Adults Living with Type 2 Diabetes: Kept Personal Health Information Items as Expressions of Need

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I dedicate this dissertation to my wonderful husband, Jim Combs, and my amazing children, Collin and Carson.

Boys, I regret that this effort stole me away from being with you at the soccer field, swimming pool, campgrounds, etc. I treasured the moments we did share, such as bedtime rituals and vacations, that much more.

I was always renewed by your bedtime hugs and smiles, or your morning sleepy heads. Our rides into school each morning, although sometimes challenging, often gave me the smile I needed to do what needed to be done.

I look forward to encouraging you as you grow, as I was able to do in my program.

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ABSTRACT

This study investigated personal information behavior and information needs that 21 adults managing life with Type 2 diabetes identify explicitly and implicitly during discussions of item acquisition and use of health information items that are kept in their homes. Research drew upon a naturalistic lens, in that semi-structured interviews were conducted in participants’ homes. The rich narratives provide insights into situational relevance associated with kept health information items, the uses thereof, and stated information needs. The descriptions of situational relevance were analyzed for themes of information keeping and use in context, as well as expressions of information need that were implicit to participants’ situations. The study and its pre-test were conducted in a mid-sized city in the Southeast from April to September 2011. All pre-test (n = 3) and study participants were recruited from diabetes education classes, conducted at a diabetes center associated with a teaching hospital. The study participants were 38-79 years old (mean = 60 years, SD = 9.5) and the majority of participants were female (n = 15, 71%), white/Caucasian (n = 17, 81%), employed (n = 13, 62%), married (n = 11, 52%), insured (n = 18, 86%), and new to diabetes (diagnosis < 3 months n = 15, 71%). Participants kept 706 items in the home, but only a subset (n = 300) were used to manage life with Type 2 diabetes. The interviews focused on these kept and used items to guide the study, similar to the notion of critical incident, to address questions of personal context, information needs, and item uses. Results showed that participants primarily kept and used paper-based items, but digital items, e.g., bookmarked websites, were also used. Results also show that the categories found in literature for ‘Item Type’ and for ‘Item Use’ required expansion. Findings also revealed that individuals with Type 2 diabetes may keep and use health information items to manage life with diabetes within four primary contexts: activity, adjustment, challenge of living with diabetes, and emotion. Analysis of information keeping and use in context showed that kept information items, when examined within a lens of situational relevance, can provide insight into information needs that individuals with Type 2 diabetes may not readily identify.
CHAPTER ONE

INTRODUCTION

This dissertation grew out of an interest in the emerging functionality of personal health information technology known as personal health records (PHRs) (Halamka, Mandl, & Tang, 2008). PHRs can take the form of a pile of paper-based records that individuals may compile from various healthcare providers and health related organizations, but are ideally digital tools. The electronic functionality would provide a means to access, store, and manage all health information, as a means to promote health management (Robert Wood Johnson Foundation |RWJFl, 2010). Ideally, PHRs would also provide tools, such as weight and blood pressure trackers, and informational tools, such as newsletters that pertain to stored conditions, e.g., Type 2 diabetes or medications. The expectation for future use of PHR-like functionality is increasing, with the increasing expectation for individuals to manage personal health (National Committee on Vital and Health Statistics |NCVHSI|, 2001), and the increasing attention to the provision of patient education materials as part of “meaningful use” and health care management (Blumenthal & Tavenner, 2010). This movement to provide information items that meet the health information needs of the user indicates the increasing trend and importance of entrusting consumers with access to a comprehensive knowledge of health management activity (Agarwal, Khuntia, & Insight Policy Research Inc., 2009, p. 117). While health management activity is expansive, based on the impetus of seeing the news items that some PHRs, e.g., WebMD, “push,” this study sought to step back from the technology and investigate information behaviors that the PHRs, and the forthcoming provision of patient education materials from healthcare providers’ electronic health record systems, serve to emulate, or at least complement. Specifically, this study aimed to investigate information keeping behaviors and the information needs and items uses associated with kept health information items. The purpose of this study was to determine what information people already keep and use, in order to inform future decisions of what news to possibly automatically push using technology, such as PHRs or electronic health information systems used by healthcare providers, or of what non-digital material may be provided or recommended. The population chosen to examine, as discussed later in this chapter, are adults with Type 2 diabetes who keep health information items in their home and use them to manage life with diabetes.
Moen and Brennan (2005) provide an exemplar of health information behavior studies in their study of health items kept by individuals in their homes. Their naturalistic study identified types of items maintained within the home, the means for storage, and the location in which each item was stored. The results showed that nearly 40% of the participants kept in the home and referred to: reference books, health magazines, and the Internet. However, the participants were more likely to consult outside sources, including: health information acquired during doctor’s visits; family and friends; clinics or hospitals; and news reports. These results served to inform the personal health information management literature regarding the development of organization and management tools. The results further offered insight into participants’ functional information behaviors, although it ignored the cognitive components, e.g., need stimulus, decision making, affect, etc. Therefore, holistic understanding of health information behaviors conducted in homes is unavailable. This research seeks to address a portion of this knowledge gap and to expand upon the work of Moen & Brennan by offering an investigation of items that individuals keep with regard to personal health, to identify the item’s use and the precipitating information need, and to assess the item’s situational relevance (Wilson, 1973), i.e., the relationship between the kept item and the information need with regard to the individual’s belief and knowledge, i.e., personal context. Similar to Moen and Brennan this study examined kept information items, uses, and associated information needs. However, it is unique in that the kept health information items were also considered as projections of information needs, similar to the notion of purchases as “extension of self” in consumer behavior research (Belk, 1988).

Wilson’s (1973) notion of situational relevance is a logical and “personal” concept that was offered to consider the user’s information needs in light of system centered information retrieval studies. His view of situational relevance is not that of a psychological concept, nor part of the cognitive paradigm. Whereas psychological relevance investigates actual uses and the effects of the information, predicting that information use results in a change in perspective or view, situational relevance is an abstract and static view of the relationship between an information item and the individual’s particular view of his or her world with regard to his or her current situation. The concept of situational relevance also does not belong within the cognitive paradigm, because an assumption of this lens is that information serves to inform and results in the transformation of an individual’s beliefs, knowledge, etc., i.e., a shift in cognition (Raber, 2003). The concept of situational relevance provided by Wilson is a “logical” (Raber) approach.
It draws upon inductive logic, taking into account the knowledge, beliefs, information needs, and
the individual, to determine if an item is situationally relevant. Information that is deemed
situationally relevant, thus, informs an individual’s context and can either strengthen or weaken a
“case,” e.g., a cookbook with diabetic recipes can promote the notion that an individual is self-
managing diabetes. Using the lens of situational relevance, therefore is a means to consider an
individual’s information needs and uses in terms of personal contexts, within the larger context
selected for this study, living with Type 2 diabetes. Note that the participants in this study are
identified as “living with diabetes” in order to indicate the assumptions that they are first and
foremost individuals, and that a secondary attribute is that they are actively managing their
disease. Additionally, the phrase “living with diabetes” indicates that the participants self-
identified as having received a diagnosis of Type 2 diabetes; participant’s specific diagnoses
were not verified.

