:

> When you first get diagnosed… what you need is motivation. You need to have information about… the can-do's, not what's going to happen to you if you die… Motivational information at the beginning stages are crucial… As you go along, once you are motivated, you… need the information on what to do to keep… yourself healthy.

The learning process was often described by participants as cumulative. When asked whether any particular information has become more useful to her over time, I34 replied, "Not really, I guess. I think it all kind of like ladders… It's like steps of education, you know?" I29 similarly pointed out, "The education has been… very useful and very motivational… It's accumulated. It's not like read a book on diabetes and get it all for the first time… I can read a book… but it fits at different times in my life." When asked if she had had any turning points in her diabetes, I25 replied, "Not that I… It's all kind of been incremental sorts of things and there has been nothing really very big."

A few participants talked about the importance of healthcare providers considering where someone is in the learning process when deciding what type(s) of information to provide to that individual at any particular time. For example, I29 stated, "Any good educationer [*sic*] tries to fit the educational intervention with where the person is. And you've got to be ready to learn, to learn." I20 similarly emphasized:

> When they're first diagnosed, people need encouragement… Some people may need to hear "Look, if you don't straighten up, you're going to lose your eyesight,

> you're going to lose your foot."… But I think the conscious thing would be… [for] the people to be assessed individually, based on where they're at at the moment.

Some participants mentioned that their doctors had successfully followed this advice, providing diabetes-related information to them in a gradual and thoughtful manner. I18, for example, explained, "[My doctor] didn't tell me nothing more than don't have sugar, you know, like watch your sugar, watch your carbs… But once I opened up and he saw that I was ready, we started talking about it." When asked whether he was okay with being provided information gradually like this, he replied:

> I think it's the only way I would have learned. I think he's smart enough to know me… and know that if he would've told me everything right in the beginning I would've… forgot it and then he would never have told me again… He knew, take a step at a time… It just seemed to help more.

I06 similarly described the information provision process followed by his diabetic clinic:

> There's information I wasn't ready for. I think the diabetic clinic kind of eases you into [it], you know, and they have like a step-up system. They started with nutrition… They got me learning about that. Then when I got that, then the next step was how to control it… They did it in stages because there's so much information that you need so rapidly and it's overwhelming and what's going to happen is you're going to have information overload and you're not going to retain most of what you learned. By doing it meticulously and methodically, then I'm able to learn and retain it… So it's much more beneficial that way… I think they don't want to overwhelm you all at once. They kind of… like spoon-feed you this information… As I go in, they tell me more and more.

d. Changes in Information-Seeking Methods and/or Sources Consulted

Some participants mentioned changes that took place in the ways they looked for information or in the specific information sources they consulted. I10 described how being diagnosed with diabetes changed how he went about looking for diabetes-related information. He explained, "Whereas before [being diagnosed] I was searching for 'insatiable thirst', now I was diabetic searching… [It] shifted direction and narrowed [my search]."

A few participants talked about changes in the information sources they use when looking for diabetes-related information. I16, for example, transitioned from asking his questions at the diabetes-related classes he had been attending to asking his doctor. I12 described a shift from relying on "books with food counts" to nutritional labels. I24

explained, “Books were more handy upfront to understand the disease and the effects…Now, it’s mostly Internet.” I09 stated, “I definitely have my go-to places now… I have all these like diabetes Websites… in my Favorites… I have definitely boiled it down.”

The results of the card-sorting exercises (see Table 18, Table 19, Table 20, and Table 21 above) also reveal some changes that took place in participants’ diabetes-related information seeking between their initial interviews and their follow-up interviews. The numbers of participants who consulted friends who have diabetes (n=22 → n=26) and alternative health practitioners (n=3 → n=6) slightly increased, while the numbers of participants who consulted librarians (n=7 → n=3), pharmacists (n=23 → n=20), friends who don’t have diabetes (n=23 → n=20), and health store employees (n=12 → n=9) slightly decreased. Participants also seemed to become less likely to use books (n=25 → n=21) and more likely to use television (n=16 → n=22). In contrast, they seemed to transition from using less formal Websites such as blogs (n=10 → n=7), videos/YouTube (n=4 → n=1), general news Websites – opinions (n=8 → n=4), and personal Websites (n=8 → n=3) to using search engines (n=15 → n=20) and medical Websites (n=17 → n=20). As far as content types, the number of participants who reported looking up stories/personal experiences (n=24 → n=27) slightly increased, while the numbers of participants who looked up information about diabetes-related emotions (n=25 → n=20), treatment facilities and/or providers (n=24 → n=20), risk factors (n=30 → n=27), medication options, side effects, and/or interactions (n=28 → n=25), medication warnings and/or allergies (n=27 → n=24), and home remedies (n=19 → n=16) slightly decreased. However, it should be noted that these figures do not provide any information as to how useful participants deemed these various sources and types of information. This topic will be covered in section 4.5, which will discuss the results pertaining to this study’s third research question about participants’ perceptions regarding the usefulness of various sources and types of information.

4.4.3.5 Information Seeking Plans

While some participants had no specific plans to look for diabetes-related information, others were able to provide detailed accounts of the information they needed and how they planned to go about looking for this information. I03, for example, planned

to try to sort out conflicting information about what is an acceptable A1C level. She planned to consult her doctor, the Internet, and books to try to sort this out; however, she indicated that if these conflict, she will go with what her doctor says. I12 said that she was going to look up information about her raised testosterone levels. She indicated that she was going to use the Internet, including both Wikipedia and Google. I17 indicated that she was going to ask her doctor for a list of other medications that would help with lowering her A1C but not have the side effect of weight gain. She indicated that she would also be "paying attention and investigating that from my sources." I26, who was initially diagnosed with diabetes in 2003 and who passed away just prior to her follow-up interview, said that she was going to take her glucometer to her doctor and ask her to show her how to use it. I29's endocrinologist had recommended to him that he take niacin to help raise his good cholesterol. This participant planned to research niacin by talking to his cardiologist and by using the Web, probably Google and WebMD. He indicated that if the side effects of niacin seem severe, he would do further research using maybe a government Website or the Website of the company that manufactures the niacin. Several participants planned to ask their doctors whether they could switch from insulin to pills (I12, I15, I28, and I35). Interestingly, several participants (I09, I11, and I33) said that they were planning to look into becoming Certified Diabetes Educators.

Although some participants had specific information needs, they had no plans to try to look for information. When I26 was directly asked whether she had any plans to try to find out more about diabetes, she responded, "I just mostly want to find out about what to eat, how often to eat, what I cannot eat, which is an absolute no-no." However, she did not mention any plans for filling this information need. I14 stated:

> The diabetic neuropathy, it's kind of interesting how it affects my nerves and things… but I don't have any plans to [research the neuropathy], but that is still kind of a question mark… because of the cramping, the… numbness in the toes and the tops of my feet… that compels me to look into the diabetic neuropathy because that's nerve damage.

Some participants who had no specific information needs said that they would simply continue to monitor their usual sources of diabetes-related information. I06 stated that he was just going to continue to go to his diabetes care clinic. He stated, "That's where I get all my information, that's where everything comes from." I04 indicated that

she had no specific plans to look up anything about diabetes. She stated, "There's really nothing more that I want to know or need to know… I know what's there and I keep an eye up on tests and upcoming research and stuff like that." This participant said that she would use the Internet, particularly WebMD, diabetesresearch.org, and magazines, to keep up to date. I16 said that he had no plans to look for information but that he was thinking that he would "maybe try and get some automated search for diabetes information," such as a Google Alert, on topics like new medications and potential cures.

4.4.4 Information Use/Non-Use

Participants described several different ways in which they use diabetes-related information; however, they also mentioned some situations in which they are/were not making use of the information they have. These uses and non-uses of diabetes-related information will be described in the subsections below. The last subsection will then discuss some of the changes that participants mentioned as far as their ability or willingness to make use of diabetes-related information.

4.4.4.1 Information Uses

The most commonly mentioned uses of diabetes-related information were ones having to do with preparing for doctor visits and engaging, or preparing to engage, in various health behaviors, such as healthy cooking and exercising.

Several participants mentioned that they bring information to their doctor appointments, just in case it's needed. I04, for example, described taking her folders of information with her to her doctor appointments. I25 explained that she has organized all of her blood test results into a notebook which she takes to her medical appointments. I34 (one of the younger participants at 40 years old) described preparing for her doctor appointments using her computer. She stated, "I've been taking the numbers [from my glucometer] and typing them up in a spreadsheet and then putting them in CareWeb… so that the pharmacists and the doctor can see what they are."

Many participants used diabetes-related information in order to engage, or prepare to engage, in various types of health behaviors such as sticking to an appropriate diet and exercising. I12 indicated that information empowers her to make "the decisions I'm making as far as how I'm taking care of my diabetes." I10 stated, "[My diabetes-related

cookbooks] pretty much sit right next to me because I'm usually looking through them all week long for next week's menu." I35 pointed out, "I used the information from the classes I was sent to to get a first step, a fresh start on what I should be or shouldn't be doing." Describing a diabetic friend that gave her a lot of support when she was first diagnosed, I31 stated, "She's still on Metformin… because she doesn't exercise like she should. She didn't take the information as seriously. The information she gave me, she's not doing it all… But I did it to the letter."

4.4.4.2 Information Non-Use

Participants mentioned several situations in which they did not use diabetes-related information that they had. Often, this non-use was driven by participants' failure to understand the seriousness of the situation, their attitudes toward the necessary health behaviors, and/or their perceptions that the information they had was irrelevant to them or unactionable for some reason or another.

Some participants failed to recognize the seriousness of the situation until it was too late. I04, who had been diagnosed with diabetes nearly 30 years earlier, stated, "Had I known at 16 that by the time I was 44 I'd be mostly blind, I would have changed a lot… [I would have changed] my eating habits, would've gotten more exercise… cut down on my portions." One participant who ended up with polyneuropathy (I20) stated, "I wish I had done what I will tell everyone else – eat right, exercise regularly, stay out of the emergency room. My cousin [who is a nurse and has diabetes] tried to tell me that, but I didn't listen." Another participant (I29) who developed retinopathy and erectile dysfunction described incognizance within the context of information use. He stated:

> I didn't know what [the] questions were… They were more about not the knowledge base, but the behavior base. Why is it that people, when they know something, don't do anything about it?... For me, that was the critical issue. I didn't even know enough to ask [my doctor] that. I didn't know that I wouldn't embrace this.

Participants quite frequently mentioned that, although they knew what they should be doing as far as health behaviors, they did not do it. I35 stated, "A lot of stuff I did know, I just didn't do it or really make a conscious effort." I21 similarly stated, "I already knew all of what I needed and didn't need to do, and I did it anyway" I34 stated, "Learn what I can do to improve my health… probably often I do that. Whether I actually

follow the advice or not… Not as often as I look it up." When asked whether she felt optimistic about her experience with diabetes, this participant replied:

> Well, as far as knowing that I can fix it or make it a little bit better, I feel somewhat optimistic. And, in a way, I don't feel optimistic because I don't know if I have the ambition to do it, I guess… I don't like to give myself credit for future acts.

Many participants qualified their ratings as to the usefulness of information about diet and/or exercise with a statement to the effect that they are not engaging in one or more of the health behaviors they should be. I05, for example, responded, "Not [useful] at all… [I] walk from the couch to the refrigerator." I08 responded, "Exercise. God, what do I say? I hate exercise… Diet, I'm neutral. I'm not doing what I'm supposed to do. I'm not compliant." I06 replied, "Not really interested in that [exercise]. I mean, that sounds way too healthy. [laughter] Scares me. I'm tired just because you mentioned the word." I35 responded, "Oh, the information [about exercise] is very helpful. I just haven't did it." I19 replied, "Exercise, neutral. I should, but I don't." I26 responded, "[My doctor] is giving me… information about [exercise]… My doctor has told me … that I should exercise more. So that was useful… It's not like I take her advice."

Several participants mentioned that they didn't use the diabetes-related information that they were given because they felt that it was irrelevant to them or not actionable. I29 pointed out, "Intention to take care of yourself is different than taking care of yourself… And so somehow moving beyond education into, 'Okay, this is for me. I've got to do something about it and here's what I'm going to do.'" This participant further described, "For me, a case study… that comes to be an anecdote… [is] interesting and powerful in its own way. But part of the denial process [is] 'Well, yeah, that's good for her or him, but that's not me.'" I05, who was a long-distance truck driver at the time of her diagnosis, described the pamphlets she was given at the time as "more stuff than I wanted to do." She explained, "When you're on the road driving a truck, how can you eat six little meals a day? You can't… You have to eat when it's possible."

4.4.4.3 Changes in Ability or Willingness to Act on Diabetes-Related Information

Some participants mentioned that their ability and/or willingness to act on diabetes-related information changed over time. Nearly all of these participants described

a transition from denying or ignoring their diabetes to taking it on. This transition tended to be fueled by the onset of one or more diabetes-related complications, a change in one's life circumstances, and/or a change in one's priorities and general outlook on life.

For some participants, the initial onset of symptoms or diabetes-related complications spurred them to begin making use of diabetes-related information. For example, I29 recounted, "My first years being a diabetic… I wasn't rigorous… The rigor came over time with little bits and pieces of diagnosis… This level of consciousness began to creep into me the older I got with the symptoms." I14 similarly described:

> I had what I thought were more important things to do than to deal with this… I've got people to see and places to go. I can't stop and check my sugar or look at the ingredients for carbohydrates and things. But I learned as my sugar was out of control that you have to pay attention to this or else.

A change in life circumstances enabled some participants to begin making more use of diabetes-related information in their lives. I29 explained:

> Having more time for self-care was an important kind of transition for me… And so kind of finally understanding that if I wanted to live and not only live, but have a quality of life which I could really embrace, I needed to take care of myself. So that transition, which was in part fueled by education and in part fueled by circumstance and in part by my own personality, just began that quick.

Some participants experienced a change in their priorities and their general outlook on life. I32 described an "awakening" that he had. He had gone to the hospital with a blood sugar level of 590 and during his 4-day hospital stay, he realized, "I was not aware totally of how much I should have known and then I decided to learn it, and then I learned it… I had never analyzed the issue." He further explained, "I was taking the skills I use at work for my own benefit. And that's when I learned that I had to take control and learn more and do this. It was a complete reversal." He went on to describe how he applied a method that he used in his work, APIC, which stands for Analyze, Plan, Implement, and Control. He explained that during his days in the hospital, he worked on analyzing and planning and that he is now working on the implementation and control phases. He described this transition in his life this way: "I had an awakening… A Jesus moment or something… I really at that point analyzed it and understood it." I20 similarly explained:

> It's a lot of things that are just a perspective in life that makes you come out of your slump… You all got a certain amount of time here. How are you going to spend it? You going to spend it wallowing in your pain and bawling, or are you going to just get up and turn around and figure out what you're going to do about this thing?

4.4.5 Summary: Information Needs and Information Seeking and Use Practices

The findings in relation to the first part of this research question – information needs – reveal that participants were not always aware of their needs for information at the time when the information would have been the most useful to them. Incognizance, which often resulted from a failure to recognize relevance at the most opportune time, sometimes led to catastrophic consequences for participants. Although the majority of participants indicated that they've never been unable to find out something they needed to know about diabetes, some participants pointed out that they haven't always known what it was they needed to know. Thus, the finding that most participants have always been able to find out what they needed to know about diabetes may actually be due to incognizance.

In regard to the second part of this research question – information seeking – participants described a wide array of solitary and social practices they use, as well as an assortment of sources they consult, when looking for diabetes-related information. Information-seeking practices included both passive and active strategies. While some participants relied on serendipitously encountering the diabetes-related information they needed, others were quite active in their information-seeking processes. Collaborative information-seeking practices, including proxy information seeking, information sharing, and joint information seeking were mentioned by many participants. Participants dealt with conflicting information using several different strategies, including consulting their doctor, checking into the source(s) behind information, and cross-verifying. Overall, participants' information seeking tended to decline in frequency as they had had diabetes for longer. Learning how to manage diabetes was perceived to be a process that unfolded across time.

The findings in regard to the third part of this research question – information use – reveal that participants primarily used information to engage in health behaviors. However, the findings also reveal that participants did not always act on information that

they had. This non-use of information was often driven by participants' failure to understand the seriousness of their situation, their attitudes toward the health behaviors necessary to manage diabetes, and/or a perception that the information they had was either irrelevant to them or unactionable for some reason. Some participants described a change that took place over time in their ability and/or willingness to act on diabetes-related information. This transition was often spurred on by the development of diabetes-related complications or by changes in one's life circumstances and/or one's priorities and general outlook on life.

4.5 Perceptions of Usefulness

In this section, results will be presented from the third research question for this study: "What sources and types of information do people with a chronic serious health condition find useful and how do these perceptions change as their knowledge about, and their experience with, their health condition change across time?" First, participants' descriptions of what it is that makes diabetes-related information useful will be explored. Next, quantitative and qualitative results will be presented regarding participants' opinions about the usefulness of different sources and types of diabetes-related information. Third, the changes that took place over time in participants' perceptions regarding the usefulness of diabetes-related information will be discussed. Last, the important roles that information plays in participants' diabetes-related experiences will be explored.

4.5.1 What Makes Information Useful?

During the follow-up interview, participants were asked to describe what it is that makes diabetes-related information useful for them. The major characteristics that participants mentioned as indicators of usefulness were personally relevant; novel (to them); factual; up-to-date; from a reputable, qualified source; accessible/usable; and instrumental in helping them to achieve some goal.

4.5.1.1 Personal Relevance

Quite a few participants emphasized that for information to be useful for them, it had to be something that is personally relevant to them. I12, for example, stated that information is useful for her "if it applies to me and my experience." I31 said that

information is useful "because it's something I need to know… Anything that deals with me, I want to know more and more and more about it." I29 stressed that personal narratives are useful to him, but only if they're relevant to his situation. He explained, "[If] I can… see myself in there. I'm an old man… I've had diabetes for X many years. So I'm going to pay attention to that man who has… those characteristics… It helps me relate to the information."

4.5.1.2 Novelty

Participants commonly mentioned that information is only useful to them if it's something they didn't already know. For I25, for example, information is useful "if it addresses a concern that I have, if it's something that I don't know." I22 stated, "It's got to be something new and interesting. It can't be the same old crap."

4.5.1.3 Factualness

Another requirement for usefulness mentioned by participants was factualness. I14, for example, stressed, "I think the most important characteristic of the information is that it's, let's say, factual or valid as opposed to hearsay or opinion." I20 similarly responded that information is useful if it is factual and honest.

4.5.1.4 Currency

One additional characteristic of useful information described by participants was currency. Participants emphasized that information has to be up-to-date for it to be useful for them. I13, for example, stated, "I want it scientific-based. I want it to be with scientific rationale for it… I want to be sure that the science is up-to-date." I17 indicated that information is useful for her "If it's new, if it's like unproven, like 'Oh, that's a good idea.'"

4.5.1.5 Reputability/Qualifications of Source

Some participants' responses had to do with the reputation and/or qualifications of the source of the information. I13 emphasized that in order to be useful, information must be from a reputable source. I34 similarly emphasized that the usefulness of information is dependent on whether it comes from "something that I would consider a good source or like an appropriate source." I09 found information from Gretchen Becker

an author and patient-expert in diabetes, to be particularly useful because she has both knowledge-based expertise and experience-based expertise. This participant described:

> She keeps up with the medical advances. I think she was a science writer before she was diagnosed. So she was in a good position to become this sort of diabetes expert… Because she's been through it, she can talk about the ways that a diabetic might interpret something, react to something, how to cope with things. So that kind of combination of things is… That's the kind of information that I find useful.

I33 also valued the expertise of other people with diabetes. He stated, "The best, useful resource is supportive groups… I think you have empathy for others, and you can… share what others are doing. And they can glean off of you and you can kind of glean off of them."

4.5.1.6 Accessibility/Usability

The accessibility and usability of information was also a consideration in participants' determinations of whether they perceived information to be useful. I03, for example, stated, "It's got to be kind of specific and… organized in a way which I can use it better… [as] opposed to something that talks about different things all together… and it's hard to find what you want." I14 stated, "It's useful to have access to [information on carb counting] on my phone or my pump." I34 said that information is useful "if it can actually… answer your question… in the first paragraph."

Sometimes participants found particular information or information from particular sources to be of limited use due to its unnecessary restrictiveness. I31, for example, complained about her dietician: "She really didn't know to tell you how to improvise… She just wanted you to stay in this little narrow box… It was like, 'I have these books and this is what we're going to go buy'." This same participant explained that the information on the Internet had a similar problem with over-restrictiveness: "The Internet, a lot of the stuff is just... It's so tight, I would say…" She went on to explain that the information on the Internet also put unnecessary limits on what she could eat. She eventually learned based on her own experience that she can eat anything she wants, but in moderation. She pointed out that people can get less "tight" information from other people who have diabetes: "When you talk to… people that have been type 2 for a long time, they can give you some tips."

I34 similarly complained about the limited usefulness of books due to their restrictive information: “It’s hard to follow some of the guidelines… their expectations of what you're really going to follow are a little bit unrealistic… They want you to eat… at… certain times and real life doesn’t necessarily fall into that mold.” I20 described transitioning from focusing on what she couldn’t do as a diabetic to what she could do:

> When you’re first a diabetic, you’re just bummed out ‘cause they said diabetes and you say, “Nah, I can’t do this, I can’t do that. I can’t eat that, I can’t eat that”… After a while, when you realize there’s stuff you can do and there’s a way you can do it, then you just look up for information that will help you with your lifestyle.

4.5.1.7 Instrumentality

The usefulness of information was also judged by participants according to whether it was instrumental in helping them to achieve some goal. I02, for example, explained that information is useful if it helps her to make better choices with regard to her diet. I08 said information is useful if “I can either help myself… or I can help someone else.” I05 indicated that information was useful for her if it provided “hope that it will help… hope that it might change things for me.” I16 stated, “It has to be relevant to my day-to-day controlling of diabetes to be useful to me.” I20 provided a specific example of some information she found to be useful. She had attended a Webinar about high cholesterol and she found the information from this Webinar to be useful because it told her “what power I have to control the good aspects of that whole deal.”

4.5.2 Perceptions of Usefulness: Types of People

During the first card-sorting exercise, participants were asked to rate how useful different types of people (e.g., doctors, nurses, diabetes educators, family members) had been in helping them to find out what they needed to know about diabetes. Participants were asked to first go through the deck of cards, pulling out any which they had not consulted for diabetes-related information. They were then asked to go through the remaining cards, placing each card into one of the following piles: very useful, somewhat useful, neutral, somewhat not useful, or not at all useful. The first subsection below presents the results from this card-sorting exercise, while the second subsection presents some of the participants’ verbal comments pertaining to their usefulness judgments about

the various types of people they have consulted in regard to their diabetes-related information needs.

4.5.2.1 Results from Card-Sorting Exercise

Table 22 summarizes the 32 participants' ratings as to how useful they found each type of person in helping them to find out what they needed to know about diabetes. Participants' choices for these ratings were: Very useful (5); Somewhat useful (4); neutral (3); Somewhat not useful (2); or Not at all useful (1). This table shows that, overall, healthcare professionals, including doctors, nurses, dieticians, and diabetes educators, were rated as the most useful types of people at both the initial interviews and the follow-up interviews. In contrast, family members and friends who do not have diabetes were rated as the least useful.

Table 22: Participants' Ratings of the Usefulness of Different Types of People

Type of Person	Initial Interview					Follow-up Interview					Change		
	n	M	SD	m	ř	n	M	SD	m	ř	n	M	ř
Doctors	32	4.42	0.83	5.0	1	32	4.41	0.90	5.0	2	0	-0.01	-1
Nurses	26	4.35	0.85	5.0	2	26	4.33	0.73	4.0	4	0	-0.02	-2
Dieticians	24	4.29	0.91	4.5	3	26	4.37	0.82	5.0	3	2	0.08	0
Librarians	7	4.29	0.49	4.0	3	3	3.67	1.53	4.0	12	-4	-0.62	-9
Pharmacists	23	4.17	0.94	4.0	5	20	3.98	0.98	4.0	8	-3	-0.19	-3
Diabetes educators	25	4.16	1.37	5.0	6	23	4.59	0.91	5.0	1	-2	0.43	5
Family members who have diabetes	22	4.05	1.17	4.5	7	21	4.33	1.11	5.0	4	-1	0.28	3
Counselors/ Therapists/ Social Workers	12	3.92	1.08	4.0	8	12	3.83	1.27	4.0	9	0	-0.09	-1
Support groups	16	3.88	1.36	4.0	9	15	4.17	1.28	5.0	6	-1	0.29	3
Other people with diabetes (other than family members or friends)	21	3.86	1.2	4.0	10	20	3.65	1.14	4.0	13	-1	-0.21	-3
Friends who have diabetes	22	3.77	1.31	4.0	11	26	3.75	1.50	4.0	11	4	-0.02	0

Type of Person	Initial Interview					Follow-up Interview					Change		
	n	M	SD	m	ř	n	M	SD	m	ř	n	M	ř
Alternative health practitioners (such as chiropractors or acupunct-urists)	3	3.67	2.31	5.0	12	6	3.83	1.17	4.0	9	3	0.16	3
Health store employees	12	3.17	1.47	3.5	13	9	4.06	1.24	4.0	7	-3	0.89	6
Family members who do not have diabetes	27	2.85	1.43	3.0	14	25	2.72	1.51	3.0	14	-2	-0.13	0
Friends who do not have diabetes	23	2.65	1.5	3.0	15	20	2.65	1.18	3.0	15	-3	0.00	0
All People		**3.85**	**1.29**	**4.0**			**3.92**	**1.26**	**4.00**			**0.07**	

Note. n = number of participants who indicated that this type of person has helped them to find out what they need to know about diabetes. *M* = mean. *SD* = standard deviation. *m* = median. *ř* = rank (based on means).