The life with diabetes context was selected for this study because this population is
rapidly growing and is a focus of many federal health care initiatives, e.g., Healthy People 2010
(U. S. Dept. of Health and Human Services, 2000) and 2020. Individuals living with diabetes are
envisioned as primary beneficiaries of health management changes, which subsequently require
use of various information resources, such as cookbooks and glucose logs. The kept items that
are of central consideration may be in print or electronic format. For the purpose of this study
kept health information items are considered physical items that are on the individual’s premises
at the time of the interview. Therefore, kept health information items may include items, such as
books, news clippings, journal articles, printouts from an Internet site, or notes of references that
are maintained in the home. Electronic items that are maintained on the individual’s computer
are also considered kept items; this includes spreadsheets, bookmarked website addresses
(URLs), etc. Given this physical connotation of “kept,” excluded items can include: a website or
file not stored on a computer in the home; a reference source not maintained in the home; items
that are kept in memory, such as or a website address or title of reference material. Note that
bookmarked URLs are similar in comparison to a note scrap that contains the name of a book
that can be accessed elsewhere. They each serve as a reminder. It is likely that in this
comparison, an individual may be more likely to be familiar with the content of the electronic
material as it is a source that is frequented; the note scrap may serve as a reminder for an
information item that requires acquiring. Excluded from this study were Facebook groups or
pages that participants may have joined. These links are not stored directly on the user’s computer. Furthermore, it should be noted that the content of kept items is outside the scope of this study; the study’s focus is on the individual’s judgment of use and need attributed to the item as a complete entity. Therefore, although content may be critical to an individual’s decision to keep or use the item, this study is not addressing what portion of the item contributed to these decisions.

This study differed from past literature in that it focused on the uses and needs of kept personal health items that individuals deem relevant to living with diabetes. Therefore, this study is unique for the following three reasons: 1) the study focuses on items that are currently maintained in the home, i.e., personal information collections (PICs), rather than articles selected following a search query; 2) the information behavior that is central to this study is information keeping; and 3) the information need, living with diabetes, is life-encompassing in comparison to previous finite studies, e.g., reference searches for development of academic papers (Barry, 1994; Park, 1997; Vakkari & Hakala, 2000). Not that this study is similar to that of St. Jean (2012) which was begun at a similar time. St. Jean conducted a longitudinal study of information behaviors of adults with Type 2 diabetes. Both studies examined the items that were kept and used. St. Jean, however, focused on factors that motivated or impeded information seeking, and the use of the items. This study focuses on information needs and uses of the kept items. Further details of this study are included within the following chapters.

The remainder of this chapter discusses the purpose and justification for this study and presents the research questions that were addressed; it additionally provides definitions of key terms. Finally, the method of inquiry is identified and an overview of the remaining study is presented. A literature review is presented in Chapter 2, and full details of the study’s methodology are presented in Chapter 3.

1.1 Background

The American health care system is undergoing structural, financial, and managerial changes in order to fix a system that is considered “broken” (Frisse, 2009; Kuttner, 2008) at “all” levels, as constituted by community, provider, and personal. Changes are targeted toward these three stakeholder groups identified by the National Committee on Vital and Health Statistics (NCVHS; 2001) - the community (“population health”), the healthcare provider, and the general
consumer (“personal health”) - in order to address a health care system that is fragmented by a multitude of complex systems, hence preventing efficient communication among providers and increasing chances for mistakes to occur. Additionally, changes to the health care system strive to address the aims put forth by the Institutes of Medicine (2001): safety, equity, timeliness, efficiency, effective, and patient-centered. Whereas the bulk of aims are addressed by a comprehensive and interconnected digital health network, e.g., a digital national health information network based on a banking model (Gold & Ball, 2007), that promotes timely communication among stakeholders, and therefore serves to “reduce medical errors, raise the quality of care, and provide better information for patients, physicians, and other health care providers” (Brailer, 2005), the aim for patient-centered health care, which is grounded in the notion of personal responsibility and participation in one’s personal care (Kaelber, 2008), is driving the push for Personal Health Records (PHRs).

PHRs are emerging and encouraged as a nascent means for individuals to monitor health and manage health information, as well as to engage in personal health management (Endsley, Kibbe, Linares, & Colorafi, 2006). Early PHRs served to provide individuals a summary of services rendered, recommendations for treatment (Tang & Newcomb, 1998), or insight into medical information maintained by health providers (Tang et al., 2003). PHRs continue to evolve, wherein further development is fueled by questions as to what information PHRs should contain and to what purpose(s) the individual aim to address (Robert Wood Johnson Foundation, 2010). Currently, PHR development and the evolution of physician electronic health records (EHRs) are focused on the goal to promote conversation between clinicians and patients (Robert Wood Johnson Foundation, 2010). Specifically, the federal government has indicated the importance of this interaction through the recent announcement of Stage 2 meaningful use requirements of EHRs: 5% of patients are required to engage with the healthcare provider’s EHR or patient portal (Centers for Medicare & Medicaid Services, 2012). Additionally, the importance of providing patient education materials has been specified and made a requirement as part of the federal EHR incentives that are provided to hospitals and healthcare providers who enroll in the incentive program and demonstrate the use the system as required.

As health supporting tools are developed, patients are viewed as “untapped sources of medical data,” and are the source of information about behaviors termed “observations of daily living” (ODLs) (Robert Wood Johnson Foundation, 2010, p.2). These ODL behaviors include
sleep, diet, exercise, mood, medication adherence, etc. This study poses that individuals are the source of additional informative ODLs, i.e., information behaviors. Studies of individual health management behaviors have shown that people perform personal health information management (PHIM) activities, e.g., information keeping (Moen & Brennan, 2005; St. Jean, 2012), beyond tracking ODLs and maintaining medical data. These PHIM activities include keeping journals, calendars, and reference material (e.g., news clippings) (Moen & Brennan). Given that adults keep journals, logs, etc. to help manage health, this study posed that PHIM behaviors of keeping and using items are potentially an additional “untapped” data source that demonstrate expressions of information need that may be useful when examined in light of the needs to self-manage life with diabetes. Therefore, this study: 1) sought to identify health items that were kept and used to help manage life with diabetes, and 2) explored the information behaviors of item usage and precipitating information needs.