Analyzing participants' responses to this card-sorting exercise in relation to their responses on the background and health condition questionnaires that were administered at their initial interviews yielded several interesting statistically significant correlations, as outlined in the subsections below. Please note that, due to space considerations, not all variables are shown in the tables included in the following subsections – only the rows and columns that contain at least one statistically significant correlation are shown.

a. Health/Physical Condition

In general, participants who provided higher ratings as to the usefulness of people in helping them to learn about diabetes indicated that they felt that they were doing better physically. Table 23 below shows the results of correlation analyses that were run based on participants' usefulness ratings for the different types of people and their ratings on the health/physical condition factors on both the background questionnaires and the health condition questionnaires. Statistically significant correlations are shown in bold font. The first column in this table shows that participants who indicated that doctors and diabetes educators were more useful to them tended to report having lower A1C's. The second column shows the similar finding that participants who provided higher ratings

regarding the usefulness of support groups, other people with diabetes (other than family members or friends), and all people (i.e., average rating across all types of people listed) rated their general health higher. The third and fourth columns show that participants who indicated that they feel that pain has less of an impact on their ability to do what they need to do and who indicated that they feel that their diabetes-related symptoms are less severe rated the usefulness of family members who do not have diabetes and all people higher. The fifth column shows that participants who indicated that they felt that more positive changes had occurred in their diabetes-related symptoms over the past few months provided higher usefulness ratings in regard to pharmacists, friends who have diabetes, other people who have diabetes (other than family members or friends), family members who do not have diabetes, and all people. The last column shows that, in contrast, the longer participants had had diabetes, the less useful they rated their family members who also have diabetes.

Table 23: Correlates between Participants' Ratings of the Usefulness of Different Types of People and their Ratings pertaining to various Health/Physical Condition Factors

	Health/Physical Condition Factors					
	(1)	(2)	(3)	(4)	(5)	(6)
Usefulness Ratings: Type of Person	A1C	General Health	Impact of Pain on Ability to do what one needs to do	Severity of Diabetes-Related Symptoms	Change in Diabetes-Related Symptoms	Number of Months with Diabetes
Doctors	***r* = -.39** ***p* = .038** ***n* = 28**	*r* = .19 *p* = .288 *n* = 32	*r* = .29 *p* = .110 *n* = 32	*r* = .26 *p* = .148 *n* = 32	*r* = .31 *p* = .094 *n* = 31	*r* = .11 *p* = .545 *n* = 32
Pharmacists	*r* = -.17 *p* = .608 *n* = 22	*r* = .35 *p* = .100 *n* = 23	*r* = .18 *p* = .408 *n* = 23	*r* = .22 *p* = .325 *n* = 23	***r* = .65** ***p* = .001** ***n* = 22**	*r* = -.68 *p* = .756 *n* = 23
Diabetes educators	***r* = -.54** ***p* = .009** ***n* = 23**	*r* = .26 *p* = .207 *n* = 25	*r* = .10 *p* = .621 *n* = 25	*r* = .38 *p* = .061 *n* = 25	*r* = .07 *p* = .749 *n* = 24	*r* = -.03 *p* = .892 *n* = 25
Friends who have diabetes	*r* = .08 *p* = .720 *n* = 21	*r* = .29 *p* = .196 *n* = 22	*r* = .22 *p* = .316 *n* = 22	*r* = .31 *p* = .168 *n* = 22	***r* = .57** ***p* = .007** ***n* = 21**	*r* = -.27 *p* = .219 *n* = 22
Family members who have diabetes	*r* = .17 *p* = .480 *n* = 19	*r* = .36 *p* = .099 *n* = 22	*r* = .16 *p* = .483 *n* = 22	*r* = .34 *p* = .120 *n* = 22	*r* = .22 *p* = .346 *n* = 21	***r* = -.53** ***p* = .011** ***n* = 22**

Usefulness Ratings: Type of Person	Health/Physical Condition Factors					
	(1) A1C	(2) General Health	(3) Impact of Pain on Ability to do what one needs to do	(4) Severity of Diabetes-Related Symptoms	(5) Change in Diabetes-Related Symptoms	(6) Number of Months with Diabetes
Support groups	*r* = -.48 *p* = .068 *n* = 15	***r* = .53** ***p* = .035** ***n* = 16**	*r* = .45 *p* = .079 *n* = 16	*r* = .22 *p* = .405 *n* = 16	*r* = -.20 *p* = .472 *n* = 15	*r* = .05 *p* = .853 *n* = 16
Other people with diabetes (other than family members or friends)	*r* = .06 *p* = .818 *n* = 20	***r* = .61** ***p* = .003** ***n* = 21**	*r* = .21 *p* = .368 *n* = 21	***r* = .45** ***p* = .043** ***n* = 21**	***r* = .64** ***p* = .002** ***n* = 20**	*r* = -.42 *p* = .060 *n* = 21
Family members who do not have diabetes	*r* = .05 *p* = .806 *n* = 25	*r* = .34 *p* = .081 *n* = 27	***r* = .47** ***p* = .013** ***n* = 27**	*r* = .15 *p* = .443 *n* = 27	***r* = .43** ***p* = .030** ***n* = 26**	*r* = -.06 *p* = .756 *n* = 27
All people	*r* = -.28 *p* = .14 *n* = 28	***r* = .45** ***p* = .010** ***n* = 32**	***r* = .40** ***p* = .022** ***n* = 32**	***r* = .46** ***p* = .008** ***n* = 32**	***r* = .40** ***p* = .028** ***n* = 31**	*r* = -.10 *p* = .592 *n* = 32

Note. Statistically significant correlations ($p < .05$) are shown in bold font.

b. Cognitive and Information Behavior Measures

Table 24 shows the results from correlation analyses that were run based on participants' usefulness ratings regarding the different types of people and their ratings on the cognitive and information behavior measures from the health condition questionnaires. Participants who rated the usefulness of support groups higher provided higher ratings regarding the importance of learning more about diabetes (see column (1)) and of participating in decisions related to their healthcare (see column (2)).

Table 24: Correlates between Participants' Ratings of the Usefulness of Different Types of People and their Ratings pertaining to various Cognitive/Information Behavior Measures

Usefulness Ratings: Type of Person	Cognitive/Information Behavior Measures	
	(1) Importance of learning more about diabetes	(2) Importance of participating in making decisions related to one's healthcare
Support groups	***r* = .55** ***p* = .026** ***n* = 16**	***r* = .56** ***p* = .023** ***n* = 16**

Note. Statistically significant correlations ($p < .05$) are shown in bold font.

c. Perceptions about Availability of Information

Table 25 shows results from correlation analyses that were performed using participants' ratings regarding the usefulness of different types of people and their ratings on the health condition questionnaire measures that pertained to their perceptions about the availability of diabetes-related information. The first column shows that participants who rated their doctors and diabetes educators as more useful indicated that they felt more satisfied with getting their diabetes-related questions answered. The second column shows that participants who rated support groups as more useful indicated that they felt that it was easier for them to get hold of diabetes-related information that they needed.

Table 25: Correlates between Participants' Ratings of the Usefulness of Different Types of People and their Ratings pertaining to their Perceptions about the Availability of Information

	Perceptions about Availability of Diabetes-Related Information	
Usefulness Ratings: Type of Person	(1) Satisfaction with getting diabetes-related questions answered	(2) Ease of getting hold of diabetes-related information they need
Doctors	***r* = .57** ***p* = .001** ***n* = 32**	*r* = .08 *p* = .679 *n* = 32
Diabetes educators	***r* = .46** ***p* = .022** ***n* = 25**	*r* = .03 *p* = .884 *n* = 25
Support groups	*r* = .18 *p* = .508 *n* = 16	***r* = .54** ***p* = .029** ***n* = 16**

Note. Statistically significant correlations ($p < .05$) are shown in bold font.

d. Affective Measures related to Diabetes Experience

Table 26 shows the results of correlation analyses that were performed based on participants' ratings of the usefulness of different types of people and their ratings on the affective measures on the health condition questionnaires. Column (1) shows that participants who rated doctors, pharmacists, diabetes educators, support groups, and all people (i.e., average rating across all types of people listed) as more useful indicated that they felt less uncertain about their experience with diabetes. Column (2) similarly shows that participants who rated doctors, diabetes educators, and support groups as more useful indicated that they felt more clear (less confused) about their experience with diabetes. The last column shows that participants who rated counselors/therapists/social workers as more useful indicated that they felt more in control of their experience with diabetes.

Table 26: Correlates between Participants' Ratings of the Usefulness of Different Types of People and their Ratings pertaining to various Affective Measures

Usefulness Ratings: Type of Person	Affective Measures (1) Feel certain about one's experience with diabetes	(2) Feel clear about one's experience with diabetes	(3) Feel in control of one's experience with diabetes
Doctors	***r* = .59** ***p* = .000** ***n* = 32**	***r* = .48** ***p* = .006** ***n* = 32**	*r* = .34 *p* = .057 *n* = 32
Pharmacists	***r* = .57** ***p* = .004** ***n* = 23**	*r* = .12 *p* = .602 *n* = 23	*r* = .11 *p* = .618 *n* = 23
Diabetes educators	***r* = .52** ***p* = .008** ***n* = 25**	***r* = .58** ***p* = .002** ***n* = 25**	*r* = .35 *p* = .092 *n* = 25
Support groups	***r* = .82** ***p* = .000** ***n* = 16**	***r* = .52** ***p* = .041** ***n* = 16**	*r* = .30 *p* = .255 *n* = 16
Counselors/ Therapists/ Social workers	*r* = -.16 *p* = .619 *n* = 12	*r* = -.03 *p* = .929 *n* = 12	***r* = .81** ***p* = .001** ***n* = 12**
All people	***r* = .48** ***p* = .006** ***n* = 32**	*r* = .16 *p* = .363 *n* = 32	*r* = .25 *p* = .168 *n* = 32

Note. Statistically significant correlations ($p < .05$) are shown in bold font.

e. Changes across Time

Figure 23 shows the changes that took place in participants' ratings of the usefulness of different types of people between the time of their initial interviews and the time of their follow-up interviews. The figures in parentheses within the data labels indicate the number of participants who indicated that they had consulted this type of person and, thus, provided a usefulness rating. Although none of these changes reached statistical significance, there are some interesting patterns. For example, doctors, nurses, and dieticians were rated as very useful at both interviews, while participants' perceptions about the usefulness of diabetes educators, family members who have diabetes, support groups, and health store employees increased dramatically. However, running paired-samples t-tests revealed that none of the changes in participants' usefulness ratings reached statistical significance.

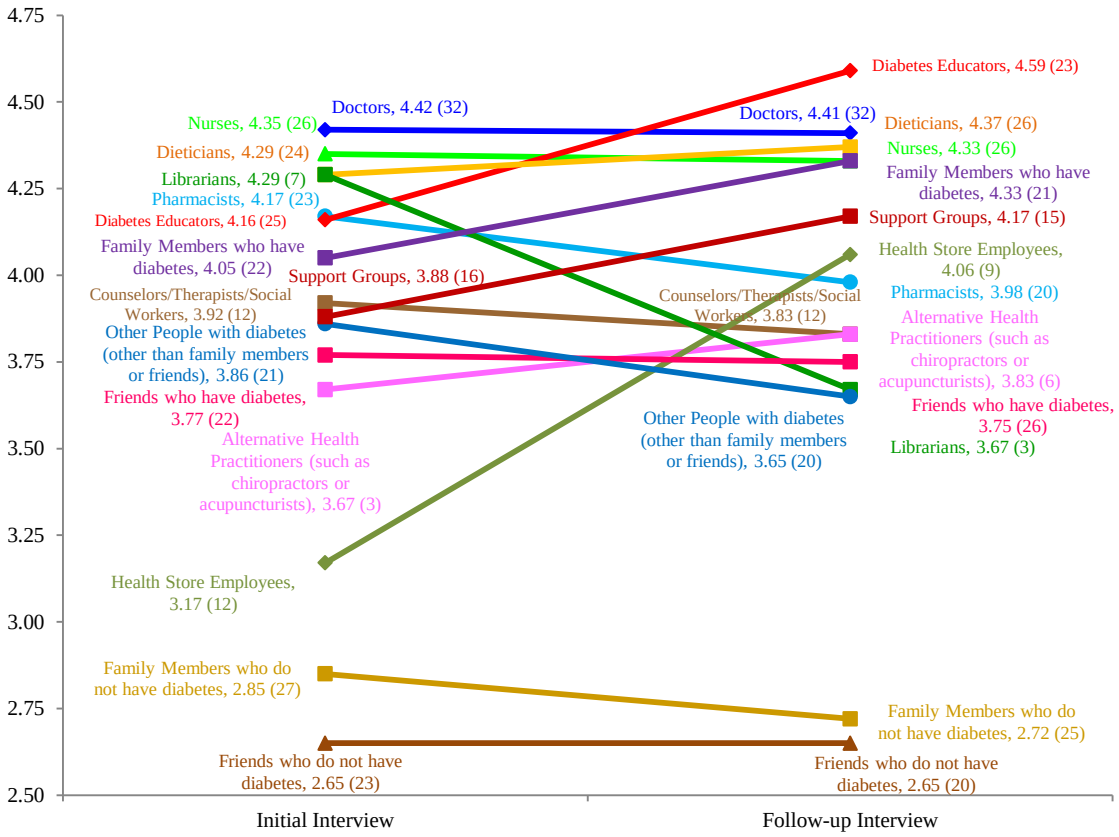


Figure 23: Participants' Ratings of the Usefulness of Different Types of People

4.5.2.2 Participant Comments regarding Usefulness of Different Types of People

At the close of this card-sorting exercise, participants were asked to indicate which type(s) of people they have found to be the most useful in helping them to learn about diabetes and to discuss why these people have been the most useful. These judgments were often based on participants' perceptions about the expertise and availability/accessibility of the person, their perceptions about the information provided by this person (e.g., was it actionable?), and their perceptions about the nature of the relationship between this person and themselves (e.g., does the participant feel close to this person? trust this person? feel that this person cares about them?). Some participants provided lists of the people that have been most useful to them. For example, I12 selected her dietician, her doctor, and family members who have diabetes, explaining, "They are

closest to me and I have the most trust in them." Other people, however, were able to pinpoint one particular person that has been the most useful to them.

Often, participants indicated that one or more healthcare providers had been the most useful to them in helping them to learn about diabetes. For example, I05 said that her doctors have been the most useful to her "because the ones I've had… have been there, have told me how to start it, how to take care of it, what to eat, what not to eat, push the drinks, exercise, this type of stuff." I14 said that nurses have been the most useful to him "because they're readily available and they seemed to be understanding the questions, concerns." I02 indicated that her dietician has been the most useful to her because "She is so helpful and she always gives out information and pamphlets… Her husband has it… so she's like his caregiver, so she's like our caregiver… That's why I really look up to her… because she knows her stuff." I04 similarly indicated that her diabetes educator has been the most helpful to her: "They're the ones who sit down with you and give you more in detail about how to do it, what to do it, why to do it, where to do it, when to do it." I06 concurred: "Diabetes educationers [*sic*]… That's where I got most of my information about what to do and what not to do… They kind of gave me the whole picture of what I needed and how to obtain that."

Some participants, however, indicated that less formal sources, such as family members, friends, and/or support groups, had been the most useful to them. I19 said that his father has been the most useful to him because "his blood sugar was very high and he managed it for a lot of years… [He]… doesn't have it anymore… He doesn't have to treat it, so obviously he's done something right." I03 similarly said that her husband has been the most useful to her because "he has the experience with it, he's done a lot of research… and [is] supportive… motivating." I15 indicated that her grandmother who is also a diabetic has been the most useful to her because "I've been in the house with her enough to ask her any questions that I feel like I want to know about… I feel comfortable enough." I08 indicated that her friend has been the most useful to her because "I talk more to her than I do to diabetes educators." I31 also said that her friend has been the most useful to her. She explained, "I was diagnosed in 2009 and she was diagnosed in 2008… right before me. So she had come out of it and she was able to really guide me and help me along." I25 indicated that support groups have been the most useful to her.

One participant (I22) selected herself as her most useful source of diabetes-related information. She explained, "I think we are our best educator… It's up to us. We want the information, all we've got to do is look."

4.5.3 Perceptions of Usefulness: Media Types

During the second card-sorting exercise, participants were asked to rate the usefulness of different types of media (i.e., television, radio, Internet, books, magazines, newspapers, journals, and brochures/pamphlets) for helping them to find out what they needed to know about diabetes. The first subsection below shows the results from this exercise, while the second presents participants' verbal comments about the relative usefulness of various media types.

4.5.3.1 Results from Card-Sorting Exercise

Table 27 summarizes participants' usefulness ratings for each of the various media types. Again, participants were able to choose from very useful (5), somewhat useful (4), neutral (3), somewhat not useful (2), and not at all useful (1). This table shows that participants rated the Internet as the most useful. Next, books and brochures/pamphlets were also found to be very useful. The least useful were newspapers, radio, and television.

Table 27: Participants' Ratings of the Usefulness of Different Types of Media

Media Type	Initial Interview					Follow-up Interview					Change		
	n	M	SD	m	ř	n	M	SD	m	ř	n	M	ř
Internet	25	4.72	0.46	5.0	1	26	4.69	0.47	5.0	1	1	-0.03	0
Books	25	4.44	0.82	5.0	2	21	4.48	0.60	5.0	2	-4	0.04	0
Brochures/ Pamphlets	29	4.38	0.56	4.0	3	30	4.45	0.67	5.0	3	1	0.07	0
Journals	12	4.08	0.90	4.0	4	15	4.20	0.86	4.0	4	3	0.12	0
Magazines	26	4.08	0.89	4.0	4	24	4.17	0.78	4.0	5	-2	0.09	-1
Newspapers	14	3.64	0.84	3.0	6	16	3.59	1.25	4.0	6	2	-0.05	0
Radio	9	3.56	1.24	4.0	7	8	3.44	1.40	4.0	7	-1	-0.12	0
Television	16	3.38	1.15	3.5	8	22	3.39	1.40	4.0	8	6	0.01	0
All Media Types		**4.15**	**0.91**	**4.0**			**4.15**	**1.01**	**4.0**			**0.00**	

Note. n = number of participants who indicated that they had used this type of media to find out what they needed to know about diabetes. M = mean. SD = standard deviation. m = median. $ř$ = rank (based on means).

Analyzing participants' responses to this card-sorting exercise in relation to their responses on the background and health condition questionnaires that were administered at the initial interview yielded several interesting statistically significant correlations, as outlined in the subsections below. Please note that, due to space considerations, not all variables are shown in the tables included in the following subsections – only the rows and columns that contain at least one statistically significant correlation are shown.

a. Health/Physical Condition

Table 28 shows the results from correlation analyses that looked at the relationships between participants' ratings as to the usefulness of different types of media and their ratings on the health/physical condition measures on the health condition questionnaires. Participants who rated their general health higher gave higher usefulness ratings to books, brochures/pamphlets, and radio.

Table 28: Correlates between Participants' Ratings of the Usefulness of Different Types of Media and their Ratings pertaining to various Health/Physical Condition Factors

Usefulness Ratings:	Health/Physical Condition Factors
Media Type	General Health
Books	***r* = .49** ***p* = .014** ***n* = 25**
Brochures/ Pamphlets	***r* = .46** ***p* = .012** ***n* = 29**
Radio	***r* = .78** ***p* = .014** ***n* = 9**

Note. Statistically significant correlations ($p < .05$) are shown in bold font.

b. Cognitive and Information Behavior Measures

Table 29 shows the results from correlation analyses that were run based on participants' usefulness ratings for each of the media types and their ratings on the cognitive/information behavior measures on the health condition questionnaires. The first column shows that participants who were less well-educated provided higher ratings as to the usefulness of newspapers. The second column shows that participants who indicated that diabetes was less on their mind gave higher usefulness ratings to television. The third column indicates that participants who gave higher ratings as to the importance of

participating in making decisions related to one's healthcare also provided higher ratings when asked about the usefulness of the Internet. The fourth column shows that participants who indicated that they were more active about finding out about diabetes rated television and Internet as more useful. The last column shows that participants who indicated that they look for diabetes-related information more frequently rated the usefulness of television higher.

Table 29: Correlates between Participants' Ratings of the Usefulness of Different Types of Media and their Ratings pertaining to various Cognitive/Information Behavior Measures

	Cognitive/Information Behavior Measures				
	(1)	(2)	(3)	(4)	(5)
Usefulness Ratings: Media Type	Educational Attainment	Extent to which diabetes is on one's mind	Importance of participating in making decisions related to one's healthcare	Active about finding out about diabetes	How often look for diabetes-related information
Newspapers	***r* = -.54** ***p* = .046** ***n* = 14**	*r* = .07 *p* = .822 *n* = 14	*r* = -.12 *p* = .678 *n* = 14	*r* = .28 *p* = .334 *n* = 14	*r* = .05 *p* = .863 *n* = 14
Television	*r* = -.26 *p* = .334 *n* = 16	***r* = -.57** ***p* = .021** ***n* = 16**	not calculable	***r* = .53** ***p* = .036** ***n* = 16**	***r* = .52** ***p* = .040** ***n* = 16**
Internet	*r* = .15 *p* = .466 *n* = 25	*r* = .04 *p* = .859 *n* = 25	***r* = .40** ***p* = .047** ***n* = 25**	***r* = .47** ***p* = .017** ***n* = 25**	*r* = .34 *p* = .098 *n* = 25

Note. Statistically significant correlations ($p < .05$) are shown in bold font.

c. Perceptions about Availability of Information

Participants who indicated that it was easy for them to get hold of diabetes-related information that they needed gave higher usefulness ratings to magazines ($r(26) = .40$, $p = .044$).

d. Affective Measures related to Diabetes Experience

Participants who indicated that they felt less uncertain about their experience with diabetes rated the usefulness of magazines ($r(26) = .54$, $p = .004$) and of all media types overall ($r(31) = .41$, $p = .023$) higher.

e. Changes across Time

There was very little change in participants' responses across time for the card-sorting exercise regarding the usefulness of different media types.

4.5.3.2 Participant Comments regarding Usefulness of Different Types of Media

After completing this card-sorting exercise, participants were asked to discuss which media type(s) they feel have been the most useful in terms of helping them to find out what they needed to know about diabetes. Participants' based their selections of the most useful media types on their perceptions about the accessibility of the various media types, the extent of information available through each of them, the trustworthiness of the information available through them, and the usability and controllability of each of them.

The Internet was frequently selected as the most useful media type. Some participants selected the Internet because of its accessibility. I09 stated, "The Internet is there when you have a question." I10 similarly described the Internet as "the largest amount of information that I can find that is readily handy." I29 selected the Internet as the most useful media type because of its "digestion quotient," which he explained by saying, "I can pretty much right-size it to the amount of information I want at that particular time." I14 stated:

> The Internet is the most important part of the information I get about diabetes… even more so than the doctor or nurses because here I can spend as much time as I want or need to get to the information and I can segue off and then come back around and it's just easier.

Some participants selected the Internet as the most useful simply because of the quantity of information available through this medium. I08 explained that the Internet has been the most useful media type to her "because of the diversity of information… It's not just about the mechanism of diabetes itself, but all the other things that interplay." I34 similarly explained her selection of Internet, "Because there's an endless amount of information that you can get in seconds just by keying in a couple of words."

For some participants, the Internet was perceived to be the most useful media type because they believed it had the most thorough and/or most accurate information. ." I08, for example, selected the Internet as the most useful media type "because that is where I can get the most thorough, complete, and concise information, exceeding anything a physician would ever say or give me in a handout." I34 stated:

> The Internet… that would obviously be the most helpful thing, very influential thing because I do base my questions... from what I find on the Internet… And sometimes I think we all want to think that the Internet's smarter than our doctor.

A few participants indicated that the Internet had been the most useful medium for them because of the degree of controllability it conferred on the medium's user. I04 explained why she selected the Internet as the most useful media type: "I know where to find it on the Internet… I control when and how and why and where… If I want to find out something, it takes me five minutes to find out on the Internet." I12 similarly described that she thinks the Internet is the most useful "because it's not limited to just what's on that pamphlet… Like, you can kind of direct, whereas the pamphlet it's just this." I32 stated, "It's quickly available, it's flexible… If you don't go down the right path when you're drilling, it allows you to go back and start over again." I08 explained why the Internet is the most useful to her: "Because I can approach a subject in many different angles… I can tailor my query to exactly what I want to know."

Some participants, however, chose written materials, such as brochures/pamphlets, books, magazines, or newspapers, over the Internet as their most useful source of diabetes-related information. I01, for example, picked brochures/pamphlets because "they come right down to the information, they're concise usually and they're small… It gets to the point usually with what you want to find out." I17 agreed that brochures/pamphlets have been the most useful "because I pick them up wherever I am if there's something geared toward diabetes… I find them short… and to the point. I like that." I21 said that brochures/pamphlets have been the most useful "basically because you're bored and you pick them up and read them… I'll read anything if I'm bored and that's usually what's there. So… I might as well read it."