This study recognized that “information needs are not necessarily the same within a particular group, and that one size does not fit all” (Bath, 2008, p. 506). The federal government has also provided direction in that healthcare needs to address different needs of specific populations, e.g., individuals living with chronic conditions, those with small children, or those who travel or live in disaster prone areas (Robert Wood Johnson Foundation, 2008). These populations have received additional attention, as individuals in these situations are perceived to benefit most from health supporting tools. Although there are a number of reasons to choose any population for study, for mere personal interest and extended-familial experience, this study focused on adults living with Type 2 diabetes.

This consideration of adults living with diabetes allows for specific considerations for this group “when designing information interventions and providing information” (p. 506). Information behavior of individuals in health contexts may be different than other groups as the path can include unique milestones, such as “time of diagnosis, when patients are coming to terms with a diagnosis … when the individual may need information on treatment options, prognosis, etc.” (p. 506). Knowledge of information items kept and used, e.g., diabetic cookbooks, specific to this population can then be used to inform PHR development as to material that would be useful to include. Insight into information keeping behavior, such as keeping obsolete glucose meters, can also provide insight into education modules that may be useful to teach successful self-management behaviors. Self-management behaviors that are
recognized as critical for diabetes self-management include: physical activity, healthy eating, medication taking, monitoring blood glucose, diabetes self-care related problem-solving, reducing risks of acute and chronic complications, and psychosocial aspects of living with diabetes (Funnell et al., 2009). This study contends that the insight into items kept can implicitly shed light into information gaps, i.e., expressions of information needs, pertaining to the necessary self-management behaviors.

This study is one of information behavior and is positioned within the user-oriented paradigm of information behavior research; additionally, it is positioned within the subordinate information behavior area of personal (health) information management (PHIM) (Moen, 2007). PHIM focuses attention on information behaviors, e.g., “consumers’ access, integration, organization, and use of their personal health information” (Civan, Skeels, Stolyar, & Pratt, 2006, p. 156) of individuals who perform information behaviors in the role as a health consumer who is well or unwell. Challenges facing consumers that are of interest to PHIM research include: integration of health related information from various sources; use of the information; and sharing of information (Pratt, Unruh, Civan & Skeels, 2006). These concerns are best studied using user-centered approaches, thus providing insight into the user’s information need in order to contribute to the ability to develop systems and methods that support self-created behaviors (Naumer & Fisher, 2007).

This study used health information items that are kept and used by adults living with Type 2 diabetes as the focus to use a naturalistic lens to examine the information needs and information behaviors that were associated with the items. The overarching question that was addressed is: What do kept personal health information items say about the needs of adults with Type 2 diabetes? Additionally, the study asked:

- Within an individual’s context of living with diabetes, what items are kept?
- How are the items used in relation to a precipitating information need?
- What does the use of these items say about the needs of the individuals?

From these questions emerged the following subordinate objectives of this study:

- To explore the types of health items that participants keep;
- To explore the role of individual characteristics and contexts, including the national standards of diabetes self-management care, with the presence and use of kept health items;
To explore the usage of kept health items;
To explore the information need participants associate with the item;
To explore participants’ information keeping behaviors in terms of situational relevance.

The results of this study are used to provide insight for professionals in library and information science, as well as diabetes educators. The knowledge of items that are kept in personal information collections may serve to inform library and information (LIS) professionals about materials that individuals do not have ready access to in their homes, or about information needs that could be satisfied by library materials. Diabetes educators can use the knowledge of kept item to understand what individuals perceive as useful information, what potentially helpful items are lacking in a home, or what items are present but are not used by an individual with diabetes. Additionally, this information can serve to inform developers of PHRs or EHRs, or as to resources that are readily available to users and do not need to be duplicated in electronic pushes of reference material.

1.2 Terms Defined

The following concepts are central to this study. General definitions are discussed and the specific definition used for the key concepts are provided. These concepts are further discussed in context of the greater body of literature presented in Chapter 2.

1.2.1 Context

Context has been defined in many ways, but in general, it is considered a socially constructed, dynamic frame of reference consisting of a “particular combination of person and situation” (Case, 2007, p. 13), which includes setting, interaction and things (Courtright, 2007). As a frame, it not only shapes action, but in turn, is also reshaped. Additionally, it may be considered “something that people do” (p. 289). With regard to this study, the general context under investigation is that of individuals with Type 2 diabetes who keep in their homes health information items – electronic or paper based – that are related to their personal experience with the disease. The study’s participants provided insight of their specific context as they discussed the kept information items, their use, and the related information need.
1.2.2 Kept (Personal) Health Information Item

As defined by this study, a kept (personal) health information item pertains to an information item that is specific to an individual’s health and wellness with regard to managing their life with Type 2 diabetes. These information items can be “acquired, created, viewed, stored, grouped (with other items), moved, given a name and other properties, copied, distributed, moved, deleted, and otherwise manipulated” (Jones & Teevan, 2007a, p. 7). Examples include journals, diaries, calendars, news clippings, cholesterol reports, weight, blood pressure readings, etc., to support their health information management behaviors (Moen & Brennan, 2005). This study uses the term “health information item” to apply to electronic, as well as paper-based items that the participants deem relevant to managing their life with diabetes. These kept items may include resources, such as books, news clippings, journal articles, printouts from an Internet site, or notes of references that are maintained in the home. Electronic resources that are maintained on the individual’s computer are also considered kept items; this is inclusive of spreadsheets, bookmarked URLs, etc. The bookmarked URLs are similar to the concept of a book title written on a paper scrap. Just as the paper scrap would serve as the kept item, so does a bookmarked URL. The accuracy of the title or URL link, however, was not be verified, nor was the site’s availability determined. Given this physical connotation of “kept,” excluded items possibly include: a website or file not stored on a computer in the home, e.g., a Facebook group or page name; a reference source not maintained in the home; items that are kept in memory, such as or a website address or title of reference material. Additionally, items that participants do not specifically consider as relevant to managing life with diabetes were excluded.

1.2.3 Information Need

An information need is generally acknowledged within the library and information studies (LIS) literature as the precursor to information seeking behavior (Marchionini & White, 2007; Wilson, 1981). Harter (1992) poses that an information need is dynamic with regard to the “current cognitive state or context of a user (rather than the initial state)” and encompasses “not only a topical statement of the subject of the inquiry and why it is of interest to the individual, but also all other assumptions that comprise the current context” (p. 606).
Historically, information needs were investigated in terms of the information that was missing from an information retrieval system relative to the information desired by a user. Studies of this discrepancy were focused on “objective” differences and were conducted within a system framework. Beginning in the late 1970s studies began to investigate information needs as subjective measures from the perspective of the user (Mizzaro, 1998), i.e., what information is missing from the user’s knowledge base (Dervin & Nilan, 1986) or as “a hypothesized state brought about when an individual realizes that they are not comfortable with their current state of knowledge” (Case, 2007, p.333). Studies of information needs conceptualized this state as “internal mental states” e.g., an "anomalous state of knowledge” (Belkin, 1978), or as situations that are addressed through “verbing” behaviors within a sensemaking framework (Dervin, 1992).