I24, however, selected books as his most useful media type, explaining, "I trust books more [than the Internet]… I have a preferences to written word on paper… Most of the stuff that I learned was out of the books." I31, who also selected books as her most useful source, explained, "The book is better [than the Internet]… If I travel in the car or on the plane, I can just pull my book out and start reading it." I22 said that magazines have been the most useful for her because "I'm always reading them because I'm always at the doctor's." I28 also found magazines to be the most useful. He explained, "They just seem like they give me a little personal touch. I mean, I can relate to a lot of the people that some of the articles are about." I06 indicated that newspapers have been the most useful to him because "I get that every day." I32 also selected newspapers. He explained,

"It's something that I would read, something that I would keep… I've tried to use books and stuff… I never get through them all."

A couple of participants indicated that their own logs and/or journals were the most useful media type for them. I12, for example, explained, "The journals help me step aside and see myself, see what I'm doing… Just objectively see how my behaviors are and how they could be impacting my diabetes." I18 stated:

> My journals have been very, very useful, like keeping track. I can even write down when I spike in my booklet. I'll put down the date and the spike… and then I can look back and go, "Wow, that was a bad day."

4.5.4 Perceptions of Usefulness: Internet Site Types

For the third card-sorting exercise, participants were asked to rate the usefulness of search engines and other kinds of Internet sites for finding out what they need to know about diabetes. The first subsection below describes the results from this card-sorting exercise, while the second discusses participants' verbal comments pertaining to their perceptions about the usefulness of search engines and various types of Internet sites.

4.5.4.1 Results from Card-Sorting Exercise

Table 30 presents a summary of participants' usefulness ratings for search engines and various other types of Internet sites. As with the other two card-sorting exercises, participants chose from the following ratings for each card: Very useful (5); Somewhat useful (4); Neutral (3); Somewhat not useful (2); and Not at all useful (1). Overall, participants indicated that they have found search engines and medical Websites to be the most useful and shopping Websites to be the least useful.

Table 30: Participants' Ratings of the Usefulness of Different Types of Internet Sites

Type of Internet Site	Initial Interview					Follow-up Interview					Change		
	n	M	SD	m	ř	n	M	SD	m	ř	n	M	ř
Search engines	15	4.80	0.56	5.0	1	20	4.68	0.47	5.0	2	5	-0.12	-1
Medical Websites	17	4.71	0.47	5.0	2	20	4.55	0.60	5.0	3	3	-0.16	-1
Government agency Websites	9	4.22	0.67	4.0	3	8	4.13	0.64	4.0	5	-1	-0.09	-2

Type of Internet Site	Initial Interview					Follow-up Interview					Change		
	n	M	SD	m	ř	n	M	SD	m	ř	n	M	ř
General news Websites – News articles	8	4.13	0.64	4.0	4	10	4.00	0.82	4.0	6	2	-0.13	-2
Lifestyle Websites	11	3.64	1.03	4.0	5	11	3.82	0.87	4.0	10	0	0.18	-5
Dictionary/ Encyclopedia Websites (other than Wikipedia)	5	3.60	0.89	3.0	6	6	3.92	0.80	4.0	9	1	0.32	-3
Forums	10	3.60	0.97	4.0	6	8	3.75	1.28	4.0	12	-2	0.15	-6
Wikipedia	11	3.55	1.29	4.0	8	13	3.77	1.30	4.0	11	2	0.22	-3
Videos/ YouTube	4	3.50	1.00	3.0	9	1	5.00	n/c	5.0	1	-3	1.50	8
Insurance Websites	5	3.20	1.30	4.0	10	5	4.20	0.45	4.0	4	0	1.00	6
Blogs	10	3.05	1.07	3.0	11	7	3.29	1.70	4.0	14	-3	0.24	-3
Personal Websites	8	3.00	0.93	3.0	12	3	4.00	0.00	4.0	6	-5	1.00	6
General news Websites – Opinions	8	2.88	1.25	2.0	13	4	4.00	0.82	4.0	6	-4	1.12	7
Shopping Websites	8	2.88	1.55	3.0	13	6	3.33	1.37	3.5	13	-2	0.45	0
All Internet Site Types		**3.77**	**1.14**	**4.0**			**4.09**	**0.98**	**4.0**			**0.32**	

Note. n = number of participants who indicated that they had used this type of Internet site to find out what they need to know about diabetes. M = mean. SD = standard deviation. m = median. $\check{r}$ = rank (based on means).

Analyzing participants' responses to this card-sorting exercise in relation to their responses on the background and health condition questionnaires that were administered at their initial interviews yielded several interesting statistically significant correlations, as outlined in the subsections below. Please note that, due to space considerations, not all variables are shown in the tables included in the following subsections – only the rows and columns that contain at least one statistically significant correlation are shown.

a. Health/Physical Condition

Participants who indicated that they felt that their pain did little to prevent them from doing what they need to do rated search engines as more useful ($r(15) = .57$, $p = .026$). Participants who indicated that they felt that their diabetes-related symptoms were less severe rated all Internet sites overall as more useful ($r(19) = .50$, $p = .031$).

b. Cognitive and Information Behavior Measures

Participants who rated their current understanding of diabetes as more adequate rated search engines as more useful ($r(15) = .72$, $p = .003$).

c. Perceptions about Availability of Information

Participants who indicated that they felt more satisfied with getting their diabetes-related questions answered ($r(10) = .73$, $p = .018$) and participants who indicated that the diabetes-related information that they need in their day-to-day life is more available to them ($r(10) = .76$, $p = .011$) rated the usefulness of forums higher.

d. Affective Measures related to Diabetes Experience

Table 31 shows the results from correlation analyses that were conducted based on participants' usefulness ratings for the various types of Internet sites and their ratings on the affective measures from the health condition questionnaires. The first column in this table shows that participants who indicated that they felt more clear (less confused) about their experience with diabetes provided higher usefulness ratings for government agency Websites, forums, and all Internet sites (i.e., average rating across all types of Internet sites listed). The second column shows that participants who rated themselves as more optimistic about their experience with diabetes rated the usefulness of search engines, lifestyle Websites, forums, personal Websites, and all Internet sites (i.e., average rating across all types of Internet sites listed) higher. The last column shows that participants who indicated that they felt less alone regarding their experience with diabetes provided higher usefulness ratings for medical Websites and government agency Websites.

Table 31: Correlates between Participants' Ratings of the Usefulness of Different Types of Internet Sites and their Ratings pertaining to various Affective Measures

Usefulness Ratings: Type of Internet Site	Affective Measures (1) Clear about one's experience with diabetes	(2) Optimistic about one's experience with diabetes	(3) Feel less alone about one's experience with diabetes
Search engines	*r* = .00 *p* = 1.000 *n* = 15	***r* = .56** ***p* = .030** ***n* = 15**	*r* = -.02 *p* = .944 *n* = 14
Medical Websites	*r* = .01 *p* = .960 *n* = 17	*r* = .15 *p* = .579 *n* = 17	***r* = .60** ***p* = .014** ***n* = 16**
Government agency Websites	***r* = .88** ***p* = .002** ***n* = 9**	*r* = .31 *p* = .413 *n* = 9	***r* = .80** ***p* = .018** ***n* = 8**
Lifestyle Websites	*r* = -.40 *p* = .229 *n* = 11	***r* = .64** ***p* = .034** ***n* = 11**	*r* = -.26 *p* = .460 *n* = 10
Forums	***r* = .73** ***p* = .018** ***n* = 10**	***r* = .66** ***p* = .038** ***n* = 10**	*r* = -.06 *p* = .869 *n* = 10
Personal Websites	*r* = .12 *p* = .780 *n* = 8	***r* = .72** ***p* = .043** ***n* = 8**	*r* = -.22 *p* = .604 *n* = 8
All Internet Sites	***r* = .54** ***p* = .017** ***n* = 19**	***r* = .74** ***p* = .000** ***n* = 19**	*r* = .29 *p* = .244 *n* = 18

Note. Statistically significant correlations ($p < .05$) are shown in bold font.

e. Changes across Time

Figure 24 shows the changes in participants' ratings between the time of their initial interview and the time of their follow-up interview. The figures in parentheses within the data labels indicate the number of participants who indicated that they had used this type of Internet site in relation to diabetes and, thus, provided a usefulness rating. This figure and Table 30 (above) show some interesting patterns. Search engines and medical Websites were rated the most useful at the time of both the initial interviews and the follow-up interviews. However, some interesting changes took place. In general, participants' ratings of the usefulness of some of the more official Websites, such as medical Websites, government agency Websites, and general news Websites – news articles decreased, while their ratings of less official Websites, such as videos/YouTube (note: only one person rated the usefulness of videos/YouTube during the follow-up

interviews), personal Websites, general news Websites – opinions, dictionary/encyclopedia Websites (other than Wikipedia), lifestyle Websites, Wikipedia, forums, shopping Websites, and blogs increased. However, paired-samples t-tests revealed that none of these changes reached statistical significance.

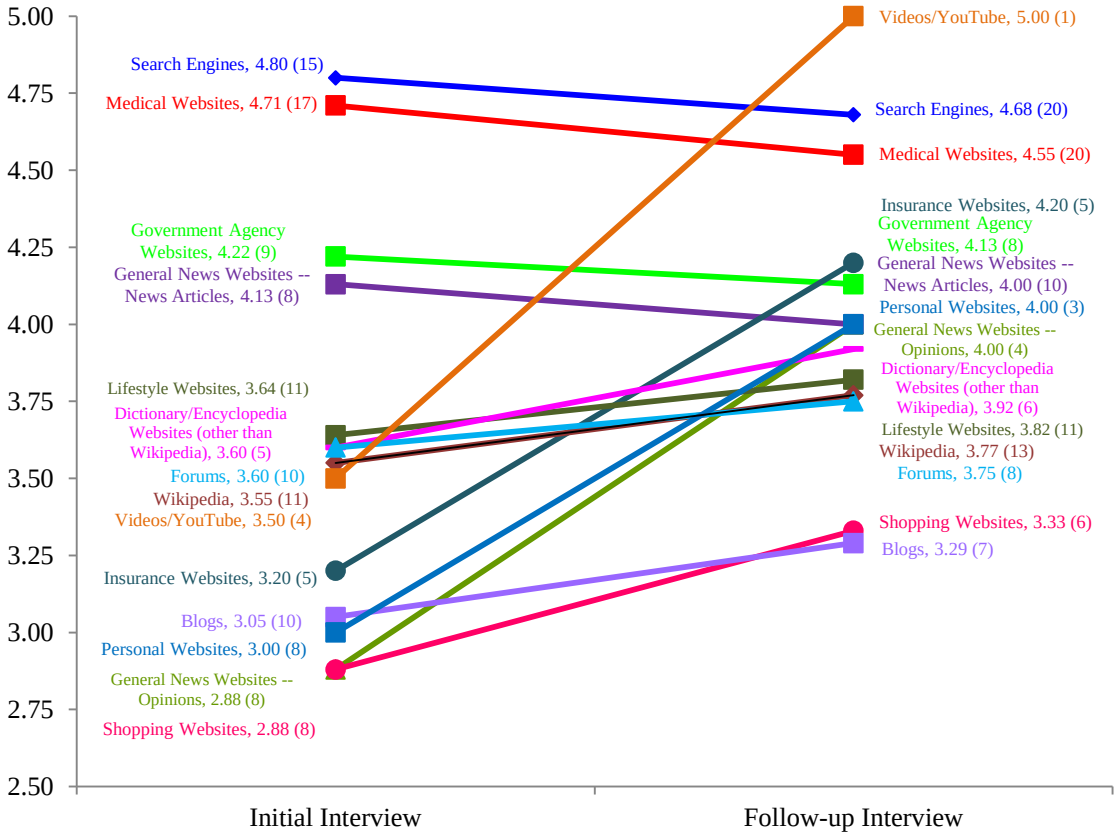


Figure 24: Participants' Ratings of the Usefulness of Different Types of Internet Sites

4.5.4.2 Participant Comments regarding Usefulness of Different Types of Internet Sites

After participants placed each of the Internet site type cards into a category, they were asked to discuss which Internet site type(s) they feel have been the most useful in helping them to find out what they need to know about diabetes. Search engines and/or medical Websites were by far the most commonly mentioned Internet site types. I29 stated, "In terms of my utility, the search engines and medical Websites are the things that I use the most." I04 also selected both of these as her two most useful sources of

diabetes-related information. She explained the reasons she has found Google to be useful: "Because it's just easy to use… That's the site when you put 'diabetes', you come up with 3,842,000 Websites… And the ones that are most important, they put… first on their list… So I like how they organize it." Participants' opinions varied, however, as to whether search engines or medical Websites were the most useful.

Some participants felt that search engines were more useful than medical Websites. Their reasoning often had to do with the functionality of search engines, such as their controllability and their ability to cut through a lot of information in order to bring you to specifically what you're looking for or to other information that you're likely to find useful. I10, for example, stated, "Search engines would trump the medical… They give you a broad amount of information right away, whereas with the medical Websites you have to dig through whole pages to find what you're looking for." I24 stated, "If I had to rank anything that's the most important, [it would be] being able to find information with your search engines." When asked to list some of the advantages of search engines, this participant replied, "Just being able to get the quantity of information… And, if you're lucky, you get the quality." I08 indicated that search engines are the most useful for her "because I can word something to definitively get the answer that I want." I14 pointed out that he likes search engines because of their ability to facilitate serendipitous discovery. He stated, "It will bring me to any one of a number of Websites… in order to uncover the information I'm looking for, and sometimes I get information I wasn't looking for." I34 also found search engines to be the most useful. Like I14, she appreciated the ability of search engines to pull up information that she wasn't specifically looking for, but that she would find interesting. She explained:

> Because… you can put a group of words in, a phrase or something in, and it will seek out something… where more than one word is related to each other… It doesn't give you always exactly what you're looking for, but it gets you a little closer. And some of them, like with Bing and Google, it gives you different ideas, like "Are any of these other subjects what you want, something you're interested in?"

Other participants, however, felt that medical Websites were more useful to them than search engines. Their reasons for selecting medical Websites over search engines often had to do with their desire to be more systematic about their surfing and with their expectations of getting high-quality and up-to-date information from medical Websites.

I33 explained, “Because what I like to do is I like to be more specific. I don’t want to be scattered here and there.” I03 said that medical Websites are the most useful because “it seems professional. There’s a lot of information. It’s specific. You can go to different parts.” I13 similarly explained, “Because they have good information in general… If I go to a good one… which I think I would know if it was good or not so bad, they have the most comprehensive explanation and it’s science based information.” I29 chose medical Websites because he felt they were more trustworthy than search engines. He explained, “I mean, I don’t think the Mayo Clinic is going to give me bullshit.” I34 similarly selected medical Websites because “I guess I feel they’re more reliable… If someone like Mayo Clinic or WebMD is backing it, it’s probably been verified and cross-checked.” I33 selected medical Websites because “I find that they’re up with the current trends, they’re up with the current medications, ideas, what’s going on.”

A few participants indicated that sites other than search engines or medical Websites were the most useful to them. I35, for example, said that general news Websites – news articles have been the most useful for him “to learn about new things they have out, like the new testing things… different ways to take care of yourself.” I30 indicated that general news Websites – opinions had been the most useful for him because, “They’re the opinions of, I guess, of someone that has diabetes and then they have an opinion about certain things.” I12 found a particular lifestyle Website, LIVESTRONG, to be the most useful “because [it] has everything on it already.” I09 indicated that blogs, particularly some of the ones on ASweetLife.org, have been the most useful because their “personal angle… brings me in, like, ‘Oh, my gosh! This person’s developed the same situation that I’ve dealt with.’” She found specific blogs posts to be the most useful when they had “positive suggestions or people talking about strategies for coping and things like that.” I18 found Wikipedia to be the most useful because “it’s easiest to get around and I understand it the most…If one Website don’t work, you just backtrack, back up to Wikipedia, there are different sites.”

4.5.5 Perceptions of Usefulness: Content Types

During the fourth card-sorting exercise, participants were asked to rate the usefulness of information covering 20 different topics. The first subsection below presents the results from this card-sorting exercise. The second subsection presents

participants' verbal comments regarding their perceptions about the usefulness of information covering these diabetes-related topics.

4.5.5.1 Results from Card-Sorting Exercise

Table 32 summarizes the 32 participants' ratings of the usefulness of information on various diabetes-related topics. Again, participants' options were: Very useful (5); Somewhat useful (4); Neutral (3); Somewhat not useful (2); or Not at all useful (1). Overall, participants found information to be very useful if it covered topics that had to with taking control of their diabetes, including diabetes management, diagnostic tests/procedures, and diet. On the other hand, they found information far less useful if it was insurance information or if it was about the causes of diabetes or home remedies.

Table 32: Participants' Ratings of the Usefulness of Different Types of Content

Type of Content	Initial Interview					Follow-up Interview					Change		
	n	M	SD	m	ř	n	M	SD	m	ř	n	M	ř
Diabetes management	30	4.71	0.53	5.0	1	31	4.61	0.62	5.0	3	1	-0.10	-2
Diagnostic tests/ procedures	31	4.61	0.56	5.0	2	31	4.87	0.34	5.0	1	0	0.26	1
Diet	31	4.61	0.84	5.0	2	32	4.84	0.37	5.0	2	1	0.23	0
Diabetes-related complications	29	4.41	0.87	5.0	4	30	4.33	0.80	4.5	9	1	-0.08	-5
Medication warnings and/or allergies	27	4.39	0.88	5.0	5	24	4.38	0.97	5.0	8	-3	-0.01	-3
Medication options, side effects, and/or interactions	28	4.36	0.91	5.0	6	25	4.48	0.77	5.0	6	-3	0.12	0
Signs/ symptoms	29	4.34	0.97	5.0	7	29	4.55	0.63	5.0	4	0	0.21	3
Exercise	29	4.34	1.04	5.0	7	31	4.52	0.63	5.0	5	2	0.18	2
Cooking/ recipes	28	4.32	1.09	5.0	9	30	4.27	0.87	4.5	10	2	-0.05	-1
Treatment facilities and/or providers	24	4.29	1.04	5.0	10	20	4.00	1.30	4.5	14	-4	-0.29	-4

Type of Content	Initial Interview					Follow-up Interview					Change		
	n	M	SD	m	ř	n	M	SD	m	ř	n	M	ř
Risk factors	30	4.27	0.94	4.0	11	27	4.00	1.07	4.0	14	-3	-0.27	-3
Vitamins/ supplements	23	4.22	0.90	4.0	12	23	4.09	0.95	4.0	11	0	-0.13	1
Product information	28	4.14	0.85	4.0	13	27	4.04	1.13	4.0	13	-1	-0.10	0
Disease prevention	23	4.02	1.17	4.0	14	25	4.00	1.15	4.0	14	2	-0.02	0
Treatment options, costs, and/or impacts	25	4.02	1.26	4.5	14	26	3.81	1.30	4.0	17	1	-0.21	-3
Stories/ personal experiences	24	3.92	1.06	4.0	16	27	4.43	0.57	4.0	7	3	0.51	9
Diabetes-related emotions	25	3.88	1.17	4.0	17	20	4.05	1.00	4.0	12	-5	0.17	5
Causes	27	3.74	1.26	4.0	18	29	3.74	1.09	4.0	18	2	0.00	0
Insurance information	18	3.28	1.45	3.0	19	20	3.35	1.42	4.0	20	2	0.07	-1
Home remedies	19	3.16	1.46	3.0	20	16	3.50	1.37	4.0	19	-3	0.34	1
All Content Types		**4.20**	**1.06**	**5.0**			**4.24**	**0.99**	**5.0**			**0.04**	

Note. n = number of participants who indicated that they have used information on this topic in relation to diabetes. M = mean. SD = standard deviation. m = median. $\check{r}$ = rank (based on means).

Analyzing participants' responses to this card-sorting exercise in relation to their responses on the background and health condition questionnaires that were administered at the initial interviews yielded several interesting statistically significant correlations, as outlined in the subsections below. Please note that, due to space considerations, not all variables are shown in the tables included in the following subsections – only the rows and columns that contain at least one statistically significant correlation are shown.

a. Health/Physical Condition

Table 33 shows the results from correlation analyses that were run based on participants' ratings of the usefulness of various types of content and their responses related to health/physical condition measures on both the background questionnaires and the health condition questionnaires. Column (1) shows that older participants rated the

usefulness of information about disease prevention lower. Column (2) shows that participants who had had diabetes for longer rated the usefulness of information about risk factors and information about disease prevention lower. Column (3) shows that participants who provided higher ratings of their general health rated information about medication warnings and/or allergies, stories/personal experiences, all content types overall (i.e., average across all types of content listed), and all people, media types, Internet site types, and content types overall (i.e., average across all four card-sorting exercises pertaining to usefulness) as more useful. Column (4) shows that participants who indicated that pain does little to prevent them from doing what they need to do rated the usefulness of information about home remedies, all content types, and all people, media types, Internet site types, and content types overall as more useful. Column (5) shows that participants who rated their diabetes-related symptoms as less severe provided higher usefulness ratings for information about medication warnings and/or allergies, all content types, and all people, media types, Internet site types, and content types overall. The last column shows that participants who indicated that their diabetes-related symptoms had gotten better over the past few months rated the usefulness of stories/personal experiences higher.

Table 33: Correlates between Participants' Ratings of the Usefulness of Different Types of Content and their Ratings pertaining to various Health/Physical Condition Factors

	Health/Physical Condition Factors					
	(1)	(2)	(3)	(4)	(5)	(6)
Usefulness Ratings: Type of Content	Age	# of Months with diabetes	General Health	Impact of pain on ability to do what one needs to do	Severity of diabetes-related symptoms	Change in diabetes-related symptoms
Risk factors	*r* = -.15 *p* = .420 *n* = 30	***r* = -.41** ***p* = .024** ***n* = 30**	*r* = .13 *p* = .486 *n* = 30	*r* = .14 *p* = .449 *n* = 30	*r* = .33 *p* = .076 *n* = 30	*r* = .06 *p* = .764 *n* = 29
Home remedies	*r* = .27 *p* = .271 *n* = 19	*r* = -.17 *p* = .946 *n* = 19	*r* = .43 *p* = .066 *n* = 19	***r* = .53** ***p* = .019** ***n* = 19**	*r* = .28 *p* = .241 *n* = 19	*r* = .21 *p* = .415 *n* = 18
Medication warnings and/or allergies	*r* = .21 *p* = .283 *n* = 27	*r* = -.12 *p* = .554 *n* = 27	***r* = .42** ***p* = .030** ***n* = 27**	*r* = .22 *p* = .266 *n* = 27	***r* = .40** ***p* = .036** ***n* = 27**	*r* = .32 *p* = .117 *n* = 26
Disease prevention	***r* = -.60** ***p* = .002** ***n* = 23**	***r* = -.59** ***p* = .003** ***n* = 23**	*r* = .20 *p* = .352 *n* = 23	*r* = .26 *p* = .230 *n* = 23	*r* = .18 *p* = .419 *n* = 23	*r* = .25 *p* = .272 *n* = 22

	Health/Physical Condition Factors					
	(1)	(2)	(3)	(4)	(5)	(6)
Usefulness Ratings: Type of Content	Age	# of Months with diabetes	General Health	Impact of pain on ability to do what one needs to do	Severity of diabetes-related symptoms	Change in diabetes-related symptoms
Stories/personal experiences	*r* = -.17 *p* = .434 *n* = 24	*r* = -.23 *p* = .282 *n* = 24	***r* = .44** ***p* = .031** ***n* = 24**	*r* = .35 *p* = .094 *n* = 24	*r* = .18 *p* = .414 *n* = 24	***r* = .43** ***p* = .043** ***n* = 23**
All content types	*r* = .00 *p* = .984 *n* = 32	*r* = -.21 *p* = .256 *n* = 32	***r* = .43** ***p* = .013** ***n* = 32**	***r* = .49** ***p* = .004** ***n* = 32**	***r* = .42** ***p* = .016** ***n* = 32**	*r* = .27 *p* = .145 *n* = 31
All card decks (1-4)	*r* = .06 *p* = .726 *n* = 32	*r* = -.15 *p* = .401 *n* = 32	***r* = .44** ***p* = .013** ***n* = 32**	***r* = .46** ***p* = .008** ***n* = 32**	***r* = .45** ***p* = .009** ***n* = 32**	*r* = .34 *p* = .062 *n* = 31

Note. Statistically significant correlations ($p < .05$) are shown in bold font.

b. Cognitive and Information Behavior Measures

Table 34 depicts the results of correlation analyses that were run based on participants' ratings regarding the usefulness of different types of content and their responses to the cognitive/information behavior measures on the health condition questionnaires. The first column shows that participants who indicated that diabetes was less on their minds rated the usefulness of information about diabetes management lower. The second column shows that participants who rated their current understanding of diabetes as more adequate rated the usefulness of information about diabetes management and cooking/recipes higher. The third column shows that participants who provided higher ratings as to how important it was for them to participate in making decisions related to their healthcare rated the usefulness of information about the causes of diabetes and disease prevention higher. The last column shows that participants who indicated that they look for diabetes-related information more frequently provided lower ratings of the usefulness of information regarding diabetes-related complications.

Table 34: Correlates between Participants' Ratings of the Usefulness of Different Types of Content and their Ratings pertaining to various Cognitive/Information Behavior Measures

	Cognitive/Information Behavior Measures			
	(1)	(2)	(3)	(4)
Usefulness Ratings: Type of Content	Extent to which diabetes is on one's mind	Adequacy of current understanding of diabetes	Importance of participating in making decisions related to one's healthcare	How often look for diabetes-related information
Causes	*r* = -.05 *p* = .812 *n* = 27	*r* = .12 *p* = .554 *n* = 27	***r* = .43** ***p* = .024** ***n* = 27**	*r* = .17 *p* = .398 *n* = 27
Diabetes-related complications	*r* = -.15 *p* = .449 *n* = 29	*r* = -.14 *p* = .461 *n* = 29	*r* = -.08 *p* = .694 *n* = 29	***r* = -.39** ***p* = .037** ***n* = 29**
Disease prevention	*r* = -.08 *p* = .711 *n* = 23	*r* = .10 *p* = .643 *n* = 23	***r* = .51** ***p* = .012** ***n* = 23**	*r* = .09 *p* = .678 *n* = 23
Diabetes management	***r* = -.51** ***p* = .004** ***n* = 30**	***r* = .59** ***p* = .001** ***n* = 30**	*r* = .02 *p* = .915 *n* = 30	*r* = .17 *p* = .383 *n* = 30
Cooking/recipes	*r* = -.28 *p* = .150 *n* = 28	***r* = .67** ***p* = .000** ***n* = 28**	*r* = .06 *p* = .770 *n* = 28	*r* = .30 *p* = .128 *n* = 28

Note. Statistically significant correlations ($p < .05$) are shown in bold font.

c. Perceptions about Availability of Information

Table 35 shows the results from correlation analyses that were conducted based on participants' ratings as to the usefulness of various types of content and their ratings on the health condition questionnaires that pertained to their perceptions about the availability of diabetes-related information. The first column shows that participants who indicated that they felt more satisfied with getting their diabetes-related questions answered provided higher usefulness ratings for information about treatment facilities and/or providers. The second column shows that participants who indicated that it was less difficult for them to get hold of diabetes-related information provided higher usefulness ratings for information about risk factors and treatment facilities and/or providers.

Table 35: Correlates between Participants' Ratings of the Usefulness of Different Types of Content and their Ratings pertaining to their Perceptions about the Availability of Information

	Perceptions about Availability of Diabetes-Related Information	
	(1)	(2)
Usefulness Ratings: Type of Content	Satisfaction with getting diabetes-related questions answered	Ease of getting hold of diabetes-related information they need
Risk factors	*r* = .02 *p* = .903 *n* = 30	***r* = .37** ***p* = .045** ***n* = 30**
Treatment facilities and/or providers	***r* = .44** ***p* = .030** ***n* = 24**	***r* = .41** ***p* = .045** ***n* = 24**

Note. Statistically significant correlations ($p < .05$) are shown in bold font.

d. Affective Measures related to Diabetes Experience

Table 36 shows the results from correlation analyses that were run based on participants' ratings regarding the usefulness of different types of content and their responses to the health condition questionnaire that pertained to affective measures. Column (1) shows that participants who indicated that they were more interested in their experience with diabetes provided higher usefulness ratings for information about diabetes management, diabetes-related emotions, and cooking/recipes. Column (2) shows that participants who said that they felt less uncertain about their experience with diabetes provided higher usefulness ratings for information about diagnostic tests/procedures, treatment facilities and/or providers, vitamins/supplements, products, insurance, and all people, media types, Internet site types, and content types overall (i.e., average across all four card-sorting exercises pertaining to usefulness). Column (3) shows that participants who indicated that they felt more clear (less confused) about their experience with diabetes rated the usefulness of information about treatment facilities and/or providers and vitamins/supplements. Column (4) shows that participants who indicated that they felt more optimistic about their experience with diabetes provided higher usefulness ratings for information about the causes of diabetes. Column (5) shows that participants who reported that they felt less alone in regard to their experience with diabetes rated the usefulness of information about diabetes-related complications higher. Columns (6) and (7) show that participants who indicated that they felt more in control of their experience with diabetes and who indicated that they felt they were coping well with having diabetes

provided higher usefulness ratings for information about treatment facilities and/or providers. Also, participants who indicated that they felt they were coping well with having diabetes also provided higher usefulness ratings for information about diabetes management ($r(30) = .36$, $p = .050$). Additionally, participants who indicated that they felt more optimistic about their experience with diabetes provided higher usefulness ratings for all people, media types, Internet site types, and content types overall (i.e., average across all four card-sorting exercises pertaining to usefulness) ($r(32) = .35$, $p = .050$). However, these last two correlations didn't quite reach statistical significance at the $p < .05$ level.

Table 36: Correlates between Participants' Ratings of the Usefulness of Different Types of Content and their Ratings pertaining to various Affective Measures

	Affective Measures						
	(1)	(2)	(3)	(4)	(5)	(6)	(7)
Usefulness Ratings: Type of Content	Interest in experience with diabetes	Feel certain about one's experience with diabetes	Feel clear about one's experience with diabetes	Feel optimistic about one's experience with diabetes	Feel less alone about one's experience with diabetes	Feel in control of one's experience with diabetes	Feel like one is coping well with having diabetes
Causes	*r* = .00 *p* = .993 *n* = 27	*r* = .32 *p* = .108 *n* = 27	*r* = .22 *p* = .264 *n* = 27	***r* = .50** ***p* = .008** ***n* = 27**	*r* = .10 *p* = .612 *n* = 26	*r* = .13 *p* = .507 *n* = 27	*r* = .21 *p* = .297 *n* = 27
Diagnostic tests/ procedures	*r* = .04 *p* = .816 *n* = 31	***r* = .36** ***p* = .045** ***n* = 31**	*r* = .14 *p* = .452 *n* = 31	*r* = .01 *p* = .954 *n* = 31	*r* = .36 *p* = .052 *n* = 30	*r* = .34 *p* = .065 *n* = 31	*r* = -.03 *p* = .870 *n* = 31
Diabetes -related compli-cations	*r* = .06 *p* = .742 *n* = 29	*r* = .11 *p* = .565 *n* = 29	*r* = .21 *p* = .266 *n* = 29	*r* = .00 *p* = .997 *n* = 29	***r* = .47** ***p* = .013** ***n* = 28**	*r* = .06 *p* = .751 *n* = 29	*r* = -.02 *p* = .924 *n* = 29
Treatment facilities and/or providers	*r* = .21 *p* = .316 *n* = 24	***r* = .51** ***p* = .012** ***n* = 24**	***r* = .62** ***p* = .001** ***n* = 24**	*r* = .10 *p* = .659 *n* = 24	*r* = .36 *p* = .088 *n* = 23	***r* = .41** ***p* = .049** ***n* = 24**	***r* = .41** ***p* = .049** ***n* = 24**
Diabetes manage-ment	***r* = .47** ***p* = .009** ***n* = 30**	*r* = .32 *p* = .087 *n* = 30	*r* = .21 *p* = .267 *n* = 30	*r* = .22 *p* = .242 *n* = 30	*r* = .15 *p* = .447 *n* = 29	*r* = .19 *p* = .309 *n* = 30	*r* = .36 *p* = .050 *n* = 30
Diabetes -related emotions	***r* = .51** ***p* = .009** ***n* = 25**	*r* = -.01 *p* = .959 *n* = 25	*r* = -.06 *p* = .787 *n* = 25	*r* = .06 *p* = .760 *n* = 25	*r* = -.25 *p* = .236 *n* = 25	*r* = .09 *p* = .657 *n* = 25	*r* = .23 *p* = .265 *n* = 25
Vitamins/ supplements	*r* = -.07 *p* = .754 *n* = 23	***r* = .47** ***p* = .022** ***n* = 23**	***r* = .42** ***p* = .048** ***n* = 23**	*r* = .10 *p* = .637 *n* = 23	*r* = .20 *p* = .370 *n* = 22	*r* = .08 *p* = .705 *n* = 23	*r* = -.15 *p* = .492 *n* = 23

Usefulness Ratings: Type of Content	Affective Measures						
	(1) Interest in experience with diabetes	(2) Feel certain about one's experience with diabetes	(3) Feel clear about one's experience with diabetes	(4) Feel optimistic about one's experience with diabetes	(5) Feel less alone about one's experience with diabetes	(6) Feel in control of one's experience with diabetes	(7) Feel like one is coping well with having diabetes
Cooking/ recipes	***r* = .42** ***p* = .026** ***n* = 28**	*r* = .29 *p* = .133 *n* = 28	*r* = -.29 *p* = .134 *n* = 28	*r* = .31 *p* = .114 *n* = 28	*r* = .18 *p* = .381 *n* = 27	*r* = .14 *p* = .494 *n* = 28	*r* = .34 *p* = .080 *n* = 28
Product information	*r* = .06 *p* = .767 *n* = 28	***r* = .45** ***p* = .018** ***n* = 28**	*r* = .30 *p* = .115 *n* = 28	*r* = .13 *p* = .510 *n* = 28	*r* = -.04 *p* = .844 *n* = 27	*r* = .11 *p* = .594 *n* = 28	*r* = -.01 *p* = .955 *n* = 28
Insurance information	*r* = .07 *p* = .772 *n* = 18	***r* = .67** ***p* = .002** ***n* = 18**	*r* = .29 *p* = .248 *n* = 18	*r* = .23 *p* = .358 *n* = 18	*r* = .24 *p* = .339 *n* = 18	*r* = .14 *p* = .587 *n* = 18	*r* = .32 *p* = .200 *n* = 18
All card decks (1-4)	*r* = .28 *p* = .118 *n* = 32	***r* = .50** ***p* = .004** ***n* = 32**	*r* = .32 *p* = .074 *n* = 32	*r* = .35 *p* = .050 *n* = 32	*r* = .17 *p* = .350 *n* = 31	*r* = .23 *p* = .201 *n* = 32	*r* = .27 *p* = .131 *n* = 32

Note. Statistically significant correlations ($p < .05$) are shown in bold font.

e. Changes across Time

Figure 25 shows the changes that took place in participants' usefulness judgments across time. The figures in parentheses within the data labels indicate the number of participants who indicated that they had used this type of content and, thus, provided a usefulness rating. This figure and Table 32 (above) show that participants' ratings of the usefulness of stories/personal experiences and information about home remedies increased quite a bit. Meanwhile, their judgments about the usefulness of information about treatment facilities and/or providers and risk factors decreased over time. Based on paired-samples t-tests, the only statistically significant changes were an increased rating [initial interview: $M = 4.61$, $SD = 0.56$; follow-up interview: $M = 4.87$, $SD = 0.34$] for diagnostic tests/procedures ($t(30) = -2.278$, $p = .030$, $d = 0.41$) and a decreased rating [initial interview: $M = 4.24$, $SD = 0.72$; follow-up interview: $M = 2.00$ $SD = 1.15$] for product information ($t(24) = 7.296$, $p = .000$, $d = 1.46$).

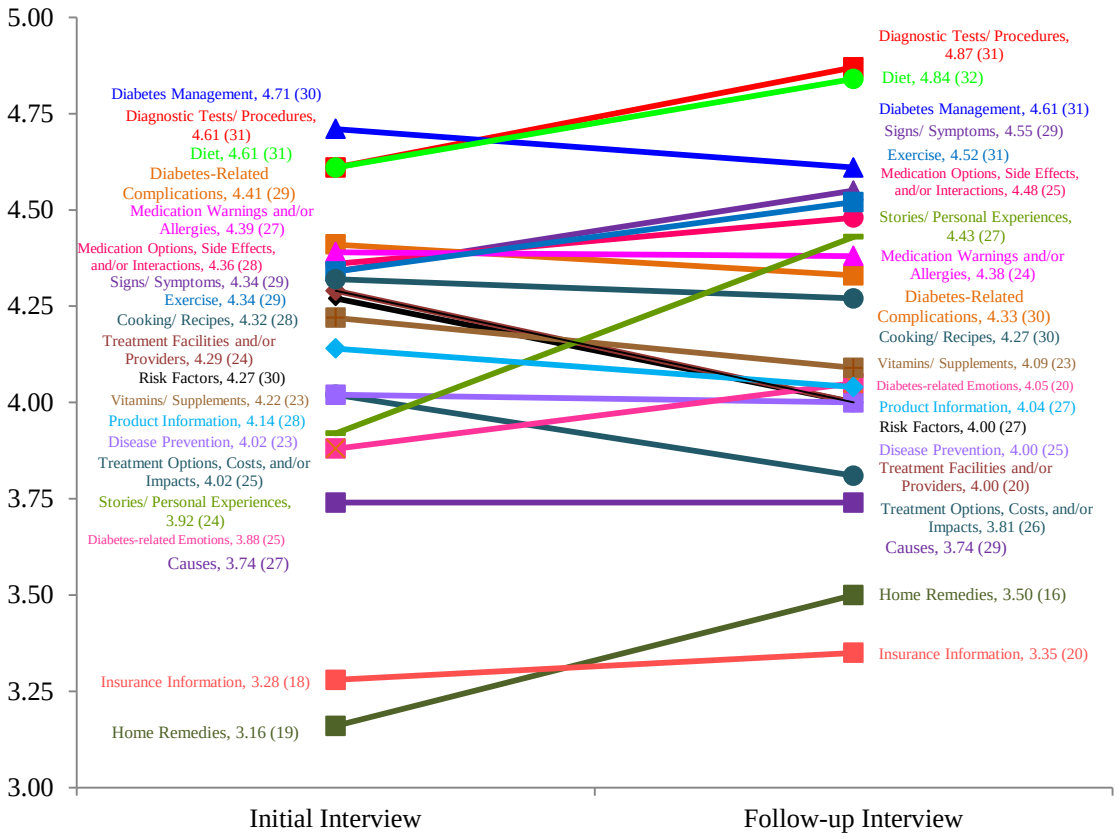


Figure 25: Participants' Ratings of the Usefulness of Different Types of Content

4.5.5.2 Participant Comments regarding Usefulness of Different Types of Content

At the close of this card-sorting exercise, participants were asked to talk about which content type(s) which have been the most useful for them. Nearly all participants selected one or more content types that had to do with managing one's diabetes, such as diabetes management, signs/symptoms, diagnostic tests/procedures, diet, cooking/recipes, and exercise. However, several participants also indicated that the stories and personal experiences of people with diabetes had been particularly useful for them.

Frequently, the information that participants found most useful was information that was helpful for them in their effort to manage their diabetes. I09 indicated that information about diabetes management and diet were the most useful. She explained, "The doctor gives me the prescription, but everything else I'm in charge of. So… I take those little pills that she ordered for me, but… my condition is determined by how well I

manage things and what I eat." I16 similarly selected diabetes management, diet, and exercise as the most useful content types. He explained that he selected these three topics because "diabetes management – diet and exercise are two big parts of it. I have diabetes but the most important thing is managing it… and diet and exercise are the keys to managing it." I31 selected diabetes management, signs/symptoms, and exercise because "You need to know what the sign is to let you know that your blood sugar is rising or that it's going down low… And then you need to know how to manage your blood sugar." I18 selected exercise and diet "because I think they've been the most useful in fighting what I now call 'the big hurt'… It hurts me in so many ways." I15 also emphasized the importance of diet: "I'd say the diet part to all of it would be the most useful to know… because if you actually look at it, that's where it all ends up to be [is] under diet basically." I08 said that diagnostic tests/procedures were the most useful for her. She explained, "Those let you know what direction you're heading in, whether there's an improvement or no improvement or it's getting worse… They're sort of like the mile signs on the highway." I23 indicated that the A1C test was the "most important thing of all" because "it tells you how you're doing… and whether you have to do something else."

A few participants mentioned that people's stories and personal experiences with diabetes were especially useful. I03, for example, indicated that her husband's stories and personal experiences had been the most useful for her. She explained, "Just because he's lived it, he's close to me, understands about me. The information that I get from him, I trust him." I01 also indicated that people's personal experiences have been the most useful for her. She explained, "My friends have really told me what they've been through and what they've done and what's helped them and what's not helped them." I31 similarly stated, "I think people and personal experiences was the biggest thing… because in talking to them, they showed me the ropes, you know, to show me what to do." I04 particularly liked the stories in *Diabetes Management* magazine about people with diabetes. She said that this magazine "give[s] these kinds of stories that says, 'Just because you got it don't mean you can't do it'… I like that. I enjoy that." I18 also indicated that stories and personal experiences have been very useful for him. This participant had described an incident after he was diagnosed when he had eaten a bag of

jelly beans: “It felt like my whole body locked up. I could feel it from my kidneys on… It hurt all over, like I had way too much sugar in me… I have not had sugar since that day.” When asked why he felt that stories and personal experiences were particularly useful, he explained, “That story I keep repeating about the jellybeans really is for me more than anybody. It’s a reminder of what mistakes I have made and how to learn from them.”

4.5.6 Changes in Perceptions of Usefulness across Time

At both the initial and follow-up interviews, participants were asked questions about whether they felt like the types of diabetes-related information that they deem useful has changed over time. During the initial interview, participants were asked to discuss whether and why they had found different types of information to be useful at different steps along their experience with diabetes. During the follow-up interview, participants were asked to talk about whether they feel like different types of information have become more useful or less useful over time. In the following subsections, participants’ remarks regarding whether any changes have taken place in their perceptions about the usefulness of different types of information are explored.

4.5.6.1 No Changes

Some participants indicated that there have been no changes in the types of diabetes-related information that they deem useful. When I21 was asked whether he had found different types of information to be useful at different steps along his experience of having diabetes, he replied, “Not really. There’s nothing any more important than any other one. You need to know as much as you can… whatever pertains to you.” I04 similarly replied, “Not really, no… There’s really no steps to it… It helps everything… I don’t say, ‘Okay, I got information for pre-diabetes or I don’t have information for advanced diabetes.’ It’s just altogether there.”

4.5.6.2 Changes

Many participants, however, did indicate that changes had occurred in their perceptions about what information is useful to them. For example, when I29 was doing the card-sorting exercise regarding content types, he stated, “Some of these… they… are related to the stage of diabetes you’re in. As my diabetes has progressed, [information about diabetes-related complications] is more important.” Some participants described

specific changes that took place in their perceptions regarding the usefulness of information. The most common patterns in participants' descriptions were: (1) A progression from finding general information useful to finding more specific information useful; (2) A sense that some of the information they had received or come across came too late for it to be useful for them; and (3) A transformation in their viewpoints on usefulness that accompanied a change in their attitudes about having diabetes and/or about the behaviors necessary to manage the disease.

a. General to Specific

An overall progression from finding more general information useful at first to finding more detailed information useful later on was described by some participants. I09, for example, described, "I felt kind of a little like lost and ill-informed in the beginning. The information I got was really basic, but maybe just at the beginning, maybe more basic stuff was okay." I32 stated, "At first, knowing what it is, general information, is useful and then being able to get detailed information when you drill down… I'd have to get a broader understanding before I got a detailed understanding." I03 explained, "I think the general information first was helpful. And then as I went along, more specific, like… specific strategies… the carbs, the whole thing about diet and exercise and all that. Those kinds of things became more important." I24 described a similar progression from more general information to more detailed how-to information: "The books were more handy upfront to understand the disease and the effects. Now if I'm going to use the Internet, I use it more for finding out like a recipe." I25 described, "When I was first diagnosed, I was looking for a lot of general information… about what it was and that sort of thing. Today, I'm fairly knowledgeable about that so I look more for specifics."

b. Information Received too Late to be Useful

It was quite common for participants to describe situations in which they had been given or came across information too late for it to be useful for them. I29, who had had a heart attack and two strokes, expressed the wish that a physician or a nurse had told him "This thing is a time bomb and you've got something ticking in you that is going to blow up at some point… If you start now, you can change that trajectory." I16 emphasized:

> The pre-diagnosis information, like the symptom information… that would have been more helpful to me than anything… I had this suspicion because of the family history when I saw some of the signs but… I wasn't… scared enough to go… to a doctor right away.

I27, who was initially diagnosed with diabetes in 1980, attended a series of diabetes-related classes when she went on insulin in 1994. She stated, "If I were to have that in 1980, I would not maybe have been where I was in '94." I18 similarly stated, "I think that some of the information I learned later on should have been early on… Like those jellybeans… Not eating the whole pack." He also mused, "Disease prevention, I wish they would have talked to me about it."

During the card-sorting exercises, many participants talked about changes that occurred over time in the potential usefulness of diabetes-related information. For example, while working on the card-sorting exercise involving different types of content, I10 offered, "If you would [have asked] me right when I got diagnosed, signs and symptoms is probably the top one… because it was the symptom of the insatiable thirst that got me." When asked how useful information about disease prevention has been for her, I13 replied, "Disease prevention? No. I could have used that 20 years ago." When asked how useful information about the causes of diabetes has been for him, I21 replied, "Neutral… It doesn't really help me now." I23 similarly replied, "I guess I would say not at all useful because I got it and I'm not interested in any more about it than what I know… Once you've got it, you've got it." When asked how often he looks for information about the signs and symptoms of diabetes, I14, who had suffered a hearing loss and who was having problems with dangerously low white blood cell counts and muscle cramping, replied: "It's a little late for the signs and symptoms with what I got going… Never."

c. Changes in Perceptions of Usefulness caused by Attitude Changes

Sometimes information became more useful to participants as their attitudes about having diabetes and about the behaviors necessary to manage it improved. I15, for example, explained:

> I was just like throwing all the information [out], pretty much all, because I just wanted it to go away… And then when you really stop and think about it, it isn't going to go away so you might as well take the information and deal with it… So

> [the information has] all been helpful when I stop and quit being so stubborn about it.

I03 similarly described, "Until I was able to personalize [the information], I wasn't ready to hear it or read it or whatever." When asked what she meant by "personalize," she explained, "The whole, like the denial versus really, really getting in tune to what it is… I didn't think of it as a major health issue." I12 stated:

> I think I had a closed mind about [meal planning] and I felt that I was going to eat what I wanted to eat then. But the more the nutritionists just kept going over and over… it was like a light went off… I understood more of the importance of meal planning.

4.5.7 Impact of Information Behavior

Both quantitative and qualitative results from this study provide evidence of the important role that information behavior plays in enabling people to feel like they are coping better physically, cognitively, and emotionally with having diabetes. The first subsection below reports the results of some regression analyses that were run using data from participants' health condition questionnaires and card-sorting exercises that were administered at their initial interviews. The second subsection discusses participants' comments regarding the impact that they feel that learning about diabetes has had on their experience with diabetes.

4.5.7.1 Information Behavior Factors as Predictors of Perceived Health and Well-Being

The results of some OLS regressions based on participants' responses to the health condition questionnaires and the card-sorting exercises that were administered at the initial interviews provided very strong evidence of the importance of information behavior in contributing to one's perceptions of one's health and of one's sense of well-being. For example, a regression analysis predicting participants' ratings of their general health from their usefulness ratings across all four decks in the card-sorting exercises was statistically significant [$F(1,30) = 7.01$, $p = .013$]. Their usefulness ratings explained a significant proportion of the variance in their health ratings ($R^2 = .19$). For every unit increase in their usefulness ratings, their rating of their general health increased nearly one unit [$\hat{Y} = 0.989X - 1.287$]. Another regression analysis predicting participants' ratings of the severity of their diabetes-related symptoms from their usefulness ratings

across all four decks was also statistically significant [$F(1,30) = 7.75$, $p = .009$]. Their usefulness ratings explained a significant proportion of the variance in their ratings regarding the severity of their diabetes-related symptoms ($R^2 = .21$). For every unit increase in their usefulness ratings, their rating of their general health increased nearly one and one-half units [$\hat{Y} = 1.413X - 2.340$]. Yet another regression analysis that predicted participants' ratings as to how certain (as opposed to uncertain) they felt about their experience with diabetes based on their usefulness ratings across all four decks was statistically significant [$F(1,30) = 9.76$, $p = .004$]. Their usefulness ratings explained a significant proportion of the variance in their feelings of certainty/uncertainty ($R^2 = .25$). For every unit increase in their usefulness ratings, their rating of their feelings of certainty about their experience with diabetes increased nearly one and one-half units [$\hat{Y} = 1.460X - 2.134$].

Two additional regressions showed that information-related variables contributed significantly to participants' feelings of being in control of their experience with diabetes and to their perceptions that they were coping well with having the disease. Educational attainment, along with participants' ratings as to how satisfied they felt with getting their diabetes-related questions answered and how alone they felt about their experience with diabetes, were found to be statistically significant predictors of participants' ratings as to how in control they felt about their experience with diabetes [$F(3,27) = 7.78$, $p = .001$]. These predictors together explained over 46% of the variance in their ratings regarding how in control they felt of their experience with diabetes ($R^2 = .46$). The predictor relating directly to information behavior – degree of satisfaction with getting diabetes-related questions answered – was found to be the most statistically significant ($p = .003$) in this regression analysis, slightly surpassing the aloneness predictor ($p = .004$) and substantially exceeding the educational attainment predictor ($p = .036$).

Perceptions regarding the adequacy of one's current understanding about diabetes and how confused or clear one felt about one's experience with diabetes were found to be statistically significant predictors of participants' ratings as to how well they felt they were coping with having diabetes. [$F(2,29) = 17.28$, $p = .000$]. These predictors together explained nearly 55% of the variance in their ratings regarding how well they felt they were coping with having diabetes ($R^2 = .54$). Participants' ratings of their current

understanding about diabetes and of their clarity/confusion regarding their experience with diabetes were both highly statistically significant predictors of their beliefs as to how well they thought they were coping with having diabetes [Current understanding: $p = .005$; Confused/clear: $p = .000$].