The health care community has also examined the concept of an “information need,” considering it a perceived reaction in response to a stimulus, such as “major life changes, other events or life-threatening or incapacitating illness” (Timmins, 2006, p. 377). These information needs are considered to be subjective and unique “personal item[s] about which individuals require information” (p. 377). This study employed this health care view of an information need in that it is a personal situation regarding life with Type 2 diabetes that serves to benefit from information.

1.2.4 Situational Relevance

Relevance is historically conceptualized in LIS literature in terms of information retrieval; it is broadly conceptualized objectively as “an evaluation of the match between a question (or search statement) and the answer (or text) retrieved by that statement” (Case, 2007, p. 336). The evolution of relevance studies led to considering subjective relevance judgments as perceived by a user. An early subjective view of relevance, situational relevance, was offered by Wilson (1973). He posed that the dynamic relationship of situational relevance relates an individual’s “stock of knowledge or information” to “questions of concern to him” (p. 463). He considered it as an individual’s assessment of an item regarding “relevance to [the concerns of] a particular [aspects of an] individual situation” from the individual’s perspective (p. 406). Wilson further posited that situational relevance is inclusive of practical relevance, which examines a relationship between goals and plans of action. Given its subjective nature, situational relevance may offer little to resolve the questions of information retrieval (Saracevic, 1975). However, it is
useful in considering context of information seeking or use (Chatman, 1996; Crystal & Greenberg, 2006).

The general context of this study is that of living with Type 2 diabetes and the use of diabetes education to instruct patients for the benefit of positive health outcomes. As such, this study is informed by the national standards for diabetes self-management education (Funnell et al., 2009) and Chatman (1996). The diabetes education standards (Funnell et al.) specify seven key behaviors or lifestyle habits that are addressed during diabetes education, which thereby offers a means to operationalize situational relevance. The guidance of Chatman is paramount in showing what a situational relevance lens can provide for this study. Specifically, situational relevance serves as one of the four categories that bound an “impoverished life-world” (p. 194), posing that situational relevance:

pertains to the notion of sense-making…the idea is that things that make sense are relevant. More importantly, sources of information must make sense to an individual who is engaged in some problematic situation. An application of relevance in an everyday context, therefore means that which were of interest is that which is useful in response to some concern or problem. (Chatman, p. 202)

This argument, when applied to this study, poses that those items that participants keep are useful to some concern or problem. Therefore, these kept items serve to provide insight into expressions of need. In order to ascertain the relevance, this study sought to categorize the participants’ decisions of item relevance to the educations categories set forth by Funnell et al.

1.3 Problem Context

This exploratory study, as depicted in Figure 1, is positioned broadly in the epistemology of constructionism, whereby “people develop meanings together and it is already interpreted before the scientist arrives” (Crotty, 2007). The study is further positioned in the context of the naturalistic paradigm (Lincoln & Guba, 1985) and applies primarily interpretivist approaches to address the research questions. Data were coded using themes and historical categories. The naturalistic paradigm posits that individuals create their reality and that truth is not measurable, but rather individually created. This individually created truth can only be understood through holistic observation, therefore must be conducted in a natural setting. Furthermore, the
naturalistic paradigm recognizes that inquiry is affected by the researcher’s values and by interaction between the observer and the observed. An interpretivist view of scientific study is that it is not possible for any data gathered to be unbiased; therefore all data are subjective in that individuals are embedded with historical, contextual, and physiological characteristics (Feyerabend, 1975).

This specific study of information needs, seeking, and usage (INSU) is further positioned under the umbrella of personal health information management (PHIM). PHIM is an inclusive information management framework, which includes various activities, e.g., acquiring, managing, and communicating information, that occur in the home as part of personal health maintenance (Moen, 2007). The goal of these PHIM activities can include “prevention, self-care, surveillance, symptom management, seeking providers’ advice, making treatment choices, or coordinate care” for purposes of “wellness, maintenance [or] desired health outcomes” (p. 222). PHIM activities are a subset of personal information management (PIM) behavior, which encompasses methods and procedures for handling and managing personally encountered information for the purpose of future retrieval (Jones & Teevan, 2007a). Naumer and Fisher (2007) broadly define PIM collective behaviors as encompassing information needs, seeking, sharing, managing, organizing, and using behaviors that occur on a daily basis during the course of a day, month, year, lifetime, illness, etc., with regard to “information communicated and stored in multiple formats, including verbally, in print, and in digital format” (p. 76).
The population selected for this study is adults who are living with Type 2 diabetes and keep and use personal health information items specific to managing life with diabetes. This population was selected for study as it is a focus of much federal government health activity (Robert Wood Johnson Foundation, 2008). According to the Center for Disease Control and Prevention (CDC) approximately 23.6 million people, 6.3% of the population, have diabetes (CDC, 2008). Although adolescent diabetes diagnoses are rising, the majority, i.e., 18.0 million individuals, are ages 20 years and older (8.7% of all people in this age group). Concerns of this population are not limited to the illness, but include many complications, such as: heart disease and stroke, high blood pressure, blindness, kidney disease, nervous system disease, amputations, dental disease, and pregnancy complications (Centers for Disease Control and Prevention, 2010, 2007; Crandall, 2007). In order to minimize the complications of the disease, patients are encouraged to learn self-management techniques, which includes major lifestyle changes in diet and exercise (Beeney, Bakry, & Dunn, 1996).

The path to successfully managing life with diabetes often includes a significant learning curve with regard various topics such as nutrition and glucose testing. It is also marked by confusion, denial, and emotional swings, such as that expressed by Cornell (2012) in her story about learning to live with diabetes:

When I received the phone call in 2005 informing me that I had Type 2 diabetes, I was sure it was a mistake. I felt fine! I wasn’t sick. They must have called the wrong person! Well, it wasn’t a mistake. I had to deal with it.

OK, so I have diabetes. Now what? When I saw the doctor, she said I needed to exercise and change my diet. Losing some weight would be beneficial. She told me to get a glucose meter to check my blood glucose at various times during the day: first thing in the morning, before a meal, two hours after a meal, at bedtime, when the moon is full, on trash day…What? What did she say?