4.5.7.2 Participant Comments regarding the Impact of Learning about Diabetes

During both the initial and follow-up interviews, participants were asked to talk about the difference that finding out about diabetes has made in their experience with diabetes. Their responses provided further evidence that learning about diabetes has enabled them to feel like they are better able to cope physically, cognitively, and emotionally with having diabetes. Primarily, there were two ways in which their information behavior influenced their experience with diabetes: (1) It helped them to *learn how to manage* their diabetes and (2) It helped them to *feel better* about having diabetes.

a. Learning How to Manage Diabetes

Learning about diabetes provided many participants with the know-how necessary to be able to successfully manage their disease. I28 stated, "Finding out that I was a diabetic gave me the opportunity that I could put up a good fight." I14 emphasized, "An educated diabetic is always going to have the upper hand on control issues." When asked what difference finding out about diabetes has made in his experience with diabetes, I06 replied, "Oh boy, it's made all the difference. It's a world of difference. Education and knowledge is the key in this disease, at least for me. You know, without the information, I wouldn't know how to take care of myself." I04 described, "The more I find out, the more I learn to control it." I10 similarly explained, "The more I know, the better it is and the more it helps… The more I know, the easier it is to notice changes, what might be causing the changes. It makes it easier to just go with it." This participant went on to say, "If my sugar is spiking, I know to get up, walk around , do things that will burn it off. If I'm crashing, eat something." I30 similarly described:

> I guess I'm very much in control of [my experience with diabetes] for the simple reason [that] I just about have the tools that I need to control it… Like the blood sugar testing and knowing what to eat, not to eat… But if I didn't know that, I wouldn't be in control.

When this participant was subsequently asked how well he felt he was coping with having diabetes, he replied, "I prefer to go with the coping very well… It's because I do know the do's and the don'ts… By me knowing that… it makes it a lot more easier for me to cope with this." I31 summed it up this way: "Once you know better, then you do better. But if you don't know better, you don't do any better. But you have the information there and you follow it."

Some participants mentioned that learning about diabetes has enabled them to be less restrictive in how they managed their diabetes. I05, for example, described:

> I can eat about anything now because I know how to judge it, I know how to take my insulin for it… You know when you can have something that's going to cause that sugar to go a little higher and when you can't.

I31 similarly lamented that diabetes-related information, both from her dietician and from the Internet, is too "tight." She explained that both of these information sources were very restrictive in terms of what they say you *can* do. She pointed out that by talking to other people with diabetes, she has learned how to successfully manage her diabetes without being unnecessarily restrictive toward herself. She explained using an analogy:

> The more information you have, the easier it is to deal with… It's like going on a trip. You know nothing about this trip, so you're in the dark. But when you find… different things like where to go, you can go to park, you can go fish, you can go to this show, and you can do that. So then it's better because then you have information.

Some participants emphasized that learning about diabetes has saved their lives. I25, for example, stated, "I probably wouldn't be here if I hadn't taken the time to educate myself." I21 indicated that diabetes-related information is "definitely a life-saving thing for me." I16 stated, "Just finding out about diabetes means that I've got it under control. Obviously, I might be dead if I had ignored it and didn't go to the doctor."

Learning about diabetes also enabled participants to communicate better with their healthcare providers and other people in their lives. I34 described the difference that finding out about diabetes has made in her experience with diabetes this way:

> I feel pretty confident when I ask questions with my doctor… I have at least an idea of what I am talking about… When she tells me things, I have a pretty good understanding of what she is trying to relay to me.

I29 similarly indicated that finding out about diabetes "has allowed me to ask more precise questions of doctors and nurses and other patients." This participant went on to describe communicating with his nurse: "I wrote her back and said, 'I also want you to know that during this last week, I've had a cold and I know that can impact your blood sugar.'" He explained, "I wouldn't have known that [I should mention that]… I wanted to give her everything I knew that was related to my situation to help her make a decision." I28 similarly pointed out: "The more information I can gather and let [my doctor] know, I think the better information I can get about what to do or what not to do."

The learning process also enabled participants to help other people in their lives to manage their diabetes or to avoid getting diabetes in the first place. I04 explained, "[Finding out about diabetes] makes me more aware of my family members. I've got two very young nephews that everybody's very scared that they'll have diabetes." When asked what difference finding out about diabetes has made in her experience with diabetes, I27 replied, "Well, my brother sees me as an authority on it. And that's kind of a good thing… They come and ask me questions and stuff… Being now an authority [chuckle]… and I survived it." I03 similarly described:

> My husband… he has diabetes also… Sometimes he asks me to check out [a diabetes-related question] and see on the Internet what it is… Where previously, he had read a whole bunch of… books and things and he would tell me. So that changed a little bit in that he'll ask me to check it out.

I08 described the role of learning about diabetes as "More helping others." She explained, "I started out with a lot of basic knowledge, but then when I got it, I wanted more than basic. And when I got more than basic, then I became frightened for other people." When asked what difference learning about diabetes has made in his experience with diabetes, I29 stated, "It's empowered me to offer the advice that comes from my experience to others with diabetes."

b. Feeling Better about Having Diabetes

Learning about diabetes led to important affective impacts, as well. While a handful of participants mentioned that learning about diabetes led to negative affects for them, most participants felt that it played a positive role in their experience with diabetes. These positive roles included helping them to feel more empowered and more in control

of their diabetes experience, motivating them to learn more about diabetes and to use this information in order to manage their diabetes, helping to combat negative affect, such as shame, loneliness, uncertainty, worry, fear, and discouragement, and inspiring them and giving them hope.

Just a few participants mentioned that they felt that learning about diabetes had led to negative affects for them, such as feeling unnecessarily restricted, confused, and vulnerable. When asked what difference learning about diabetes has made in her experience with diabetes, I01 replied, "Well, just that I've had to be on a stricter diet than I thought I should be on… I'm still miffed about the potatoes [laughter]." I26, who passed away just before her follow-up interview, similarly replied:

> Well, it's stopped me from eating some of my favorite foods. I don't have as much appetite as I used to. I don't know if that's just because with the things I know, that I really don't even know what I'm able to eat but the things that I figured that I'm able to eat, I don't have a taste for them, I only have a taste for something else.

I34 replied, "I feel I know more, but I feel more confused now that I know more… I don't feel like I have a complete picture whereas before my misunderstanding was that it was simple. [laughter]" I22, who had recently developed gastroparesis (i.e., partial paralysis of the stomach), replied, "It made me hate the disease… I don't think I hated it as much as I do now." This participant emphasized, "You can try to control diabetes, but do you ever control it? It's like cancer, you can try to keep it under… but you never really control it, it controls you. I feel that way." I18 replied, "I used to think I was invincible… And now I find out that something as simple as sugar is my kryptonite… I have to be careful because it could sneak up at any time."

Participants particularly valued the ability of learning and information to empower them and to enable them to feel in control of their experience with diabetes. Several participants (I03, I06, I16, I28, and I32) emphasized, "Knowledge is power." I28, for example, stated, "Knowledge is power… The more I know about what's happening within my body by my numbers… I'll be alright." I12 explained the likely impact of not having learned about diabetes: "I could be in a lot worse shape… Health-wise, I could be in pretty bad shape right now… I wouldn't be empowered… to make choices… decisions I'm making as far as how I'm taking care of my diabetes." I15 similarly stated, "I feel

very little in control of my experience with diabetes. I'll put 'somewhat in control' even though if I learn more about it, I can totally be in control, I think." I11 emphasized, "The more information you have, the more control you feel." I09 stated, "I have a very strong sense now that the choices that I make with diet and exercise can have a positive effect." This participant went on to explain that gathering information helps her to reduce her uncertainty: "I like to know that I'm… in normal range. I like to know that I'm making good choices… It helps me feel like I'm in control, the more informed I am." I06 similarly explained, "As I get more information and become educated about it… it kind of gives me more control."

Participants also mentioned that learning about diabetes motivates them to learn more about diabetes and/or to use their diabetes-related knowledge to manage their diabetes. I33 described, "I think in my situation… being diagnosed, learning about it, being motivated, and then wanting to learn more because, to me, it's like a game, I've got to be on top of it." I16 stated, "Definitely finding out about all of the effects that it can have on your body has really made we want to take care of myself… keep my A1C under control." I23 similarly explained, "I think just finding out more about it and… the complications that can come from it makes you want to make sure you stay on your, not a diet, but eating the proper foods and not eating the cake." I29 said that he would call his diabetes education "very useful and very motivational."

Some participants emphasized the potential of information to combat negative affects, such as shame, loneliness, uncertainty, worry, fear, and discouragement. For example, I03 stated, "Disease prevention… That's where I get into my feeling ashamed about it. [Laughter] So I probably haven't gotten enough information about it, the prevention, or I might feel better about it." When asked how alone he felt regarding his experience with diabetes, I16 replied, "Not alone at all… I got relatives that have it and I have all the good access to information and stuff." I01 said that talking to other people with diabetes "made me feel better about myself." She further stated, "I felt much better because they all have the same problems." I32 stated, "I don't feel uncertain [about my experience with diabetes] at all. Now that I know what's going on and I'm very knowledgeable about it, I feel very good about it." I05 described the value of talking on her CB with other truck drivers about having diabetes: "It… made me not worry about

it… because it helped me to get things eased up in my mind." I09 described "feeling like the more information I have… the less stressed out I am." I06 stated, "As you get educated and as you learn, then the fear subsides and you realize that you do have some control." I35 similarly indicated that learning about diabetes has made her "more comfortable with dealing with it. Not to be afraid." I28 indicated that learning about diabetes has provided encouragement for him. He stated:

> It has encouraged me to don't let diabetes be the downside of my life. Don't concentrate on because I have diabetes that I can't do certain things. I may have diabetes but I can still continue to do certain things. It's just that I just have to regulate things.

The capacity of information to inspire and give one hope was also greatly valued by participants. I20 emphasized:

> Information does give you hope… positive examples of people being threatened with the same kind of threats you have and then being able to overcome them through a certain regimen… I think the information that I got helped me go through those stages, helped me get from the "Oh, I have diabetes. Oh, I'm depressed." to "Okay, I got it… Of all the diseases to have… this is the best disease… because you can get over this one."

I09 explained that information she has gotten from the Website ASweetLife.org "makes me realize that my life doesn't have to be limited [chuckle] with diabetes… It's nice to know that people can make choices and take charge and still lead very active full lives." I17 similarly described, "I like reading the stories about other people and their success with managing diabetes… If someone could do something different… and it made a difference for them, then it might be something I can try." This participant went on to say, "I'm always curious about how someone managed or someone progressed with the disease and how they did so well for so long… If they were really good for a really long time, then that's hopeful to me."

4.5.8 Summary: Perceptions of Usefulness

The findings from this study relevant to the third research question about participants' perceptions regarding the relative usefulness of different sources and types of information reveal that participants define usefulness in terms of the traditionally recognized criteria of relevance, novelty, factualness, currency, reputation/qualifications of the source, accessibility/usability, and instrumentality. Above all, however, they

wanted information that would help them with their day-to-day attempts to manage their diabetes.

Regarding different types of people, participants found more formal sources of information, such as doctors, nurses, dieticians, and diabetes educators, to be more useful for helping them to learn about diabetes. Simultaneously, they found family members and friends who do not have diabetes to be the least useful. Among different media types, participants rated the Internet, books, and brochures/pamphlets as the most useful and they rated the mass media forms of newspapers, radio, and television as the least useful. Participants found search engines and medical Websites to be the most useful types of Internet sites and shopping Websites to be the least useful. Regarding different types of content, participants found information on topics that had to do with taking control of their diabetes, such as diabetes management, diagnostic tests/procedures, and diet, to be the most useful. However, they found insurance information and information about the causes of diabetes and home remedies to be the least useful.

The findings from this study also show that participants' perceptions about the usefulness of information did change across time. This was most clearly revealed by participants' answers to interview questions that asked about whether they feel like the types of diabetes-related information that they deem useful has changed over time. The majority of participants answered these questions in the affirmative. Furthermore, they identified some characteristic patterns in these changes, such as progressing from finding general information useful at the beginning to finding more detailed information useful later on. They also indicated that they sometimes received information too late for it to be useful to them and that they sometimes found that their opinions as to the usefulness of information changed as their attitudes about having diabetes and about the behaviors they need to adopt in order to manage it improved.

Correlation analyses that looked at the relationships between participants' responses on the card-sorting exercises and their responses on the background and health condition questionnaires at their initial interviews revealed some interesting findings. In general, participants who rated the usefulness of the different sources and types of information higher tended to be younger, to have had diabetes for a shorter length of time, and to report that they were in better health. They also tended to report that they

were more interested in participating in making decisions related to their healthcare, more active about looking for information about diabetes, and more satisfied with getting their diabetes-related questions answered. Furthermore, they tended to report feeling more positive emotionally (e.g., feeling more certain, more clear, more optimistic, less alone, more in control, and like they are coping better with having diabetes) about their experience with diabetes.

Participants described a number of important ways in which finding out about diabetes made a difference in their experience with diabetes. They pointed out that learning about diabetes provided them with the know-how they needed to be able to successfully manage their diabetes. It also enabled them to minimize unnecessary restrictiveness in the ways that they managed their diabetes. Participants also emphasized that learning about diabetes had even saved their lives. Another importance difference that finding out about diabetes made in the lives of participants was that they felt that it enabled them to communicate better with their healthcare providers, and thus, be able to get better information from them. Participants also mentioned that finding out about diabetes has made them more aware of and more able to help other people in their lives who have diabetes or who are at increased risk of developing it. Learning about diabetes also contributed to a number of positive affect-related outcomes. Participants emphasized that finding out about diabetes made them feel more empowered and more in control of their experience with diabetes and provided motivation for them to learn more about diabetes and to use the information they had in order to manage their diabetes. They also indicated that finding out about diabetes helped to combat numerous types of negative affect, such as shame, loneliness, uncertainty, worry, fear, and discouragement. Furthermore, it also inspired them and made them feel more hopeful.

4.6 Impact of Participating in this Study

Many participants commented that participating in this study has been helpful for them. They appreciated having an opportunity to reflect on their experience with diabetes and this reflection sometimes led to self-discovery. They also reported that participating in this study increased their awareness of their information needs, information seeking practices, and the diabetes-related resources available to them. Additionally, they

indicated that participating in this study provided them with increased motivation to look for and make use of diabetes-related information.

4.6.1 Appreciation of the Opportunity for Reflection and Self-Discovery

The last question during the follow-up interview asked participants to reflect on whether participating in this study had influenced, or will influence, their behavior in any way. A considerable number of participants mentioned that it has been helpful to them from an emotional standpoint and/or that it has helped them to become more self-aware and to learn from themselves. I01, for example, stated, "It's therapeutic… I think it helps me out, especially lately when I've been so… upset with my doctor." I15 described how the initial interview helped to bring her out of her denial about having diabetes:

> [The denial] went all the way until like right after we had our first meeting… That's when I kind of realized… When we first met… because you was asking me all them questions kind of made me aware of everything that I'm not thinking about.

I34 emphasized that participating in this study was helpful because she was being asked questions rather than simply being told what to do: "I think it helps because… you ask a lot of questions… So it makes me think more about different things that I might not think [of] ever… subjects that I wouldn't come up with on my own." This participant further explained, "Nobody else really asks questions so much as they tell you, 'This is what you need to do'… Maybe just the questions, like I said, just opening up doors that maybe weren't opened by anybody else's questions."

Some participants simply appreciated the opportunity to talk about their experience with diabetes. As I01 described, "I appreciate [it]… because I can't always tell my daughters things… And my sisters, they just don't always want to hear it or they got their own problems or they may think that I'm not doing things right." I34 similarly pointed out, "I found… that actually just talking to somebody about stuff [helps]… because my husband, he doesn't have a clue. And my friends don't really know. Obviously, they're not at risk for diabetes, at least not fat people diabetes." This participant further stated that she considered these interviews somewhat of a support group. She explained, "Like I said, you're probably the person I've talked to most about it… other than my doctor. I told my husband and he was like, 'I don't want to know

about this. It scares me.'" She later re-emphasized: "As far as putting it on an emotional level… how it is affecting me, how do I feel about it, I probably talk to you more than anyone… I have my own little therapy." I17 similarly stated:

> It was helpful, yeah. It feels like you listen to me. I think people want to preach at you and you're supposed to take it all in… I find it satisfying to meet with you. It's like a one-on-one thing and I like that… I don't think you can get enough support.

This participant went on to describe, "It's just been really nice to talk to somebody one-on-one. You don't seem judgmental… And it feels good to air it, say things." She also indicated that participating "builds my confidence as far as the diabetes is concerned." I28 similarly described, "I think this was a very informative study… It brought my attention to… Even though I didn't know a lot about diabetes… through this study… I have been gathering I've been… doing the right things to learn about diabetes." I22, who was helping her husband (I23) deal with his much more recent diabetes diagnosis, stated:

> I think it'll make me aware of that I give more information than I think I do, that I do more than I think I do. I think it did make me aware that I do have more purpose than I think I do.

Some participants valued their participation in this study because it enabled them to become more self-aware and to learn from themselves. I31 said that participating is "making me be more aware of myself and circumstances and knowing that I can help somebody, make a difference in someone else's life." I17 stated, "I've said things that maybe I didn't even know… There's something being drawn out of me that helps me know myself… This has been a discovery for me… I'm learning something from this." When completing his timeline, I20 stated:

> You made me think. You made me sort out some issues, organize my thinking… And… whenever you flesh things out with somebody else, it helps you to focus. And it just helps you to articulate really what's going on inside… It's almost like when you're writing, you have to first think about it and you have to organize your thoughts before you can project this… This is… really good.

I21 similarly stated, "Basically, it just let me see what I'm thinking a little bit… now that it's on paper. Kind of like doing a journal except what you're doing is writing in it first instead of after you get done." I18 stated, "Today is positive. I'll circle it… Thinking

about… Anytime that you can go back over it and you think to yourself, 'Oh, yeah. You know what?'…"

4.6.2 Increased Awareness of Information Needs, Information-Seeking Practices, and Available Resources

Several participants said that participating in this study made them more aware of their needs for information. I03 stated, "This was really helpful for me too in terms of… bringing up things that I hadn't really thought of or put a finger on... I kind of identified some things that I'd like to find out more about." I30 described the influence of participating: "I guess I could say more of keeping me on my P's and Q's about diabetes… It's been a… help." I13 stated, "You've added to my list of questions." I01 stated, "You made me aware that I do want to find out more information." I09 emphasized, "I feel like these interviews have made me a little more… aware of my attitudes and my journey." I14 described his participation in the initial interview as one of the turning points in his journey with diabetes:

> [The initial interview] raised my awareness of… my diabetes… I don't think about getting questions answered or anything like that… I really never thought that way until the first interview when you were asking me these questions. They just made me think.

Several participants pointed out that participating in this study has made them more aware of their information-seeking practices and the sources that they turn to for diabetes-related information. I12 stated, "It makes me more cognizant of what I do to get information." I34 pointed out:

> Actually, doing this has been a good thing… It makes me more aware of what I'm… doing and how I'm doing it, because… you don't really think about maybe your methods or what you're actually gathering as you go along… [It makes me more conscious of] where I'm gathering my information, how I'm going about it.

Some participants specified that participating has made them more aware of the various sources of diabetes-related information. I11, for example, stated, "I think [participating] makes me more knowledgeable about some of the sources… It definitely made me think more about how do people get information about medical stuff." I14, referring to his initial interview, stated, "It was a turning point…. It kind of opened my eyes… not at anything in particular other than the fact that there are resources."

Some participants concluded based on their interview sessions that they weren't doing everything that they could be doing in terms of getting information about diabetes. While completing one of the card-sorting exercises, I03 stated, "Deal with my emotions about diabetes… To get information about that… Never. I need to. Some of my never's are the things that I need to do." I16 similarly stated, "Keep up to date on new discoveries, treatments… I should, but I really haven't." I18 said, "Learn what I can do to improve my health and/or prevent disease. You know what? I never even thought about that… Probably not… I should." When completing the card-sorting exercise about the usefulness of different types of diabetes-related content, I15 exclaimed, "Wow! See, you're just showing me what I need to do… I'm going to have to do some studying, ain't I? This makes me feel bad – to know I ain't done none of this."

4.6.3 Increased Motivation to Look For and Make Use of Information

For some participants, the interview sessions motivated them to look for diabetes-related information. I29 said, "It's been a long time since I've looked at [a specific diabetes-related book]… If I wanted to go back to that book, which… this conversation… stimulates me to do it..." When specifically asked how participating in this study has influenced his behavior, this participant replied:

> I think I will be a … probably more active searcher… Just the focus and attention on information and how I use it and what I value in the information that I seek… I think it will enhance my information collection behavior.

I03 described looking for information following her initial interview: "I checked out… about the stress. I remember that because I was like, 'I want to know that and I never even thought to check it out.' So I did." I13 pointed out that participating in this study has made her want "to use the Internet to track down a couple of those things that we talked about." I01 stated, "You made me aware that I need to find more information… So when I get these funerals over with, I'll try to go on the Internet and see if I can find something new." I16 stated, "Now that you've got me thinking about it, maybe I'll… try and get some automated search for diabetes information." I14 described the influence of participating in this study:

> I think I'm more compelled to get information, raise questions to the practitioners… I think some of that [looking up information in order to prepare for a doctor appointment or following a doctor appointment] I had thought about

> from time to time, but not always. But I think from this point on, I'll definitely be seeking more information… [I'll] be a little more conscientious.

I34 stated, "[This has] probably been as much a resource or motivator as other things… [Motivating me] to get more and better information." I23 explained:

> I think you're emphasizing to me the importance of keeping up to date with what's going on in the diabetes world… And I think it will make me read… the full information that I get each time when I renew the prescription… I won't just put that away, I'll read it… I think I might talk a little more to other friends that I have that have diabetes and talk to them a little more about it… A little more awareness, I guess.

Some participants indicated that their participation in this study motivated them to use diabetes-related information in order to do a better job of managing their diabetes. I15 said that, as a result of the initial interview, "I started paying more attention to little stuff… like what brings my sugar up and down and stuff like that." I03 pointed out, "When you talked about these things, I think I was a little bit more motivated to get information [and]… to follow that information." I05 stated that participating in this study:

> Makes me watch my food more. It makes me watch my symptoms more and it makes me just do more… It brings to mind… instead of eating laying down, get out a little bit or get up and walk around a little bit or don't eat so much… Make sure I do my medication.

I18 described his behavior after our initial interview session: "I started looking up more information… Changed my diet just after that, too… I became more carb-conscious, staying out of sugar, lowering my A1C, keeping my diet right… It made me put more thought and effort into it." I17 talked about the value of participating in this study in terms of it helping her to rededicate herself to trying to manage her diabetes: "I think I need a renewal. Probably this conversation has prompted me to renew… I think with diabetes, you can level up and then you need to get excited about it again." I25 stated, "I think it's made me more aware of where some of my problems are. And, hopefully, I'll act on some of those issues." At his follow-up interview, I33 stated:

> It has motivated… The next time I have this interview… there will be progress and there will be more changes… 'cause you hate to be doing interviews and interviews and we're still stuck in the same, doing the same thing. It's like what's the sense of doing these interviews if you're not going to change?

When asked whether participating in this study has influenced or will influence her behavior in any way, I34 replied, "Yeah. I'm guessing that the next few weeks, I'll probably do better at maintaining things because… talking to someone about it makes it more prevalent in your daily activities."

4.6.4 Impact of Participating in this Study: Summary

Based on participants' comments, it appears that simply participating in this study led to some important benefits for them. They felt that having the opportunity to talk about their experience with diabetes was helpful both cognitively and emotionally. Participating in the interview sessions helped them to become more self-aware and enabled them to learn from themselves. It also felt therapeutic to some of the participants. Another benefit of participating in this study mentioned by participants was that it increased their awareness of their information needs, as well as their information seeking practices and the diabetes-related resources available to them. Participants also mentioned that the interview sessions motivated them to look for diabetes-related information and/or to use this information in order to better manage their diabetes. These benefits that were mentioned by participants may be able to be re-created within an information provision/sharing context.

4.7 Summary: Results

The findings from this study are based on initial interviews with 34 participants and follow-up interviews with 32 of these individuals. Participants were quite diverse, ranging in age from 32 to 81, ranging in educational attainment from some high school to graduate/professional degree, ranging in initial diagnosis date from 1980 to 2010, and ranging in initial A1C results from 5.6 to 14.0. Both qualitative and quantitative data were collected through administration of background questionnaires, health condition questionnaires, semi-structured interviews, card-sorting exercises, and elicitation of timelines. The results from this study reveal four central themes: (1) Information plays a very important role in enabling participants to feel better able to physically, cognitively, and affectively cope with having diabetes; (2) Participants were not always aware of their information needs (incognizance); (3) Participants did not always act on information they had; and (4) Participants' information needs and information seeking and use practices,

as well as their perceptions about the usefulness of information, did, indeed, change over time.

Participants emphasized that learning about diabetes saved their lives. Furthermore, they pointed out that this learning process also enabled them to communicate better with their doctors, both in terms of being able to understand them and knowing what information was relevant and should be passed on to them. They noted that because of their improved ability to communicate with their doctors, they were able to get better information from them. Participants also emphasized that finding out about diabetes increased their positive affect, making them feel more empowered, more hopeful, more motivated, and more in control of their experience with diabetes. Simultaneously, they reported that the learning process decreased their negative affects, including shame, loneliness, uncertainty, worry, fear, and discouragement.

The importance of information and information behavior in participants' journeys with diabetes was supported by quantitative data from the questionnaires and card-sorting exercises that were administered during this study. Many statistically significant relationships involving information and information behavior factors were found. Participants who rated information as more useful tended to report that they were in better health, more interested in participating in making decisions related to their healthcare, more active about looking for information about diabetes, and more satisfied with getting their diabetes-related questions answered. They also tended to report feeling more positive about their experience with diabetes in that they indicated that they felt more certain, more clear, more optimistic, less alone, more in control, and like they are coping better with having diabetes.

One of the central findings of this research is that participants were not always aware of their information needs at the time when information would have been the most useful to them. This state of incognizance, which often resulted from a failure to recognize relevance at the most opportune time, sometimes had disastrous consequences. Incognizance may actually be the key to understanding why in this study and in many other studies (Carlsson, 2000; Gollop, 1997; Kutner et al., 1999; Warner & Proccacino, 2004) the majority of people with a health condition indicate that they have all the health-related information they need. It may also help to explain the declines that took place

between the initial interviews and the follow-up interviews in participants' assessments about the availability of diabetes-related information.

Another important finding of this study is that participants did not always act on the information they did have. Sometimes this was because they believed that the information they had was not relevant to them or because they felt that it was not something that was actionable for them. Other times, however, their inaction was caused by either their failure to understand the seriousness of diabetes or their attitudes toward the behaviors that are necessary to manage the disease (e.g., healthy eating, exercising, monitoring one's blood glucose levels).

Overall, this study found considerable evidence that participants' information needs and information seeking and use practices, along with their perceptions about the usefulness of information, did change across time. Regarding information needs, their awareness of these needs definitely unfolded across time. Also, participants definitely viewed learning about diabetes as a cumulative process that took place over time. They also indicated that this process tended to be more intense immediately following diagnosis (or acceptance of the diagnosis) and then taper down over time. Participants also described changes that took place over time in their ability and/or willingness to make use of diabetes-related information. Often, these changes were brought about because the participant developed a diabetes-related complication or because something changed in his/her life circumstances, relative prioritization of diabetes, and/or general outlook on life. Participants' perceptions about the usefulness of information also changed over time. They described some general patterns, such as finding general information more useful at first and then finding specific information more useful later on. They noted that changes in their perceptions of usefulness were sometimes caused by changes in their attitudes toward diabetes and the behaviors necessary to effectively manage it. Participants emphasized that, at times, they have received information too late for it to be of the most use for them.

Chapter 5

Discussion

This study has investigated the consumer health information behavior of people with diabetes and the ways in which it changes over time. It has resulted in the identification of many factors that motivate, demotivate, and/or impede these individuals' information seeking and use at various points in their journey with diabetes. Furthermore, it has identified the methods that they use to look for and implement diabetes-related information in their lives and the ways in which their information seeking and use practices transform over time. Lastly, it has identified the sources and types of diabetes-related information that they find useful and how their perceptions of usefulness change as they have had diabetes for longer and as their information behavior changes across time.

Many of the findings from this study represent novel and important contributions to both information behavior theory and information-related professional practice. Overall, they provide support for the initially proposed conceptual framework in which people's information behavior and their health condition change over time, driving and being driven by one another. However, they have also permitted the adaptation of this framework to more fully represent the information-related attitudes and information behaviors of participants and how they tend to change across time. Not only have other types of factors, such as social and affective factors, been incorporated into the revised conceptual framework, but also characteristic stages in participants' journeys with diabetes have been discovered. For each of these stages, a predominant attitude and the typical level of information behavior activity are identified.

This chapter first provides a recapitulation of this study's central findings. Next, the degree to which this study's findings provide support for the initially proposed conceptual framework and the ways in which this framework might be revised to more

accurately and comprehensively reflect these findings are discussed. In the final section of this chapter, the limitations of this study are described.

5.1 Recapitulation of Findings

This section will summarize the main findings of this study, comparing and contrasting them with those of earlier studies within each of the following major topic areas: (1) Information needs, specifically people's opinions as to whether or not they have sufficient information about their health condition and the influence that incognizance may have on people's perceptions in this regard; (2) Information avoidance and the role of information seeking in enabling a person to cope with their disease; (3) Factors that motivate, demotivate, or impede information seeking and use; (4) People's perceptions as to the usefulness of information about their health condition; and (5) The centrality of the time dimension to consumer health information behavior.

5.1.1 Information Needs: Perceptions regarding Sufficiency of Information and the Influence of Incognizance

Many of the participants in this study emphasized that they haven't always known what it was they needed to know until after they had found it out. The identification of this state of unawareness of one's information needs ("incognizance") represents one of the novel and important contributions of this study to both information behavior theory and information practice.

Similar with other studies (Carlsson, 2000; Gollop, 1997; Kutner et al., 1999, Warner & Proccacino, 2004), however, this study found that the majority of the participants reported that they have sufficient information regarding their health condition. Nevertheless, as other researchers (Baker, 1998; Degner et al. 1997, Hack et al., 1992; Mills & Davidson, 2002) have found, some participants did indicate some dissatisfaction with the amount and/or types of diabetes-related information that they have been able to find. Also, in support of work by Schoenberg, Amey, & Coward (1998) and Burke et al. (2006), several participants in this study pointed out that their needs for diabetes-related information are ongoing and dynamic, rather than one-time and static.

Incognizance may help to explain the common finding that the majority of study participants tend to report that they have sufficient information regarding their health

condition. A person who is unaware of his/her information needs is unlikely to recognize that his/her needs for information are not being adequately met. As participants in this study indicated, there were times when they only became aware of an information need when they subsequently encountered information that would fit that need or developed full-blown symptoms of a diabetes-related complication. Unfortunately, this order of events, encountering information or developing a diabetes-related complication and only then recognizing a need for information, sometimes led to participants not having information at the time when it would have been most useful for them. For example, one participant (I27) who had been initially diagnosed with diabetes in 1980 and whose diabetes then progressed to the point where she was put on insulin in 1994, was not sent to a diabetes-related class until 1994. She stated, "If I were to have that in 1980, I would not maybe have been where I was in '94."

5.1.2 Information Avoidance and the Role of Information Seeking

The longitudinal design of this study permitted the discovery that information avoidance, at least for the participants in this study, tended to be a temporary stage that occurs directly following diagnosis and that is outgrown over time. Most of the participants in this study who mentioned that they went through an initial period when they did not want information about diabetes described some type of turning point that put an end to this phase. For some participants (e.g., I06), this turning point involved getting an additional health condition, such as a mental illness, under control. For others (e.g., I18), it involved developing physical symptoms perhaps related to the onset of a diabetes-related complication. While several other consumer health information behavior researchers (e.g., Hack et al., 1994; Miller, 1995; Miller, Brody, & Summerton, 1988; Wong et al., 2000) have also found that people may seek to avoid information about their illness, the cross-sectional nature of their studies hindered their ability to identify that information avoidance was a temporary phase rather than a stable personality characteristic, role preference, or coping style.

Like the work of many other researchers (e.g., Ankem, 2006a, Hack et al., 1994; Mills & Davidson, 2002; Wong et al., 2000), this study found that information seeking plays a crucial role in enabling participants to cope with and feel in control of their illness. Learning about diabetes helped the participants in this study not only to manage

their diabetes, but also to cope better emotionally with the disease. For the vast majority of participants, diabetes-related information empowered them, made them feel more in control of their experience with diabetes, helped to mitigate some of their negative affects, such as shame, loneliness, uncertainty, worry, fear, and discouragement, inspired them, and gave them hope.

5.1.3 Factors Motivating, Demotivating, or Impeding Information Seeking and Use

This study resulted in the identification of several factors that motivate people's health-related information seeking, including physical factors such as symptoms and desired future physical state. The importance of symptoms in driving the information seeking of many of this study's participants provides support for Johnson's (1997) claim that salience is what "provides the underlying motive force to seek information." (p. 72) Other novel motivating factors that were identified were social in nature. These included a desire to take care of themselves so they would be around for other people (often their children) and an interest in helping others who have diabetes or who are at an increased risk of developing diabetes. Still others were related to contextual factors that changed over time. The degree of accessibility of information within one's everyday environment, as well as changing life circumstances and priorities, were also identified as factors that can motivate information seeking and use.

Some of the factors that were identified in this study as motivating information seeking and use simply support the findings of other researchers. For example, as Clark (2005) found, many of the participants in this study were motivated to look for diabetes-related information in order to reduce negative affects, such as fear, anxiety, and uncertainty. Wong et al.'s (2000) finding that patients look for information in order to regain a sense of control was also supported by this study. This study's findings also supported Czaja et al.'s (2003) finding that patients' information seeking is bolstered by the possession of social support and a desire to be involved in health-related decision-making.

The findings from this study also revealed some factors that demotivate and/or impede information seeking and use. For example, participants mentioned that their desire to find out more about diabetes was decreased by physical factors such as a lack of symptoms or an abundance of symptoms, and social factors such as stigma and a lack of

social support. Some of the impeding factors identified in this study include comorbidities and lack of resources such as money, transportation, insurance, computers/Internet access, and time; not prioritizing the disease in one's life; feeling dissatisfied with how doctors and other healthcare providers treated them; and several types of cognitive barriers including incognizance and other types of cognitive limitations.

Some of the factors that participants in this study mentioned as barriers to their information seeking and use have been identified by other researchers. For example, as Baker (1998) found, participants in this study were impeded by physical disabilities, negative emotions, and a lack of relevant information. Another impeding factor identified in this study, mistrust of physicians, was identified previously by Matthews et al. (2002). Fishbein's (1967) finding that people's attitudes toward a behavior are a much better predictor of that particular behavior than their attitudes toward the object at which that behavior is directed proved to be particularly apt. Many of the participants in this study mentioned that they were dissuaded from looking for diabetes-related information because of their attitudes toward the behaviors they perceived to be necessary in order to manage their diabetes, such as engaging in healthy eating and exercising.

5.1.4 Perceptions Regarding Usefulness of Information

Although the criteria that participants used in judging the usefulness of information (e.g., novelty, perceived personal relevance, factualness, currency, reputability/expertise of source, accessibility/usability, and instrumentality) largely support the findings already in the literature, this study yielded one novel finding in this regard. Participants described sometimes making predictive judgments that information was not pertinent to them that turned out, in retrospect, to have been incorrect. Foskett (1972) pointed out that scientific revolutions are fueled by information that is pertinent even though it is not relevant. It was quite the reverse in this study – diabetes-related complications resulted when participants failed to recognize the pertinence of relevant information. Wilson's (1973) definition of situational relevance helps to explain why this may occur. He emphasized that situationally relevant information is information that is relevant to a person's situation "as he sees it, not as others see it or as it 'really' is" (p. 460). Wilson further specified that information is only situationally relevant if it relates to

an aspect of someone's situation that is currently of concern to him/her. For participants in this study, the lack of symptoms in the current moment often led them to erroneously deem information as not pertinent and as not potentially useful. Later, as symptoms developed, they recognized, in retrospect, the pertinence and usefulness of information that they had previously encountered.

Taylor (1968) found that within the primarily cognitive-oriented context of information seeking within the library setting, people's information needs, as well as their understanding of and their ability to articulate these needs, evolve across time. However, this study further found that, within the context of consumer health information behavior, people's *awareness* of their information needs and their ability to accurately discern the potential relevance and usefulness of information also change over time. By incorporating a social dimension as well as the dimension of time, this study revealed that people may have information needs that are as yet unknown to them, and thus, information may be relevant to their situation even though it does not appear to fit with any of their known information needs at the time. Subsequently being provided with or coming across relevant information may prompt them to recognize information needs of which they had been previously unaware. People within the participants' everyday lives, including their family members, friends, and/or healthcare providers were often able to help them in this regard. People who had had diabetes for longer and who had been successfully managing it for an extended length of time were often perceived to be particularly helpful in enabling participants to know what the questions are. As I17 put it, "The older people in the support group… I like the questions they ask because some of them might be questions that I wouldn't even ask."

5.1.5 Centrality of Time in Consumer Health Information Behavior

As many researchers (e.g., Ankem, 2006a; Baker, 1998; Matson & Brooks, 1977) have previously found from their own studies, time was identified as a very important dimension of the consumer health information behavior of the participants in this study. Overall, participants became less active about trying to find out about diabetes between the time of their initial interviews and the time of their follow-up interviews. Furthermore, the factors motivating and impeding their information seeking and use also changed over time, particularly as they gradually learned to adapt to having diabetes, as

changes in their life circumstances and priorities occurred, and as they built up a personal history of successfully managing their diabetes.

Several researchers (Ellison & Rayman, 1998; Paterson & Sloan, 1994; Paterson & Thorne, 2000; Price, 1993) that have studied how people with diabetes learn to manage the disease have identified a series of stages that are characteristic of their learning process. Often, this set of stages begins with an initial stage of denial during which information is not sought, followed by a stage of engagement during which information is very avidly sought from multiple types of sources. A final stage involves taking control of one's disease and getting on with one's life.

The findings from this study confirm that there does appear to be such a set of stages that commonly describe how people learn how to manage their diabetes. From an information behavior standpoint, these stages tended to look like: (1) Stasis: "Diabetes isn't relevant to me"; (2) Diagnosis: "I'm so upset!"; (3) Engagement: "I want to know everything"; and (4) Adaptation: "I know everything I need to know (for now)". However, as noted by Matson and Brooks (1977), Paterson and Sloan (1994), and Paterson and Thorne (2000), progression through these stages was neither guaranteed nor linear. For example, some participants described being in denial at one or more points in their journeys with diabetes, which was basically a regression back to the Stasis stage from the Diagnosis stage. Also, several participants described regressing from the Adaptation stage to the Engagement stage when they developed new symptoms or when they came across new information about diabetes. These stages will be discussed further in the next section, which looks at the suitability of the initially proposed conceptual framework and how it might be revised to better reflect the findings from this study.

5.2 Revisiting the Initially Proposed Conceptual Framework

The findings from this study support the two central tenets of the framework initially proposed for this research: (1) The importance of looking at information behavior within context, as information behavior occurs within and across a backdrop containing other types of cognitive, physical, social, and affective factors and (2) The importance of looking at information behavior as something which unfolds over time. The first two subsections below address these two topics, while the last subsection

outlines the development of a revised conceptual framework which takes into account this study's findings.

5.2.1 Context-Dependent Nature of Information Behavior

The results from this study confirm, both qualitatively and quantitatively, that information behavior cannot be looked at in isolation as it is inextricably intertwined with other cognitive, physical, social, and affective factors. Qualitatively, the importance of looking at information behavior within the context of other factors is evidenced by the fact that people's descriptions of their information behaviors nearly always encompassed one or more other types of factors. Quantitatively, several statistically significant correlates of various information behavior measures were identified. For example, participants who reported that they were more active about finding out about diabetes indicated that they felt more certain and more clear (i.e., less confused) about their experience with diabetes. Participants who reported a greater degree of satisfaction with getting their diabetes-related questions answered indicated that they felt more certain, more clear, and more optimistic about their experiences with diabetes. Furthermore, they also felt more in control of their experience and like they were coping better with having diabetes. Participants who felt that diabetes-related information was more available to them reported less severe diabetes-related symptoms and they also indicated that they felt more clear and more optimistic about their experiences with diabetes. Finally, participants who reported that it was easy for them to get hold of diabetes-related information indicated that their diabetes-related symptoms were less severe and that they felt less alone regarding their experience with diabetes. Thus, active engagement in information behaviors and satisfaction with the results of this information behavior were linked with a wide variety of positive cognitive, physical, social, and affective factors. More specifically, being more active in terms of information behavior and feeling like one can get one's hands on any needed diabetes-related information were found to be linked with several positive outcomes, such as feeling better physically and feeling more certain, less confused, more optimistic, less alone, and more in control of one's experience with diabetes.

5.2.2 Time Dimension of Information Behavior

The results from this study also provide strong support for the contention that it is important to consider the dimension of time when looking at people's health-related information behaviors. Many dimensions of participants' information behavior, including their information needs and information seeking and use practices, the factors that motivate, demotivate, and/or impede their information seeking and use, and their perceptions regarding the usefulness of different types and sources of information, changed over time. In fact, one of the main problems identified by this study is that people may be at least temporarily incognizant; that is, they may fail to identify an information need, and thus, the potential relevance of information, at the most opportune time. This mismatch between when information was most needed and when it was actually provided, obtained, and/or acted upon sometimes contributed to the development of serious diabetes-related complications. Furthermore, incognizance was experienced at various, and often multiple, times during participants' journeys with diabetes.

5.2.3 Adapting the Initial Conceptual Framework

The conceptual framework initially proposed for this study is shown in Figure 26.

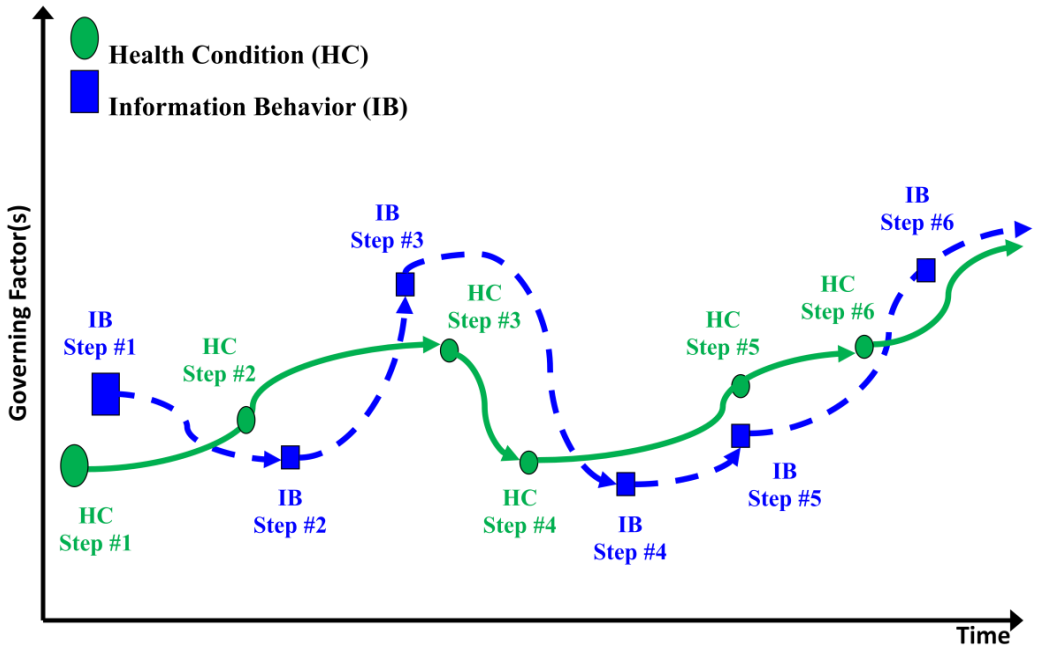


Figure 26: Initial Conceptual Framework

While this framework did prove to be accurate, particularly in terms of the crucial importance of the time dimension to consumer health information behavior and to the interwoveness of information behaviors and health condition factors, it was too simplistic to accurately reflect and encompass the entire reality. Along with the interview data, the timelines completed by participants provided crucial information as to how the initially proposed conceptual framework could be improved. For example, the major elements of I06's timeline are depicted in Figure 27.

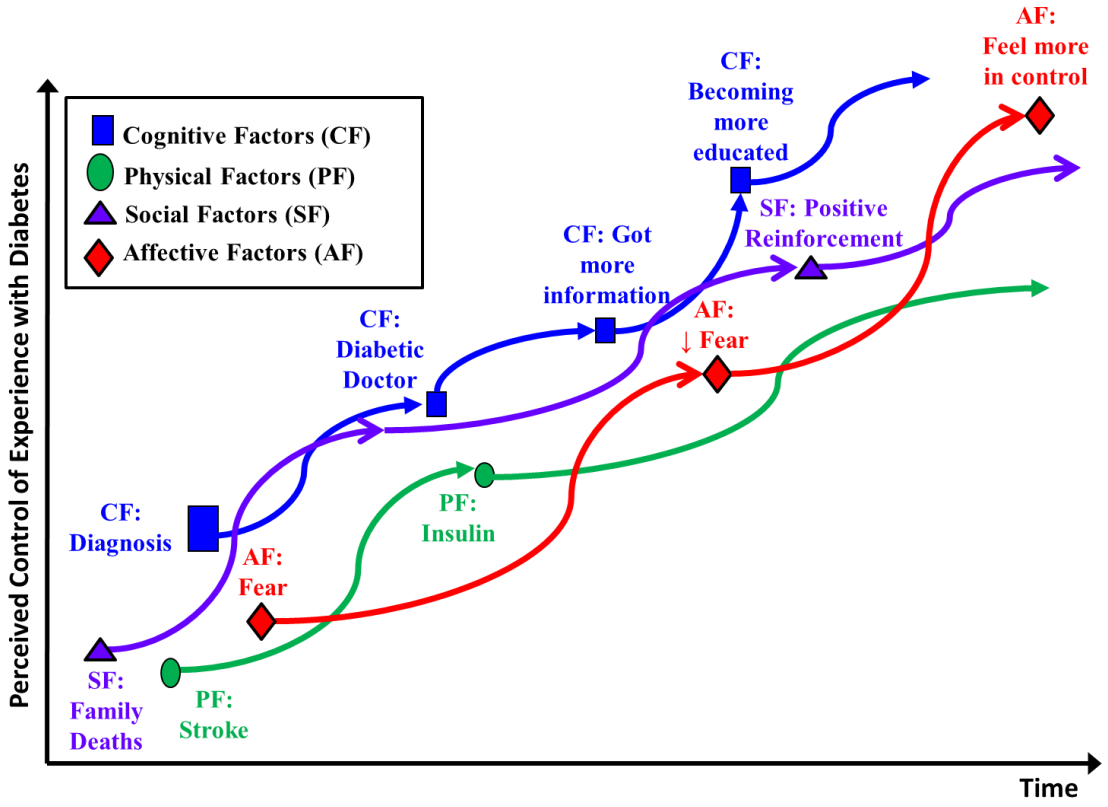


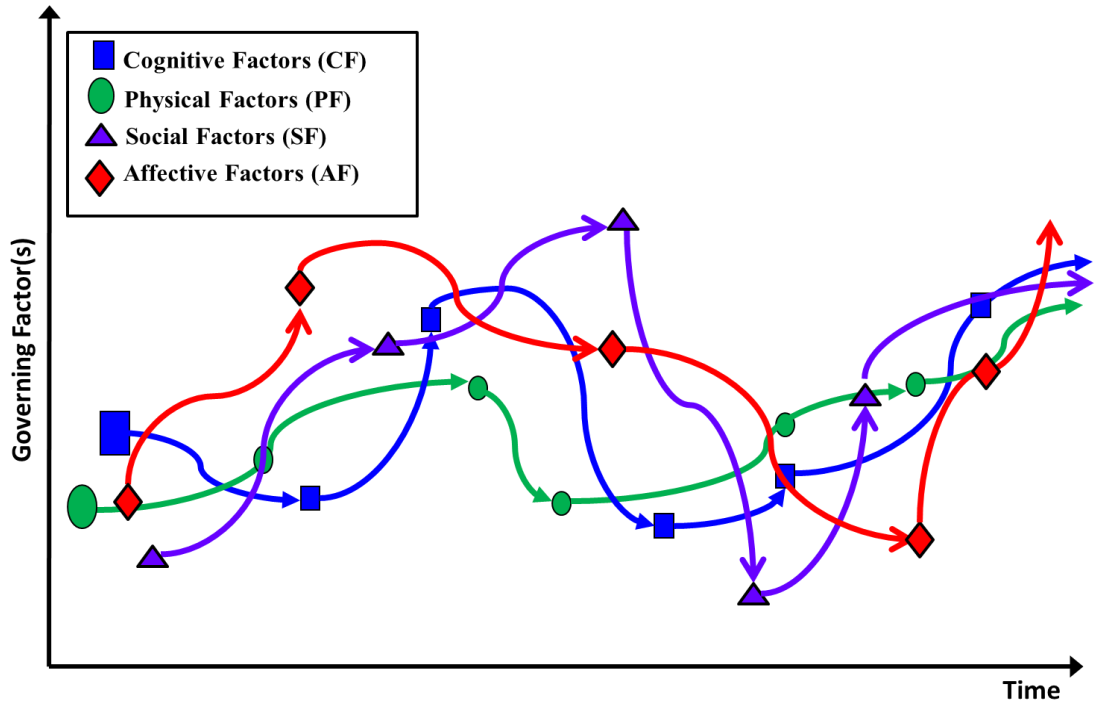
Figure 27: Depiction of Major Elements in Participant I06's Timeline

This participant (I06) described a general trend of feeling like he was more and more in control of his diabetes as time went on. His diabetes-related experience began long before his own diagnosis, with his mother, father, sister, grandparents, and uncle all dying from diabetes-related complications. These deaths occurred between 2003 and 2008. In December of 2009, this participant had a stroke in his sleep and woke up with

one of his legs no longer working. He had no idea this was diabetes-related and believed that he had just slept on it wrong. He happened to have a doctor's appointment that day anyway, so he told his doctor about his leg. His doctor determined that his blood-sugar level was 1200 and put him in an ambulance to be immediately transported to the hospital. Once at the hospital, he was told that he had diabetes and that he had had a diabetic stroke. This participant was terrified that he was going to die. He was sent to a doctor that specialized in diabetes and this doctor put him on insulin. Over the ensuing months, I06 learned more and more about diabetes, which helped to assuage his fears. Also, as he became more educated about diabetes and received positive reinforcement from his doctor for his efforts at managing his diabetes, he felt more in control of his experience with this disease.

Figure 28 (see next page) shows a revised conceptual framework that reflects what has been learned from this study. This revised framework differs in that it incorporates not only health condition and information behavior factors, but also social factors, affective factors, and additional cognitive factors. The findings from this study show that people with diabetes experience changes in many different types of cognitive, physical, social, and affective factors across time and further, that these factors drive, and are driven by one another. Information behavior takes place amid all of this chaos, ideally enabling people to feel and to actually be more in control of their journey with diabetes.