Be mindful of what you’re eating and how much of each thing: no more than so many grams of fat, so much protein and about 30 grams of carbs per meal. Huh? What’s a ‘carb’? I later discovered that a ‘carb’ is something that I absolutely adore. Damn the luck! (paragraphs 3 – 5)
Cornell’s story is similar to that of other individuals who successfully accomplish self-management techniques and can be found blogging encouragement and advice for fellow readers who are experiencing life with Type 2 diabetes, e.g., Mendosa (2011) and Pitt (2011). Like Cornell, these bloggers, however, are frequently writing at a time that is several years past their diabetes diagnosis and they often focus entries on optimism and encouragement. Cornell shares a glimpse into her original struggle, but diabetic community forums, such as DiabeticCommunity.com, offer more insights into the difficulty and inconvenience that individuals may experience following a Type 2 diabetes diagnosis. In these community forums, members post questions on topics such as medications and their side effects, recipes, or disease complications, thus providing a window into the information needs experienced by individuals with diabetes who participate in discussion forums. It is these information needs, and the information items that are suggested, that emerge from discussions about needs, uses, and experience that diabetes educators and information professionals need to be aware of in order to provide timely and relevant information items that may be of assistance.

1.4 Statement of Problem

Personal health information management tools, e.g., PHRs and patient portals as part of electronic health records offered by hospitals and health care providers, are being developed and implemented in order to improve an individual’s ability to self-manage their health and wellness. The American federal government is contributing to this development by funding research in partnership with corporations (Brewin, 2008; Broder, 2006) who are developing solutions for both personal and national levels. System development for a user is best accomplished with user involvement during the development process (Barki & Hartwick, 1989; Tait & Vessey, 1988). Limited insight that may inform PHR development is currently available. Results of Moen and Brennan (2005) illuminate health information management behaviors that individuals demonstrate in the home with regard to general health. Literature also reveals that the majority of individuals primarily consult doctors, family and friends, clinics or hospitals, and news reports for health information (Fox & Duggan, 2013). Longo et al. (2010) found that individuals with diabetes prefer additional personal sources for information, such as a nurse, nurse practitioner, dietitian, and diabetes educators. The preference for media fell below that of classes or seminars, support groups. According to Moen and Brennan, nearly 50% of the participants identified the
following sources as the next line of reference: reference books, health magazines, and Internet; nearly three-quarter of the respondents consulted health reference literature kept in the home. The findings of Longo et al. and Moen and Brennan are important in that they demonstrate the various sources used to address health information needs and manage health. Moen and Brennan further show how the individual manages that information within the boundaries of their home.

These findings, however, did not explore what the individuals and collection of kept items says about the implicit information needs. The studies seem to assume and imply that the sources used outside of an electronic tool should be duplicated in the tools. These studies did not capture items such as cookbooks or glucometers that are also important to the management of diabetes. This knowledge is as important to capture for possible development of training modules. This study proposes to address the gap and poses that documenting reference material possibly serves to provide insight into an individual’s concern with health and may be used to inform medical providers, as much as observations of daily living (ODL) (e.g., sleep, diet, exercise, stress and adherence to medication regimens) (Robert Wood Johnson Foundation, 2010).

Successful health management, however, entails more than identification of what information is stored and how it is managed. Knowledge is needed regarding the use of the information relative to the individual’s need. Therefore, this study focused on the intersection of information use and need, in light of relevance that individuals place on kept health items. Specifically, the study investigated how these items reflect the individual’s situational relevance, e.g., beliefs, knowledge, and information needs (Wilson, 1973). The aim of this approach was to explore individual’s perceptions of their use of kept items with regard to (relevant to) their perceived situational information need.

In so doing, this study addressed a crucial gap of personal health information management (PHIM) research identified by Agarwal, Khuntia, and Insight Policy Research Inc. (2009), “comprehensive and situated understandings of what individuals actually do when they manage their personal health information” (p. 8). Specifically, this study focused on addressing the “situated understanding” portion of this challenge, i.e., the situational relevance of the kept items. This aim is unique in that past research into information needs has primarily focused on the process that led to selection of information, including decision making, seeking behaviors
and relevance judgments (Case, 2007). The selection and use of a kept item grounds this research in order to examine the context that encompassed the behaviors.

The process oriented lens of past studies is grounded in the information behavior, information need seeking use (INSU) cycle posed by Wilson (1995) and bases investigations of an individual’s construction of information use by focusing on the originating need, such as the writing of a term paper. As depicted in Figure 2, this study stands in contrast to this historical methods in that it assumed that items sought and kept as a result of a need can provide insight into original the perceived need. This perspective is derived from a consumer behavior lens, wherein possessions, e.g., watches, clothing, vehicles, are viewed as reflecting an extension of self (Belk, 1988). This study assumed that kept health information items are similar to possessions and that information needs reflect the extended self. Additionally, this study departs from historical studies, in that it examines individuals at the conclusion of a seeking-retrieval process. As a result of the preceding seeking-retrieval process, the individual is positioned in a new context. Lastly, this study is different from past literature in that it addressed questions of information need and item usage based on items that are kept and used by individuals living with diabetes and who identify the item as relevant to their health condition. Therefore, this expands the knowledge base for information usage because it examines health information items after they have been used.

Figure 2. Portrayal of this study within the context of the cyclical pattern of information behavior posed by Wilson (1995).
1.5 Significance of Problem

The anticipated significance of this study is that it provides insight into information items kept by adults living with Type 2 diabetes and addresses a lack of attention paid to the associated information use and needs. It potentially serves to:

- Inform future diabetes education with insight of patient knowledge needs.
- Inform information professionals and health technology developers of health information technologies and types of health information items that are used by individuals with Type 2 diabetes.
- Inform information professionals with regard to the adequacy of current health information item uses taxonomy used to organize health information item resources.
- Inform information professionals and health technology developers of reference materials currently used by individuals with Type 2 diabetes to educate themselves and to manage life with diabetes.
- Demonstrate that knowledge of kept items can provide additional knowledge of information needs.

Diabetes education, as it promotes self-management, is considered critical to successful diabetes management (Longo et al., 2010). However, 76% of persons with Type 2 diabetes reported never attending any kind of educational class about diabetes (American Distance Education Consortium |ADEC|, 2008). The low rates of education class participation may be due to lack of access to education. The ratio of Certified Diabetes Educators (CDE) to diabetic patients in the state in which the study was conducted is approximately 1 to 1700 (ADEC). While it may be beneficial to train additional diabetes educators to meet the demands for education, this will take time. Additionally, some individuals may not have access to diabetes education classes for various reasons, e.g., cost. Thus, future development of personal health records (PHRs) may be used to address these education needs. In order to develop these tools to meet these needs, the results of this study provide insight into the information usage and the needs associated with health information items kept and used may serve to illuminate the concerns of adults living with diabetes.