Another way in which the initial conceptual framework needed to be revised is that, in the specific example regarding the hypothetical person's [Jane's] paths through her situation involving a health condition, it was presumed that the first thing that occurred was that she experienced some initial symptoms. However, the findings from this study suggest that information behavior, and perhaps even the more crucially important information behavior, often begins long before the symptoms become manifest. For example, when a person who does not have diabetes learns that a relative has been diagnosed with diabetes, but fails to perceive this as relevant to his/her own situation, this is, in itself, an information behavior. And one that may have a devastating impact on the person later in life.



STAGE:	Stasis	Diagnosis	Engagement	Adaptation
ATTITUDE:	"Diabetes isn't relevant"	"I'm so upset!"	"I want to know everything"	"I know everything"
INFORM-ATION BEHAVIOR	Very Inactive	Somewhat Active	Very Active	Somewhat to Very Inactive

Figure 28: Revised Conceptual Framework

One further enhancement was made to the revised conceptual framework shown above in Figure 28 in order to delineate the stages that participants tended to traverse during their journey with diabetes. Most participants progressed through four stages: (1) Stasis; (2) Diagnosis; (3) Engagement; and (4) Adaptation. However, as mentioned earlier, their movement through these stages was neither guaranteed nor linear.

The first stage, Stasis, was the period up until the point at which the person was first diagnosed with diabetes. During this stage, participants may have had relatives who had been diagnosed with diabetes, but they perceived no personal relevance at this point.

Diabetes was not much on their minds and they did not tend to look for diabetes-related information. For most participants, their own Diagnosis was the point at which they left the Stasis stage. The Diagnosis stage, itself, tended to be very affect-laden, with emotions sometimes clouding participants' ability to look for and make use of diabetes-related information.

Most participants described entering a stage of Engagement shortly after their initial diagnosis; however, a considerable number of participants first went through a (usually quite temporary) stage of denial before entering the Engagement stage, attempting to return to the Stasis stage. During the Engagement stage, participants tended to make a conscious decision to take on diabetes, realizing that it was up to them to manage it. During Engagement, participants tended to be motivated by a desire to feel in control of their experience with diabetes. Engaging in information behaviors, such as information seeking, information monitoring, information management, and information use, was one of the major activities that helped them to achieve this goal. During this stage, participants became more able to perceive the relevance and potential usefulness of diabetes-related information.

The next stage, Adaptation, began at the point at which the participant began to feel that they had sufficient information about diabetes. As nothing new seemed to be occurring, either in terms of bodily symptoms or developments within the field of diabetes, they tended to decrease their information seeking as they felt like they already knew everything they needed to know about diabetes. During this stage, participants tended to be less likely to recognize the potential relevance and usefulness of diabetes-related information.

Like Matson and Brooks (1977) and Paterson and Sloane (1994) found, the progress of the participants in this study through these stages was neither guaranteed nor linear. Some participants went through one or more periods of denial during which they returned (or attempted to return) to the Stasis stage. Also, some participants (usually those who had been more recently diagnosed) had not yet reached the Engagement stage and some other participants had not yet reached the Adaptation stage as of the time when they were interviewed for this study. Additionally, some participants described moving

backwards from Adaptation into the Engagement stage if they began to experience symptoms and/or developed a diabetes-related complication.

Throughout all of these stages, incognizance was present; however, it manifested itself in different ways. During the Stasis stage, participants had unidentified information needs of which they were unaware. During the Engagement stage, many participants described a developing awareness of their own incognizance – they began to realize that they did not know what it was they needed to know. Although they became more aware that they had needs for information, they often were unable to identify what these needs were. Their growing awareness that they had as-yet-unidentified diabetes-related information needs often spurred on the increased information seeking characteristic of the Engagement phase. They described engaging in very open-ended information seeking, during which they actively consulted and passively monitored many different types of information sources in the hopes that they would come across information that they needed, but didn't yet realize they needed (or even that it existed). Several participants emphasized that their awareness of their incognizance was very unsettling. They worried about the potential impacts of not being aware of what they needed to know.

Incognizance often persisted into or reappeared in the final stage, Adaptation. Often, this incognizance was triggered by a budding assumption that they now knew everything they needed to know about diabetes. While the reduced information seeking characteristic of this stage reduced their odds of coming across relevant and potentially useful diabetes-related information, their incognizance prevented them from perceiving the relevance and potential usefulness of diabetes-related information that they did, in fact, come across. However, the onset of any new symptoms or encountering any information about new developments in the diabetes field sometimes prompted participants to leave the Adaptation stage and to reenter the Engagement stage.

The insidiousness of incognizance is that people who wait for symptoms to appear or for new developments in diabetes-related research to cross their paths may be receiving information later in time than when it would truly be most useful for them. People will not be able to recognize the relevance of information that pertains to an unidentified information need and they certainly will not actively pursue information to fulfill an information need that they don't even perceive.

5.3 Limitations

This study has some limitations due to the research design and the specific methods employed. This study covers just a small span of time – just four to six months in people's journeys with diabetes. Thus, the results do not reflect more long-term types of changes that might occur across time. Maturation, which is commonly viewed as a potential threat to the internal validity of a (usually experimental) study, was actually one of the central variables of interest in this research. One of the major goals of this study was to explore the types of changes that took place as participants' knowledge about, and experience with, diabetes changed over time. However, some of this study's findings, such as the fact that participants tended to report feeling better over time, could be due to the phenomenon of regression toward the mean. Since I recruited participants at a time of crisis (i.e., when they had been recently diagnosed with diabetes or when they had recently developed a diabetes-related complication or gone on insulin), the likelihood is that the degree of their crisis would tend to lessen over time.

This study relied purely on self-reported data, which could be of limited accuracy and/or comprehensiveness. Demand characteristics is a potential threat to the validity of this study's findings, as participants could have attempted to discern the researcher's purpose and then changed their behavior accordingly. They could have inferred based on the questions they were being asked that the researcher was focusing on how important information is to someone who is trying to manage their diabetes and then, sensing this, tailored their answers to help confirm this. Additionally, they could have self-censored their answers to questions in an attempt to ensure their social desirability. Although this potential threat could not be completely eliminated, an attempt was made to be open-ended and even-handed when conducting the interview sessions with participants.

Researcher expectancy effects is another potential threat to the validity of this study's findings. The preconceived notions of the researcher about the importance of information in enabling people with diabetes to cope with their disease could have been unconsciously communicated to participants and then influenced their responses. In an attempt to prevent this type of bias, the researcher strove to word questions in an open-ended and neutral manner.

Another limitation of this study is selection bias. That is, people who responded to the study announcement on U-M's engage Website or to the flyer or to requests for participation made during diabetes-related support group meetings likely systematically differed in some significant way(s) from the people who do not. In fact, they probably tended to be people who were more actively trying to manage their diabetes. If this was the case, the fact that incognizance was found even among this particular population is of great interest and importance. An attempt was made to limit potential selection bias by using multiple methods to recruit potential participants.

The Hawthorne Effect was very clearly evident in this study, as many participants admitted that simply participating in this study had influenced, or would influence, their behavior in some way. Because of the longitudinal nature of this study, the researcher was able to directly ask participants about their perceptions of the influence of participating in the initial interview and of participating in the entire study. Although it was not possible to completely eliminate the Hawthorne Effect because of the very interpersonal nature of the data collection process, it was possible to gauge the extent and nature of its perceived influence through direct questioning of participants.

The small sample size of this study resulted in a lack of both statistical power and generalizability. Only *bivariate* correlations could be calculated from the quantitative data collected. There could be more complicated relationships between variables that could not be discerned from this type of analysis. Also, the findings from this study are not generalizable beyond the particular sample of people who participated in this study due both to the small size of the sample and due to the non-random recruitment methods that were used. Lack of generalizability is inherent in nearly any qualitative research design; fortunately, however, alternative measures of validity, reliability, and objectivity for qualitative studies have been proposed, such as credibility, transferability, dependability, and confirmability (Lincoln & Guba, 1985, p. 189). Additionally, several researchers (Barry, 1994; Fletcher, 1988; Schamber 2000) have concluded, "Researchers who are attempting to elicit cognitive perceptions for purely exploratory purposes can expect reasonably representative results with as few as 10 respondents" (Schamber, 2000, p. 743). Although this study was not limited to people's *cognitive* perceptions, it did include more than three times this number of participants.

In the next chapter, following a delineation of the implications and contributions of this research, some ideas for future research which address these limitations are proposed.

Chapter 6

Conclusion

This chapter opens with a discussion of the practical implications of the results from this study. Next, the theoretical, methodological, and practical contributions of this study are delineated. Some suggestions for future research in this area are then provided. The chapter then closes with some concluding remarks.

6.1 Practical Implications

The findings from this study not only confirm that information provision is of crucial importance, but also that there are specific ways in which this process can be optimized for people with diabetes. To maximize its effectiveness, information provision should be structured, interactive, bit-at-a-time, and ongoing. Furthermore, it should be positive and forward-looking, focusing on helping people to learn what they can do now and into the future in order to prevent diabetes and/or to control their experience with the disease. Also, information providers need to take into account not only information content, but also the affective qualities of both the person and the information, ensuring that there is a good fit between where the person is at the moment and both the content and tone of the information to be provided and the ways in which it is provided.

Ideally, information provision should be carefully tailored to the individual and what he/she is experiencing physically, cognitively, socially, and affectively in the current moment. However, it also needs to take into account and address likely current and future areas of incognizance given a person's current situation. While some participants (I05, for example) assumed that they would not experience incognizance because their doctors would surely tell them everything they needed to know, other participants (I06, for example) lamented that their doctors only provided information in response to their specific questions. This combination suggests a dangerous situation may be occurring in which patients may be assuming that their doctors will tell them what

they need to know – what the questions are – while their doctors are, in reality, merely responding to the questions these patients are actually posing to them. This underscores the need for doctors and other information providers to try to identify and remedy incognizance as proactively as possible. Also, as mentioned by several participants, participation in support groups may be another way in which patients' incognizance can be remedied.

Although some participants expressed a preference for just-in-time information, diabetes is a disease that necessitates looking backward and forward, as well as at the present. Information needs are not limited to the diagnosis process itself – they both precede and succeed the diagnosis period. Learning to manage diabetes consists of looking at what has worked and what has not worked in the past, what is going on in the present, and what could happen in the future. Learning upon developing a symptom that that symptom suggests that one might be experiencing a diabetes-related complication is way too late. By minimizing current and future incognizance as much as possible, we can help arm people with the information they need so that they will have it when it will be of the most use to them.

This study's results also suggest that merely *providing* information is insufficient. People need assistance with a wide array of information activities, including identifying their information needs, looking for information, processing and understanding information, evaluating and verifying information, synthesizing information and assessing its personal relevance, and enacting information in their own lives. In fact, the findings from this study suggest that it may be helpful to develop a new type of job, perhaps called "diabetes informaticist," in which a diabetes expert, whether their expertise has been developed through education or experience (preferably both), works one-on-one with people who have diabetes. The major role of the people in this profession would be to use general diabetes-related information to develop a personalized plan for each client that would help him/her to manage their diabetes. The diabetes informaticist would assume an ongoing role in his/her client's life, helping him/her to implement, assess, and iteratively adapt the plan as needed. By maximizing the personal relevance of this information and by making it actionable through careful tailoring to an

individual's specific situation, we can help people with diabetes to more effectively and more efficiently, as well as less painfully, get their diabetes under control.

Another role that information professionals could play involves helping to ensure that high-quality diabetes-related information is available within people's everyday life contexts. Several of the participants in this study emphasized that, although they do not actively seek diabetes-related information, they will look at it if they come across it in the course of their daily life activities. Thus, making diabetes-related information accessible in this manner may help to combat incognizance. It may also help to decrease the level of stigma that is attached, or that is perceived to be attached, to this disease. Furthermore, by making this disease more salient to the general public within the context of their everyday lives, it may help diabetics to be more aware of their diabetes and of the importance of prioritizing the management of this disease while also helping non-diabetics to be more aware of the types of symptoms that could indicate that one has diabetes.

Another implication of this study is that there are several social factors that can be harnessed to help people with diabetes. Participants learned from witnessing the success, as well as failure, of others with diabetes. However, many expressed a particular preference for hearing or reading about and learning from the success of others. Furthermore, many of the participants were very interested in helping others with diabetes or others who were at increased risk for diabetes. The natural intersection of both of these is to facilitate information sharing between people who have become experts at managing their diabetes and people who have either been recently diagnosed or who are facing struggles in this regard. This study strongly suggests that this will benefit both sides. Not only do the novices or the people having difficulties benefit from the learning and experiences of the experts, but also the experts are likely to benefit just from the act of helping others. As demonstrated in this study, people may learn about themselves simply by listening to themselves talk about their journey with diabetes.

6.2 Contributions

This study has led to a number of different theory-related, method-related, and practice-related contributions. These are delineated in the subsections that follow.

6.2.1 Theoretical Contributions

This study makes a few different theoretical contributions. On a very general level, it adds to our knowledge of consumer health information behavior, and to our very limited knowledge about information behavior specifically within the context of having type 2 diabetes. Furthermore, it lends strong support to the notion that information behavior needs to be looked at both longitudinally and within the wider context of a person's life. However, this study's main theoretical contribution is its identification of the state of incognizance.

Within the cognitive approach, information behavior has traditionally been defined to begin with a person's recognition, or at least sensed presence, of an information need. By incorporating not only the cognitive dimension but also the social dimension and the dimension of time, this study reveals that within the consumer health information behavior context, information needs may exist even without the holder's awareness of them. This incognizance tended to arise due to either not having yet been exposed to relevant information or having been exposed to relevant information but being unable and/or unwilling to recognize and/or accept its personal relevance at the time of exposure. Ideally, people's unidentified information needs can be inferred and/or elicited by experts who take into consideration a person's current situation. By helping people to become aware of their needs for information as soon as possible, the incidence of situations in which people develop this awareness only after developing problems due to their unidentified and unfulfilled information needs can be reduced.

The identification of incognizance represents a novel and important contribution to information behavior theory. The recognition of this state expands the scope of information behavior backwards in time to encompass information needs of which one is as yet unaware. This state of incognizance precedes Anomalous State of Knowledge (Belkin, 1980), which is a state that begins at the point when a person perceives that there is an inadequacy in his/her state of knowledge. Incognizance involves the presence of unidentified information needs, which are at a level below (in terms of degree of consciousness) Taylor's (1968) visceral need, in which a person has a recognized, but perhaps as yet inexpressible, information need. Taylor's (1968) research regarding the question negotiation process aimed to enable librarians to better fulfill the information

needs of their patrons by helping them to become better able to articulate their needs. This study found, however, that within the context of consumer health information behavior, people may need help at an even earlier stage with the process of developing an initial awareness that they have an information need.

Unidentified information needs may be identified retrospectively by the person himself at some later point in time or they may be presumed and/or elicited and perhaps fulfilled by domain experts, such as healthcare providers or people who have learned to successfully manage their diabetes. The latter identification method is preferable in that it may help to ensure that people have the necessary information and that they are able to recognize its personal relevance closer in time to the point at which they begin to need it. This may help to maximize the potential usefulness of information across the person's entire journey with diabetes.

6.2.2 Methodological Contributions

This study makes several methodological contributions to information behavior research. First, it underscores the need to study people's information behavior both contextually and longitudinally, considering a wide array of factors and how these factors proceed in parallel and/or interact with information behavior across time. Second, the richness of the findings lend support to the notion that using a combination of multiple methods, some qualitative and some quantitative, will yield more contextually rich data. The unique combination of data collection and data analysis methods used for this study proved to be particularly advantageous. While the interviews elicited people's stories about their journeys with diabetes in their own words, the health condition questionnaires and the card-sorting exercises provided quantitative data that enabled a comparison of participants' perceptions across time. Third, this study offers new adaptations of data collection methods that might be of use to other researchers: (1) elicitation of timelines in order to learn about people's journey through a situation and what they perceive to be important about that journey and (2) Use of a card-sorting technique to gather information about people's perceptions regarding the usefulness of various types and sources of information and regarding the frequency with which various motives drive their information behavior.

The open-endedness of the timeline technique proved very useful in this study, as it allowed the researcher to learn from participants about the events that they saw as pivotal in their journey. The timelines also provided evidence of the intertwined nature of the various dimensions in participants' lives, which formed a backdrop for their consumer health information behavior. The card-sorting technique proved advantageous in that it enabled the researcher to collect *relative* judgments, as participants felt free to re-categorize cards into different bins (e.g., move a card from 'very useful' to 'somewhat useful') as they proceeded through each deck. With the written questionnaires that were used in this study, participants were far less likely to change their answers to earlier questions depending on later questions that they were asked. Obtaining participants' relative judgments about the usefulness of different sources and types of diabetes-related information likely resulted in more accurate answers, as participants very carefully considered and reconsidered what should go into each of the available response categories. Additionally, many participants seemed to enjoy doing the card-sorting exercises. In fact, a few even asked at their follow-up interview if the researcher had brought the cards.

6.2.3 Practical Contributions

This study has also yielded a few important practice-based contributions. As outlined in the practice-based implications section above, it has led to several suggestions as to how people with diabetes might be best assisted from an information standpoint. Furthermore, the fact that so many participants found it helpful to participate in this study suggests that some of the methods incorporated in this study could be used to help people to become more aware of their information needs, as well as their information seeking and use practices. For example, participants seemed to really enjoy the card-sorting exercises and they often pointed out that this process helped them to become more aware of what they were doing and what they were not (but should be) doing about their diabetes from an information standpoint. For some participants, the timeline exercise proved to be of particular value. Discussing one's story and seeing how it unfolded across time sometimes enabled them to make connections that they hadn't really noticed before. Just having an opportunity to talk over and answer questions about one's experience with diabetes was appreciated and perceived to be beneficial. Furthermore, participants were

very excited about the idea of participating in research and about the possibility that their participation could help other people who have, or who are at an increased risk of developing, diabetes.

6.3 Suggestions for Future Research

As mentioned earlier, the research design and specific methods employed for this study have some limitations. These limitations could be addressed by future studies. For example, conducting a similar study with an extended data collection period would enable us to learn about the types of changes that take place in people's consumer health information behavior further out from the time of diagnosis. The findings from this study suggest that it is highly likely that important changes could be observed by investigating people's consumer health information behavior across a longer period of time. Also, using a diary method, perhaps in addition to the point-in-time interviews, would facilitate the collection of data about information behaviors closer in time to when they actually occur. This could reduce reliance on participants' memories and thus enable the collection of more accurate and more comprehensive data. Including family members and/or friends in interviews could not only yield more accurate and/or comprehensive data, but also allow us a glimpse into the important information-related roles that these people play in the diabetic's life. The unsolicited and unexpected joint participation in this study's interviews by patient and spouse or by patient and adult child suggest that family members and friends can be an important source of information about the disease-related and illness-related experiences of the patient. Lastly, constructing a survey informed by these findings and then administering this survey to a much larger group of people with diabetes could help us to confirm the external validity of some of these findings. Furthermore, it could enable us to identify some additional significant factors that relate to the information behavior of people with diabetes and how it unfolds over time.

In addition to the above suggestions for methodological adaptations to this study, another idea for future research is to broaden the scope of this study to encompass other types of chronic, serious health conditions that require patients to look for and use information in order to manage them across time. The findings from this study suggest that these future studies should be longitudinal in nature and should cast a wide

contextual net. This study provides strong evidence of the importance of looking at consumer health information behavior in a longitudinal manner. Participants' information needs and their awareness of these needs, their information seeking and use practices, as well as their attitudes toward information and their ability and willingness to implement information in their own lives underwent important transformations. Furthermore, their information behaviors took place across a backdrop of other changing contexts which involved other cognitive, physical, social, and affective factors. All of these different types of factors were found to interact with each other across time. Findings from future studies that focus on other types of health conditions could be used to assess the applicability of this study's initial and revised conceptual frameworks and the conceptual framework could be further enhanced and refined so that it represents consumer health information behavior across a broader range of contexts.

Social, information-focused programs that aim to address one or more of the practical implications from this study, such as people's needs for assistance with various types of information activities and/or their preference for learning from the success of other people with diabetes, could be developed and outcome-based evaluations of these programs could then be conducted in order to assess their effectiveness. The findings from these studies could inform the development of future such programs.

Including doctors, along with their patients, in future studies could help to illuminate whether, and the extent to which, patients' assumptions about their doctor's information provision practices actually match their doctor's intentions and actions in this regard. The identification of any mismatches could be of crucial importance and could help to inform the development of more transparent doctor-patient communication processes regarding doctors' information provision philosophies and patients' information-related needs and expectations.

Future research that focuses on the long-term impact of incognizance and having unmet or insufficiently met information needs on a patient's ultimate health outcome is also needed. A longer-term study that looks at the effects of being unaware of one's information needs and/or of not having information that one deems to be relevant and actionable on one's illness trajectory could yield some very important findings.

6.4 Concluding Remarks

The results of this study provide evidence that the information behavior of people with diabetes plays a very crucial role in enabling them to feel better able to cope physically, cognitively, and affectively with this disease. Learning about diabetes was perceived to lead to important outcomes for participants, including an improved ability to successfully manage their diabetes, an increased possibility of avoiding diabetes-related complications and premature death, an enhanced ability to communicate with their healthcare providers in terms of both providing and receiving relevant information, and increases in positive affect and decreases in negative affect.

Two major factors, however, were found to mitigate the potential capacity of information behavior to positively influence one's journey with diabetes. First, incognizance sometimes prevented participants from having access to, or recognizing the relevance of, information that they needed at the point in time when it would have been of the most use to them given their current situation. Second, possession of information did not necessarily translate into use. Information that was deemed not personally relevant, not actionable, or not desirable was particularly prone to being perceived as not useful and tended to be simply ignored and discarded, at least temporarily.

The information behavior of participants in this study changed over time. For example, their information needs, along with their awareness of these needs, underwent important transformations. Also, they viewed learning about diabetes as a cumulative process that unfolded over time. Participants also described important changes that took place in their ability and/or willingness to use diabetes-related information in the service of managing this disease. These changes were often prompted by the onset of new symptoms, perhaps related to the development of a diabetes-related complication, or by some transformation(s) in the participant's life circumstances, his/her prioritization of diabetes, and his/her general outlook on life. Furthermore, participants' perceptions as to the relative usefulness of different types and sources of information also changed over time.

One of the central threads running through this study is the importance of having, and acting on, the right information at the right time. For some participants, information came too late to be of help to them. Although this sometimes stemmed from simply not

having access to the needed information, it often was caused by incognizance, which rendered them unable to proactively see the potential relevance and usefulness of diabetes-related information within their own lives. With the prevalence of diabetes projected to increase both globally and domestically, growing to afflict approximately one-third of the United States adult population by 2050 (Centers for Disease Control and Prevention, 2010), working toward the twin goals of increasing timely access to useful diabetes-related information and combating incognizance across all of the stages of the disease is of dire importance.

Appendices

Appendix A: Posting for Michigan Institute for Clinical & Health Research (MICHR) engage Website

IRB Number: HUM00036474

Title: Information Behavior of Patients with a Chronic Serious Health Condition: A Longitudinal, Exploratory Study

Condition Category: Diabetes

Study Description: This study focuses on the experience of type 2 diabetes patients with getting help and information about their condition. If you are at least 18 years old and have recently been diagnosed with type 2 diabetes, have recently started on insulin for this condition, or have recently developed a complication related to this condition, please contact me to participate in an interview. This interview will take up to 2 hours and will be conducted at a location of your choice. Your willingness to share your experience could help others in a similar situation.

Eligibility:

- Age Range: 18 years of age or older
- Gender: Any
- Ethnicity: All
- Race: All
- Smoking: Both smoking and non-smoking
- Medication: No restriction
- This study is seeking: patients with specified condition
- Other eligibility factors: None

Location of study visits: To be selected by each participant

Principal Investigator: St. Jean, Beth

Compensation: $40 for participation in initial interview

Expected Recruitment End Date: October 2010

Contact for this Study

Beth St. Jean
(734) 218-4758
bstjean@umich.edu

For University of Michigan Staff

IRB Number: **HUM00036474**
Formal Title: Information Behavior of Patients with a Chronic Serious Health Condition: A Longitudinal, Exploratory Study
MCRU Study: No
Cancer Center Study: No
Department: School of Information

Appendix B: Recruitment Flyer

Willing to talk about your experience with type 2 diabetes?

If you are at least 18 years old and have recently been diagnosed with Type 2 Diabetes, have recently started on insulin for this condition, or have recently developed a complication related to this condition, please contact me to participate in an interview. This interview will take up to two hours and will be conducted at a location of your choice. You will receive $40 for your time.

Your willingness to share your experience could help others in a similar situation.

I am a doctoral candidate in the School of Information at the University of Michigan. My dissertation research focuses on the experience of type 2 diabetes patients with getting help and information about their condition.

Diabetes Study
Beth: 734-218-4758
bstjean@umich.edu

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Appendix C: Informed Consent Form

Diabetes Study
Informed Consent Form

Thank you for agreeing to participate in this interview. This study seeks to investigate how people diagnosed with type 2 diabetes get help and information about their condition. This session will take up to 2 hours and will consist of a brief background questionnaire and an interview. Following the interview, you will be asked to answer some questions about your experience with diabetes and with related information sources. You will also be asked to participate in card-sorting exercises in which you will arrange information resources in terms of their usefulness to you and group your purposes for gathering information into different bins based on how often they tend to apply to your situation. During this session, I may also ask you if I may take photos of your diabetes-related items and/or information that I can later use to prepare and illustrate reports based on this research. You will have the option to participate in a follow-up interview session, as well. You will be paid $40 in cash upon your completion or your voluntary termination of this initial interview and an additional $50 after the follow-up interview. The findings from this study will be useful for other people with type 2 diabetes, as well as for information professionals striving to assist people with diabetes in meeting their needs for relevant and timely information.