The development of PHRs began as a means to provide patients with information pertaining to a medical visit and additional reference material relevant to that visit. Early in PHR
development, Tang and Newcomb (1998) showed that patients “want…more information about their illness and treatment plan” and that they “prefer…to receive information tailored to their own situation” (p. 564). However, the current impetus on PHRs has been to integrate the medical information found in medical systems with a personal view of the medical information and to enable individuals to create, review, annotate, or maintain a record of their health condition, medication, medical problems, allergies, vaccination history, visit history, or communications with their healthcare providers (Cheow and Win, 2007; Win, 2006). This medical view of a PHR is visible in the formal definition of a PHR developed by the National Alliance for Health Information Technology (NAHIT) (2008), a working group of corporate, medical, governmental, academic, and private representatives. The official definition of a PHR is “an electronic record of health-related information on an individual that conforms to nationally recognized interoperability standards and that can be drawn from multiple sources while being managed, shared, and controlled by the individual” (NAHIT, 2008, para. Personal Health Record).

However, it is paramount to remember that a PHR is a consumer-focused effort, grounded in the primary stakeholders identified by the National Committee on Vital and Health Statistics (NCVHS) (2001) in their proposed national health information infrastructure, a technological solution for healthcare. Their vision identified the three key stakeholders as: the community (“population health”), the healthcare provider, and the general consumer (“personal health”). In order to best meet the needs of general consumers, user behaviors that are to be modeled and serve as product requirements should be documented. The benefit of documenting user information behaviors for PHR development is that kept reference material possibly serves to provide insight into an individual’s concern with health. These observations of kept information material may be useful for medical providers, and give them insights into a patient’s concerns. For example, an individuals’ collection of sleep tips could tell a healthcare provider that sleep is an issue. When considered in this light, it is possible to extrapolate that knowledge of kept information items may be as useful as other observations of daily living (ODL) (e.g., sleep, diet, exercise, stress and adherence to medication regimens) (Robert Wood Johnson Foundation, 2010).

Knowledge of kept health information items can serve to benefit may stakeholders, including PHR developers, information professionals, and diabetes educators. Significant time and money is currently being spent to develop PHRs, and the federal government is further
encouraging adoption with current trials of PHR usage among Medicare clients. Insight into current beneficial health management practices only serves to promote effective development of PHRs. Healthcare providers and libraries strive to support consumer involvement by providing access to pertinent health information; additional insight and effort pertaining specifically to use of kept material would be beneficial.

1.6 Research Questions

This study sought to address the overarching question: What do the health information items kept in homes of adults living with Type 2 diabetes, and used to help manage life with diabetes, say about the information needs of the individuals? The specific research questions related to this umbrella notion that were investigated are:

RQ1. What personal health items do individuals keep with regard to living with diabetes?
   1.A. What types of items (e.g., book, internet site) are kept?
   1.B. Are certain types of items kept more frequently than others?

RQ2. What role does personal context play in the presence of kept personal health items?
   2.A. Are factors of personal context associated with kept personal health items?

RQ3. What use was made of the kept personal health items?
   3.A. How was each item used?
   3.B. Is an item related with multiple uses?

RQ4. What information needs are associated with kept personal health items?
   4.A. What specified need is associated with kept personal health items?
   4.B. Are multiple needs associated with an item?

RQ5. What is the relevance of kept health information items to living with diabetes?
   5.A. What relationship (situational relevance) is attributed to the kept item with regard to a specific component of living with diabetes?
   5.B. How does the framework of the national standards for education curriculum categories map to the information needs and item uses?
   5.C. What is the congruency of information needs, item use, and relevance decisions that are attributed to kept health information items?
   5.D. What do kept health information item attributed with incongruent information needs or uses say about the needs of individuals?
1.7 Method

This investigation used an exploratory, naturalistic research design to investigate the information needs and uses associated with kept health information items, as well as the relevance participants assign to the items. Specifically, data were gathered using semi-structured interviews that used kept and used health information items as a focus during the investigation process. These items served as the sources of evidence about which information needs, uses, and situational relevance were explored. The information keeping behaviors, the participants’ information needs, and the item usages were examined through a lens of situational relevance (Wilson, 1973), wherein the focus is on the kept item. This framework was selected in that it provided a means to explore whether “a person’s idiosyncratic expression of need is…a singular, isolated expression” (Chatman, 1996, p. 204), or if the presence of items in the home serves to represent larger information needs.

Data collection consisted of individual interviews in order to gain guided tours of health information items kept in the home, which the participants felt were related to the individual’s life with and management of diabetes. Kept health information items were considered physical items that were on the individual’s premises. These items included items, such as books; news clippings; journal articles; notes of references that were consulted, but not maintained in the home; or printouts from an Internet site. Electronic items that were maintained on the individual’s computer were also considered kept items; this included spreadsheets, bookmarked URLs, etc. Given the physical connotation of “kept,” excluded items included: a website that was not bookmarked; files not stored on the home computer; a reference source not maintained in the home; items that are kept in memory, such as or a website address or title of reference material.

The data analysis methods applied interpretivist techniques which included tabulations, themes, and supporting narrative evidence. Specifically, analysis began by coding data using an initial framework of categories found in the literature. The research questions were addressed using methods of tabulations and interpretive considerations.

1.8 Conclusion

This chapter presented a discussion of the purpose and justification for the study, as well as the specific research questions that were addressed. These questions served to provide insight
into the overarching questions: What personal health items do individuals living with diabetes keep with regard to this diagnosis and what does the use of these items say about the needs of the individuals? Additionally, this chapter provided definitions of key terms and identified that naturalistic inquiry provided the framework for the research plan.

The outline of the remaining document includes a literature review (Chapter 2), the study’s methods (Chapter 3), the results (Chapter 4), and a discussion and final conclusions (Chapter 5). The literature review provides a summary of the relevant literature pertaining to context, information need, kept (personal) health item, and situational relevance. This section also presents the foundation of this study and presents the gaps that are addressed. Chapter 3 describes the methods used to recruit and select research participants, and to collect, analyze, and interpret the research findings. Also included is a discussion of techniques used to ensure the trustworthiness of the data analysis and the limitations of the methods used. The results of this study, as well as ancillary findings, are presented in Chapter 4, while a discussion of these findings is presented in Chapter 5.
CHAPTER TWO

BACKGROUND LITERATURE

This chapter aims to provide a review of the foundational literature in which this study is grounded in order to provide context for the decision to explore the relationship between kept personal health documents and information needs with regard to the individual’s life in context of living with Type 2 diabetes. Specifically, this chapter serves to highlight: how this study is positioned within the literature of personal information behavior; the literature of self-management of diabetes, specifically as it pertains to the current American health climate; and the concept of relevance. This review will further clarify the definitions of the key concepts identified in Chapter 1, specifically those of context, information need, kept (personal) health information item, and situational relevance. The focal concepts are placed in context of the broader themes of the LIS literature pertinent to this study, specifically: studies of information use and information need conducted within personal information behavior, the concept of relevance, diabetes as a pertinent population, and information behavior specific to diabetes.

This review of the literatures serves to demonstrate that this study is an extension of current literature and describe how this study contributes knowledge in each of these areas. It extends past literature of information needs, information keeping behaviors, and information use, to specifically examine the overarching question: What do kept personal health information items say about the needs of adults with Type 2 diabetes? The subordinate questions, provided below, further serve as logical extensions of the literature and the primary question:

- Within an individual’s context of living with diabetes, what items are kept?
- How are the items used in relation to a precipitating information need?
- What does the use of these items say about the needs of the individuals?

The order of the literature presented in this chapter is: personal information (keeping) behavior within the context of personal information management; diabetes and its selection as the targeted context; and the concept of relevance.

2.1 Personal Information Management

Research conducted within the broad umbrella of information behavior (IB) generally includes “studies of how people need, seek, give, manage and use information in different
contexts” (Naumer & Fisher, 2007, p. 78). This study is generally positioned within IB research in that it is a study of user information needs and uses. It is more specifically positioned within a stream which is closely related to IB, personal information management (PIM) (Naumer & Fisher; Wilson, 1996). PIM specifically encompasses the behaviors of finding, keeping, organizing, and maintaining information, as well as managing privacy and the flow of information (Jones, 2008). Whereas past research has focused on information behaviors that are active or intentional, recent research has begun to focus on passive behaviors, such as accidental discovery or opportunistic acquisition of information (Erdelez, 1997; Erdelez, 1999). This concept poses that individuals construct information based on actions outside behaviors of active searches. This notion that individuals make health decisions and take action in response to chronic health conditions, e.g., Type 2 diabetes, informed the current study. As shown by literature, however, not all individuals actively seek information (Miller, 1987). Furthermore, individuals may keep information items that are not actively sought, i.e., are gifted, or that are obtained during other active information searches, i.e., during information encountering. Therefore, it is important to fully understand information needs and seeking behavior, such as the actions individuals take to construct and act upon information, in order to inform educational needs or the development of personal information tools, such as personal health records.

In order to address the gap in the literature as to what information items adults with Type 2 diabetes keep in their homes and what these items may signify with regard to their health information needs, this study investigates the items that are kept in the homes and examines the personal significance that individuals attribute to health information kept, specifically with regard to managing their life with diabetes. This study did not investigate other related information behaviors, i.e., information seeking or keeping decisions, which led to the presence of the information in the home.

2.1.1 Information Needs and Uses

A need for information is frequently conceived as the beginning of information behavior process and is described in many ways in LIS literature. Courtright (2007) provides a comprehensive overview of this literature, encompassed within a stream termed information needs, seeking and uses (INSU), pointing out that there is little consensus about questions such as, what constitutes a context, how it is understood by participants, how best to study information
needs, seeking, and use from a user-centered standpoint and in context. As a means to
demonstrate the progression of user studies Courtright describes the evolution of several research
streams, such as that of perceptions of an information need as an anomalous state of knowledge
(ASK) (Belkin, 1978) or as uncertainty (Kuhlthau, 1993). Case (2007) contends that an
information need “is a recognition that your knowledge is inadequate to satisfy a goal that you
have” (p. 5), while, Dervin (1992), however, views information as a process in her
conceptualization of sensemaking as theory. She poses that individuals construct their conduct
and judgment during situations and respond within a discontinuous time-space frame to make
sense of the moment. Thereby, an information need is viewed as a “gap” arising from a situation;
the terminal end is information usage. Whereas Belkin’s concept of information need provides a
means to study needs within an information retrieval (IR) framework, Kuhlthaus’s principle of
uncertainty, a cognitive state of anxiety and lack of confidence, provides a methodology to
investigate psychological processes associated with information seeking. Specifically, Kuhlthau
uses it to explain users’ information seeking actions (physical) in light of the feelings (affective
aspect) a user encounters during each phase of the seeking process, in addition to relevant
thoughts (cognitive aspect). This principle is guided by the assumption that a user moves through
the various phases of the information seeking process. Therefore, the information need is
dynamic and the need iteratively progresses through the process from need to retrieval of
relevant items.

The overarching information need under investigation is the health context, specifically
managing life with Type 2 diabetes. According to Bawden (2006), this general context is a users’
life world. This philosophical notion is a “subtle” concept that is similar to Vakkari’s 1997
notion of “information in context” (Bawden, p. 674) that is represented by work of Elfreda
Chatman (1996). The existence of this information need specific to the context of managing life
with diabetes is implied by the changes in the American health care system, wherein consumers
are increasingly asked to take active roles in their health care and are also increasingly
responsible for coordinating their own care (Macstravic, 2000).

Individuals generally do not seek information unless there is a need. The “solution” to
this need is thought to be “information,” wherein the concept of “information” has many
definitions in the field information studies, e.g., as “something that is constructed by people in
their interactions with other people, technology, and structures as the individual move through
life and work” (Solomon, 2002, p. 257). The general types of needs, or “questions,” that may require resources in order for an individual to address them can either be self-generated or imposed (Gross, 1999). Questions that are asked for the benefit of another are considered imposed; while the answer does not benefit the individual specifically, the importance and personal investment placed on the question and answer can vary. Self-generated questions, however, “spring from the context of an individual’s life and are pursued by the person who thought them up” (Gross, 2005, p. 159). These self-generated questions are thereby innately situationally relevant (Wilson, 1973), i.e., there is a relationship between the question (information need) and the individual’s belief and knowledge (personal context). The questions provide a snapshot of an “individual's personal view of the world and his situation in it” as is relevant to the notion of situational relevance. Situational relevance (Wilson, 1973), which were discussed in more detail in this chapter, is a foundational concept in the study of information retrieval.

Note that there are also individuals who seek information for the pleasure of learning, as well as individuals, termed “blunters,” who do not seek information when faced with a stressful situation, as could be caused by a health concern (Baker & Pettigrew, 1999). Despite the nature of “blunters” and that the study’s methods required that participants keep and use health information items, it is still possible that this study included individuals who could be considered blunters. Items kept in the homes did not have to be personally acquired. It was also possible that this study may include participants who keep health information simply for the purpose of knowledge. As long as the participant considered this “use,” then it would be included in the study.