Your participation in this project is voluntary. Even after you sign the informed consent document, you may decide to leave the study at any time without penalty or loss of benefits to which you may otherwise be entitled. It is possible that some of the questions I will be asking may be sensitive or upsetting depending on your health situation. If at any time a question makes you feel uncomfortable or asks you to reveal information that you would not like to share, please indicate that you would like to skip the particular question.

You will not be identified in any reports on this study. Records will be kept confidential to the extent provided by federal, state, and local law. However, the Institutional Review Board or university and government officials responsible for monitoring this study may inspect these records. In order to ensure that the information you provide cannot be linked with your identity, this form will be kept separate from your questionnaires and interview data. At the conclusion of this study, all links that tie your pieces of data together will be removed and the data will then be stored for a period of three years for the future research use of the principal investigator. You will be given a copy of this form to keep for your own records.

Should you have questions regarding your rights as a research participant, please contact the Health Sciences and Behavioral Sciences Institutional Review Board, 540 E. Liberty Street, Suite 202, Ann Arbor, MI 48104-2210, (734) 936-0933, email: irbhsbs@umich.edu. For all other questions about this study, please contact the principal investigator [Beth St. Jean, Doctoral Candidate, School of Information North, University of Michigan, 1075 Beal Avenue, Ann Arbor, MI 48109-2112, bstjean@umich.edu, (734) 218-4758] or her faculty advisor [Professor Soo Young Rieh, Associate Professor, School

of Information, University of Michigan, 304 West Hall, 1085 South University, Ann Arbor, MI 48109-1107, rieh@umich.edu, (734) 647-8040].

1. **I have read the information above and I consent to participate in this interview.**

   _____ _____
   Signature Date

2. **I am willing to have this interview audio-taped. Please note that you may still participate in this study if you are not willing to have the interview recorded.**

   _____ _____
   Signature Date

3. **I agree that you may use any photos of my diabetes-related items and/or information that I permit you to take during the course of this interview.**

   _____ _____
   Signature Date

4. **I agree that you may contact me for an additional follow-up interview in approximately 4 to 6 months.**

   _____ _____
   Signature Date

   Contact Information: _____ _____ _____
   First Name Phone Number E-mail Address

Appendix D: Background Questionnaire

Participant #: _____

Date: _____

Background Questionnaire

I. Basic Personal Information

1. What is your gender?

   _____ Female

   _____ Male

2. What is your age? _____

3. What is your first language? _____

4. What is your current marital status?

   _____ Married/Living with partner

   _____ Separated

   _____ Divorced

   _____ Widowed

   _____ Never married

5. How many adults live with you? _____

6. How many children (under age 18) live with you? _____

7. What city/town do you live in? _____

8. Do you have a personal computer at your home?

   _____ Yes

   _____ No

9. Do you have Internet access from home?

   _____ Yes (Please circle one: Dial-up Broadband/Cable)

   _____ No

10. Do you access the Internet from any of the following places? (please mark all that apply):

    _____ Work

    _____ School

    _____ Library

    _____ Other: _____

11. On average, approximately how many hours do you spend using the Internet per day? ___

II. Educational Background

12. Please mark the highest level of education you have completed:

    _____ Some high school

    _____ High school graduate

    _____ GED

    _____ Some college

    _____ College degree

    _____ Some graduate or professional school

    _____ Graduate or professional degree

    _____ Other: _____

13. Please list any educational degree(s) you are currently pursuing: _____

III. Work Experience

14. What is your current employment status?

    _____ Employed

    _____ Unemployed

    _____ Disabled

    _____ Retired

    _____ Student

    _____ Homemaker

15. What is your current (or most recent) occupation or job title? _____

IV. Experience with Type 2 Diabetes

16. When were you first diagnosed with type 2 diabetes? _____
(month/year)

17. Have you ever attended any type of diabetes-related class and/or support group?

_____ Yes

_____ No

If yes, please describe: _____

_____

_____

Appendix E: Interview Protocol for Initial Interview

I. Opening

1. Could you please tell me about when you were first diagnosed with diabetes? [Probes: When was this? Who diagnosed you? Are you still seeing this doctor?]
2. How did you first know that something was wrong? [Probe: What were your initial symptoms?]
3. How does having diabetes affect your day-to-day life?
4. Do you know anyone else who has diabetes? If so, who?
5. If your friend or family member were to tell you that he/she was recently diagnosed with diabetes, what would you tell him/her? [Probe: What do you think people who are newly diagnosed with diabetes need to know?]

II. Pre-Diagnosis

6. Before you were diagnosed, did you try to find out about any symptoms you were having? If so, could you please tell me about that? [Probes: How did you go about this? Where did you turn? Why? Did you find out what you needed to know? If so, did this lead you to make some decision or take some other type of action? What was most useful to you at this time? What was least useful to you at this time?]
7. Can you recall any particular time before you were diagnosed when you tried to find out about your symptoms? If so, could you please walk me through what you did?

III. Diagnosis Process

8. Could you please tell me what happened when you were first diagnosed? [Probes: What kinds of things went through your mind? What kinds of things did your doctor tell you or give to you when you were first diagnosed? What did you think of the information that your doctor gave you? Was it helpful? Why/why not?]
9. Looking back, is there anything you know now that you wish you had known at this time?

IV. Post-Diagnosis

10. After being diagnosed, did you still have unanswered questions? If so, could you please tell me about that? [Probes: How did you go about getting your questions answered? Where did you turn? Why? Did you find out what you needed to know? If so, did this lead you to make some decision or take some other type of action? What was most useful to you at this time? What was least useful to you at this time?]

11. Do you think that being diagnosed has changed how you go about trying to learn about your symptoms? If so, in what way(s)?

12. Can you recall any particular time after you were diagnosed when you tried to find out more about diabetes? If so, could you please walk me through what you did?

V. Across Time

13. How has your A1C varied across time and how have you felt about these changes?

14. Were there times when you were not able to find answers to the questions you have about diabetes? If so, could you please tell me about that?

15. What sorts of things have made you want to try to find out more about diabetes? Has there been anything that decreased your desire to do so? If so, please describe.

16. How do you keep track of all the diabetes-related information that you come across? Do you have any strategies that you use? If so, could you please describe them?

17. Do you think that you have found different types of information to be useful at different steps along your experience with diabetes? Could you please tell me about that?

18. What difference do you think finding out about diabetes has made in your experience with diabetes?

19. Do you plan to try to find out more about diabetes? If so, please tell me about your ideas on this.

VI. Closing

20. That is all the questions I have – is there anything you would like to add?

21. Do you have any questions that you would like to ask me?

22. Just in case I am unable to contact you for a follow-up interview, is there some name and phone number you can give me for someone who is likely to know how to reach you?

Appendix F: Health Condition Questionnaire

Participant #: _____

Date: _____

1. Would you say that in general your health is:

1	2	3	4	5
Poor	Fair	Good	Very good	Excellent

2. To what extent do you feel that physical pain prevents you from doing what you need to do?

1	2	3	4	5
An extreme amount	Very much	A moderate amount	A little	Not at all

3. How severe have your diabetes-related symptoms been?

1	2	3	4	5
Very severe	Somewhat severe	Neutral	Not very severe	Not at all severe

4. Have your diabetes-related symptoms gotten worse, stayed the same, or gotten better over the past few months?

1	2	3	4	5
Much worse	Somewhat worse	Stayed the same	Somewhat better	Much better

5. When was your last A1C test? _____ What was the result? _____

(month/year)

6. Are you currently taking insulin?

_____ Yes (When did you begin taking insulin? _____)

_____ No

7. To what extent has diabetes been on your mind?

1	2	3	4	5
Very much so	Somewhat so	Neutral	Somewhat little	Very little

8. How would you rate your current understanding of diabetes?

1	2	3	4	5
Very inadequate	Somewhat inadequate	Neutral	Somewhat adequate	Very adequate

9. How important is it to you to learn more about diabetes?

1	2	3	4	5
Very unimportant	Somewhat unimportant	Neutral	Somewhat important	Very important

10. How important is it to you to participate in making decisions related to your healthcare (especially in regard to diabetes)?

1	2	3	4	5
Very unimportant	Somewhat unimportant	Neutral	Somewhat important	Very important

11. How active have you been about trying to find out about diabetes?

1	2	3	4	5
Very inactive	Somewhat inactive	Neutral	Somewhat active	Very active

12. How often do you tend to look for information about diabetes?

1	2	3	4	5
Never	A few times per month	A few times per week	Nearly every day	Every day

13. How satisfied have you been with getting answers to your questions about diabetes?

1	2	3	4	5
Very unsatisfied	Somewhat unsatisfied	Neutral	Somewhat satisfied	Very satisfied

14. How available to you is the diabetes-related information that you need in your day-to-day life?

1	2	3	4	5
Not at all	A little	Moderately	Mostly	Completely

15. How difficult is it for you to get hold of any diabetes-related information that you might need?

1	2	3	4	5
Very difficult	Somewhat difficult	Neutral	Somewhat easy	Very easy

16. How interested are you in your experience with diabetes?

1	2	3	4	5
Very uninterested	Somewhat uninterested	Neutral	Somewhat interested	Very interested

17. How uncertain do you feel about your experience with diabetes?

1	2	3	4	5
Very uncertain	Somewhat uncertain	Neutral	Somewhat certain	Very certain

18. How confused do you feel about your experience with diabetes?

1	2	3	4	5
Very confused	Somewhat confused	Neutral	Somewhat clear	Very clear

19. How optimistic do you feel about your experience with diabetes?

1	2	3	4	5
Very pessimistic	Somewhat pessimistic	Neutral	Somewhat optimistic	Very optimistic

20. How alone do you feel regarding your experience with diabetes?

1	2	3	4	5
Very alone	Somewhat alone	Neutral	Somewhat not alone	Not at all alone

21. How "in control" do you feel regarding your experience with diabetes?

1	2	3	4	5
Not at all in control	Somewhat not in control	Neutral	Somewhat in control	Very in control

22. How well do you feel you are coping with having diabetes?

1	2	3	4	5
Not coping well at all	Somewhat not coping well	Neutral	Coping somewhat well	Coping very well

Appendix G: Card-Sorting Exercises

Participant #: _____

Date: _____

Now I would like to ask you about how useful you feel specific people, media types, types of Internet sites, and content types have been in helping you to find out what you need to know about diabetes. For each category, I will give you a pile of cards. First, please go through the pile of cards and remove any of the cards that are about some source or type of information that you have not used. Next, please go through the remaining cards and place each of them in one of five categories – very useful, somewhat useful, neutral, somewhat not useful, and not at all useful. Please talk aloud while doing this, explaining what you are doing and why.

1. People

a. Doctors
b. Nurses
c. Pharmacists
d. Diabetes Educators
e. Dieticians
f. Counselors/Therapists/Social Workers
g. Alternative Health Practitioners (such as chiropractors or acupuncturists)
h. Health Store Employees
i. Librarians
j. Family Members who do not have diabetes
k. Family Members who have diabetes
l. Friends who do not have diabetes
m. Friends who have diabetes
n. Other People with diabetes (other than family members or friends)
o. Support Groups
p. Other: _____

2. Media Types

a. Television
b. Radio
c. Internet
d. Books
e. Magazines
f. Newspapers
g. Journals
h. Brochures/Pamphlets
i. Other: _____

3. Internet: Site Types

a. Search Engines
b. General News Websites – News articles
c. General News Websites – Opinions
d. Medical Websites
e. Government Agency Websites
f. Insurance Websites
g. Lifestyle Websites
h. Shopping Websites
i. Dictionary/Encyclopedia Websites (other than Wikipedia)
j. Wikipedia
k. Blogs
l. Forums
m. Videos/YouTube
n. Personal Websites
o. Other: _____

4. Content Types

a. Risk Factors
b. Causes
c. Signs/Symptoms
d. Diagnostic Tests/Procedures
e. Diabetes-Related Complications
f. Treatment Options, Costs, and/or Impacts
g. Home Remedies
h. Medication Options, Side Effects, and/or Interactions
i. Medication Warnings and/or Allergies
j. Treatment Facilities and/or Providers
k. Disease Prevention
l. Diabetes Management
m. Diabetes-related Emotions
n. Exercise
o. Diet
p. Vitamins/Supplements
q. Cooking/Recipes
r. Stories/Personal Experiences
s. Product Information
t. Insurance Information
u. Other: _____

5. How often do these goals prompt you to look for diabetes-related information? [Sort into three groups – often, sometimes, never]

a. Keep up to date on new discoveries, treatments, etc.
b. Find/select health provider
c. Decide when/whether to go to the doctor
d. Prepare for doctor appointment
e. Find out more following a doctor appointment
f. Learn about the signs/symptoms of diabetes
g. For self-diagnosis
h. Learn about the causes of diabetes
i. Learn about potential diabetes-related complications
j. Deal with my emotions about diabetes
k. Gain and/or maintain hope
l. Reduce uncertainty or anxiety
m. Sort out conflicting information
n. Learn how to manage diabetes
o. Learn how to prepare meals
p. Learn about possible treatment options
q. Decide when/whether to get treatment
r. Learn what to expect from a particular procedure or treatment
s. Decide whether to take or stop taking a medication
t. Learn about the side effects of a medication
u. Learn about potential interactions between medications
v. Learn what I can do to improve my health and/or prevent disease
w. Make decisions about purchasing vitamins, supplements, or anything else that may help to improve my health
x. Learn how to help someone else who has diabetes
y. Read about others' experience with diabetes
z. Share information about my experience with other people
aa. Gather information just because I'm curious
bb. Other: _____

Appendix H: Interview Protocol for Follow-up Interview

I. Opening

1. How have you been since we last met? [Probe: Has your experience with diabetes changed in any way since we last met? If so, how?]
2. How does having diabetes affect your day-to-day life?
3. If your friend or family member were to tell you that he/she was recently diagnosed with diabetes, what would you tell him/her? [Probe: What do you think people who are newly diagnosed with diabetes need to know?]

II. Update Questions

4. Since the last time we met, have you had questions about diabetes for which you have tried to find answers? If so, how did you go about getting your questions answered? [Probes: Where did you turn? Why? Did you find out what you needed to know? If so, did this lead you to make some decision or take some other type of action? What did you find useful to know? What did you find not so useful to know?]
5. Can you recall any particular time from the past several months when you tried to find the answer to some question you had about diabetes? If so, could you please walk me through what you did?
6. Have you made any further use of the information your doctor gave you when he/she first diagnosed you? If so, please describe.
7. Have you come across anything (facts or documents or anything) that you wish that you had been given or told when you were first diagnosed? If so, please describe.
8. Do you think that the ways in which you try to get your questions answered has changed over the past several months? If so, how?

III. Across Time

9. What sorts of things have made you want to try to find out more about diabetes? Has there been anything that decreased your desire to do so? If so, please describe.
10. Have there been times when you have not been able to find out what you needed to know about diabetes? If so, could you please tell me about that?
11. How do you keep track of all the diabetes-related information that you come across? Do you have any strategies that you use? If so, could you please describe them?
12. What is it that makes diabetes-related information useful to you? [Probe: Please describe an ideal piece of diabetes-related information. What is it that makes this piece of information ideal?]

13. Do you feel like different types of information are more useful now than they were before? Please tell me your thoughts on this.
14. Do you feel like different types of information are less useful now than they were? Please tell me your thoughts on this.
15. What difference do you think finding out about diabetes has made in your experience with diabetes?
16. What do you feel are the three most important things someone needs to know in order to be able to successfully manage their diabetes?
17. Has any particular piece of information or source of information been especially influential to you in terms of how you understand and/or deal with having diabetes? If so, why?
18. Do you plan to try to find out more about diabetes? If so, please tell me about your ideas on this.
19. [Ask interviewee to construct a timeline of their experience with diabetes.]

IV. Closing

20. Do you feel that participating in this study has influenced (or will influence) your behavior in any way? If so, please describe.
21. That is all the questions I have – is there anything you would like to add?
22. Do you have any questions that you would like to ask me?

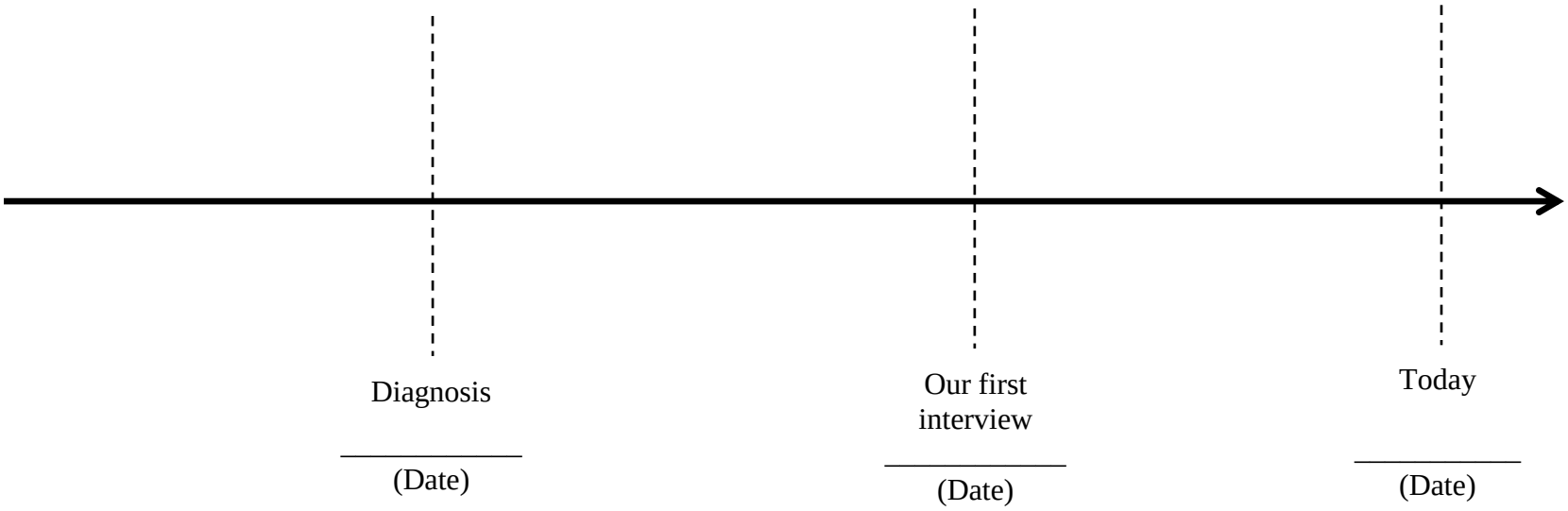
Appendix I: Timeline

Instructions: Using the timeline on the following page, please indicate any important points along your journey with diabetes. Please include about 10 different events or factors, placing positive ones above the line and negative ones below the line. As you draw this timeline, please describe for me what you are doing and why. Include things such as:

- Test Results
- Events
- Setbacks
- Decisions
- Turning Points
- Questions you had, questions you tried to get answers for, and/or questions you got answered
- Help you needed, sought, and/or received
- Anything else that you feel is important

Participant #: _____

Date: _____



Appendix J: Structural Codebook (Initial Interview)

1. Interview Questions	
	1-01: Diagnosis
	1-02: Initial symptoms
	1-03: Effects of diabetes
	1-04: Knows others with diabetes
	1-05: Would tell family member or friend
	1-06: Pre-diagnosis information seeking
	1-07: Pre-diagnosis information seeking incident
	1-08: Diagnosis-detail
	1-09: Wish had known
	1-10: Unanswered questions
	1-11: Diagnosis change information seeking?
	1-12: Post-diagnosis information seeking incident
	1-13: A1C variations across time and related feelings
	1-14: Unable to find answers
	1-15: Motivators and demotivators
	1-16: Keep track
	1-17: Usefulness across time
	1-18: Difference finding out makes
	1-19: Plans for information seeking
	1-20: Add anything
	1-21: Questions for me
	1-22: Alternate Contact Information
2. Health Condition Questionnaire	
	2 01-06: Physical
	2 07-12: Cognitive
	2 13-15: Perceptions
	2 16-22: Affect
3. Card-Sorting Exercises	
	3-01: People
	3-02: Media Types
	3-03: Internet Site Types
	3-04: Content Types
	3-05. Purposes
4. Wrap-Up	

Appendix K: Structural Codebook (Follow-up Interview)

1. Interview Questions	
	F 1-01: How have you been
	F 1-02: Effects of diabetes
	F 1-03: Would tell family member or friend
	F 1-04: Recent questions
	F 1-05: Recent information seeking incident
	F 1-06: Further use of information provided by doctors
	F 1-07: Wish had known
	F 1-08: Changes in information seeking
	F 1-09: Motivators and demotivators
	F 1-10: Unable to find answers
	F 1-11: Keep track
	F 1-12: What is useful
	F 1-13: More useful now
	F 1-14: Less useful now
	F 1-15: Difference finding out makes
	F 1-16: Three most important things to know
	F 1-17: Most influential information or source of information
	F 1-18: Plans to find out more
	F 1-19: Timeline
	F 1-20: Influence of participating in this study
	F 1-21: Add anything
	F 1-22: Any questions
2. Health Condition Questionnaire	
	F 2 1-6: Physical
	F 2 7-12: Cognitive
	F 2 13-15: Perceptions
	F 2 16-22: Affect
3. Card-Sorting Exercises	
	F 3-01: People
	F 3-02: Media Types
	F 3-03: Internet Site Types
	F 3-04: Content Types
	F 3-05. Purposes
4. Wrap-Up	

Appendix L: Thematic Codebook

Code/Subcode	Number of Transcripts	Number of Passages
Information Needs	**232**	**879**
Information needs	46	72
Information wish list	30	77
Information-related preferences	43	83
Not knowing what I don't know	47	145
Sufficient or insufficient information	66	502
Information Seeking	**203**	**846**
Cross-verification; Use of multiple sources	28	43
Information seeking plans	66	98
Information seeking practices	66	618
Joint information seeking	5	5
Passive information seeking	16	29
Proxy information seeking	22	53
Information Sources	**271**	**1,069**
Doctor's orders	19	40
Internet and search engines	66	464
Learning from one's own body and experiences	32	64
Learning from others' experiences (incl. narratives)	62	345
Libraries and librarians	53	91
Referral	32	55
Vetting	7	10
Information Use	**188**	**538**
Difference finding out makes	66	146
Information management practices	66	243
Information use	56	149
Great Quotes	**34**	**101**
Affect	**529**	**1,245**
Acceptance; Adaptation	41	123
Affective factors	66	288
Anger	16	31
Caring	4	10
Certainty; Uncertainty	47	70

Code/Subcode		Number of Transcripts	Number of Passages
	Confusion; Frustration	44	133
	Denial; Avoidance	32	77
	Depression	17	37
	Disappointment	7	12
	Empowerment	3	3
	Fear	33	79
	Giving up	15	28
	Glad; Happy; Pleased	4	4
	Grateful	4	6
	Hope	24	38
	Lucky; Fortunate	6	9
	Openness; Willingness to discuss diabetes	41	80
	Opportunity	6	8
	Optimism; Pessimism	44	80
	Overwhelm	6	9
	Pride	4	6
	Shame; Guilt	8	11
	Surprise	36	70
	Upset	5	11
	Vulnerability	1	1
	Worry; Concern	15	21
Beliefs/Perceptions		**640**	**2,305**
	Attitudes toward information; Perceptions regarding information	43	108
	Causal attributions	49	152
	Cognitive factors	66	69
	Conflicting information	66	159
	Control; Coping	61	311
	Fatalism	7	10
	Goals	8	13
	Home remedies; Alt. Medicine	59	221
	Most useful	65	264
	Relevance	16	28
	Religion	9	19
	Self-efficacy	55	203
	Trust; Distrust	54	273
	Usefulness; Non-usefulness	66	455

Code/Subcode	Number of Transcripts	Number of Passages
Wishes and fantasies	16	20
Physical	**187**	**1,357**
Effects & impacts of diabetes	66	179
Health behaviors	55	663
Physical symptoms; Health condition	66	515
Social	**355**	**1,896**
Advice for other people with diabetes	66	188
Authoritarianism	14	18
Camaraderie	16	35
Desire to help others	49	125
Individual differences	34	73
Inquiry by others; Interference by others	34	60
Relationship with doctor(s) & other health professionals	66	943
Social support	62	428
Stigma	14	26
Path Markers	**321**	**991**
Affective barriers	2	2
Cognitive barriers (e.g., illiteracy, information overload)	40	86
Financial barriers	33	80
Impeding factors	48	204
Most frequent motivating factor	34	34
Motivating or demotivating factors	66	322
Physical barriers	18	47
Serendipity	4	5
Setbacks	11	16
Success or failure	49	169
Turning points	16	26
Path Changes	**386**	**749**
Changes in affective factors (e.g., receptivity)	29	47
Changes in cognitive factors (e.g., ability to recognize relevance or comprehend information)	16	24
Changes in diabetes practice or research	20	28
Changes in information seeking practices	54	73
Changes in motivation or barriers to information	2	2

Code/Subcode		Number of Transcripts	Number of Passages
	seeking and use		
	Changes in needs or preferences for information	7	7
	Changes in perceptions of usefulness	66	144
	Changes in physical condition or symptoms	61	134
	Changes in progress	1	1
	Changes in willingness or ability to internalize, own, or act on information	6	15
	Continuity; Discontinuity	38	64
	Effects or influence of participating in my study	51	109
	Learning as process; Phases	35	101

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