Of further importance to note, while the work of Gross (1999) focuses only on the nature of questions as imposed or self-generated, this study applied this concept to both the kept item and the associated information need. While it is not possible for an item to be self-generated, it is possible for the participant to personally obtain an item, rather than receiving it from another, i.e., imposed. Data were collected regarding the source of each item, thereby giving some insight into whether an information need may have resulted in a self-generated or imposed query. The nature of a diagnosis of diabetes is an imposed concept that catapults the individual into a process of acceptance. While the study did not ascertain the participants’ current level of acceptance of the diagnosis or requirements to manage life with the disease, information needs
were assumed to be self-generated in that the participant is actively taking steps to manage life with diabetes.

2.1.2 Personal Information Keeping and the Collection

Information keeping, one of the key activities of PIM (Jones & Teevan, 2007a), is a decision to keep or not keep information items in the face of “ordinary events,” rather than an activity of storing and organization. Knowledge of information keeping and “the many ways we interact with the information” is important for PIM developers in order for developers to fully understand the “utility, serendipity, and pleasure of re-encountering what we have saved” (Marshall & Jones, 2006, p. 67). Decisions of information keeping can range from: (1) “ignore, this has no relevance to me”; (2) “ignore, I can get back to this later”…(3) “keep this in a special place or way so that I can be sure to use this information later” (Jones, 2007a, p. 39). An end result of these decisions across time is a personal information collection (PIC) that resides in an information space, whereby PICs are “islands of relative structure and coherence… and includes a set of information items… and their organizing representations” (Jones & Teevan, 2007b, p. 12). Bruce (2005) proposes that PICs develop in response to a perceived need and challenge and become “collection(s) of information sources and channels” that are organized over time, thereby reflecting the organic and dynamic nature of PICS. Bruce further offers that personalized “subsets” of information articles, e.g., documents, web pages, mail, notes, calendars, address books, etc., can be used to meet an information need and therefore, broadly depict a personal perspective on information, inclusive of information organization and representation structures (folder hierarchies, piles, lists, etc.), and information pointers (people, links, favorites, etc.). PICs are carried “into, and out of, the various information events that frame our daily working and personal lives” (Bruce, section Personal information collections). As such, PICs are considered “the space we turn to first when we need information to do a task or pursue an interest” (Bruce, section Personal information collections). Therefore, a PIC is of great interest in studying information needs, as were investigated in this study.

PICs may be considered strongly related to an application, such as the collection of health information items, as is the case in this study. Specifically, PICs of interest in this study are the health information items that individuals living with Type 2 diabetes keep in their “home” in order to manage their life with Type 2 diabetes; this study did not examine or capture
information items that have been discarded for some reason, or ask specifically why the information item was chosen over others. This study focused on the information needs, information item uses, and the relationship between these characteristics. There exists a vein of information keeping behavior research that seeks to categorize a spectrum of acceptable behavior that includes “hoarding” (Finneran, 2008; Frost & Gross, 1993). This study, however, did not address this topic. Additionally, this study, although counting the number of items kept by participants, did not produce a scale of “amount” or examine “acceptable” numbers of information items. The examination of kept and used quantity served to further inform the personal narratives surrounding the kept items and information behaviors.

Health information maintained in a home is generally specific to conditions experienced by the household and may contain several different categories and types of information according to concepts for future use or for management of health conditions (Basch, Thaler, Shi, Yakren, & Schrag, 2004; Moen & Brennan, 2005; Pratt, Unruh, Civan & Skeels, 2006). For example, research of patients undergoing treatment for breast cancer (Pratt, Unruh, Civan, & Skeels) found that patients primarily organized their information by phase of care, events and timing, or prominent organizing principles. In a qualitative, naturalistic study of home health management behaviors of rural, Midwestern health managers who were of fair health at the worst, Moen and Brennan find that many of an individual’s health management methods include stacks of receipts, journal clippings, and lab results and indicated several types of information, including health condition specific information, health specific equipment, logistical information, personal information of another family member, and reference material (Table 1). Additionally, the authors note that consumers’ practice of health management often arises from health concerns, and focuses on goals for prevention and health problem management.

These studies of personal information keeping are important in the context of health in that understanding of definite behaviors, specifically with regard to the developed PIC in response to a challenge or need, can provide insight into the development of technological management tools (Elsweiler, 2008; Elsweiler, Ruthven, & Jones, 2007; Lansdale, 1988). The insight provided can yield knowledge of resources that are contained in health specific PICs. For example, the work of Basch, Thaler, Shi, Yakren, and Schrag (2004) examines information resources, both paper and electronic, which are used by patients with cancer and their companions. This study sought to inform technological tool development literature, e.g., personal
health records, similar to that of Basch et al. Specifically, this study aimed to provide insight into the resources that adults living with Type 2 diabetes maintain in their home to support activities to manage their health, as well as to identify information needs that is implicitly indicated through keeping and use of the items. This insight may inform patient-centered information of “observations of daily living” (Robert Wood Johnson Foundation, 2010) that are important for the development of “smart, interpretive and intuitive tools” that will allow patients to “turn data into useable information in order to identify important health information,” (Robert Wood Johnson Foundation, para. 7), thereby allowing them to effectively participate in health care.

Table 1. Types of information maintained in homes.

<table>
<thead>
<tr>
<th>Information Type</th>
<th>Description</th>
<th>Cite</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health specific</td>
<td>special cards holding vital information like medication, blood type, medication information; folders and notebooks with personal health information or insurance information; medical record information; and general books, printouts from Internet searches, and information from mass media, most commonly television and radio</td>
<td>Moen &amp; Brennan, 2005</td>
</tr>
<tr>
<td>Equipment</td>
<td>support devices like walker, crutches, knee brace, wheelchairs, monitoring devices like a blood pressure and monitor, scale, glucose meter, thermometer, and treatment devices like a first aid kit, insulin pump, asthma chambers, pill box organizer and medication containers</td>
<td>Moen &amp; Brennan, 2005</td>
</tr>
<tr>
<td>Logistics information</td>
<td>doctor’s appointment, health insurance, doctor’s contact information, prescription information, provider information, doctor hospital clinic information, medical schedules</td>
<td>Moen &amp; Brennan, 2005</td>
</tr>
<tr>
<td>Personal information</td>
<td>birth/death certificates, medical history, immunization records, personal observations</td>
<td>Moen &amp; Brennan, 2005</td>
</tr>
<tr>
<td>Information Type</td>
<td>Description</td>
<td>Cite</td>
</tr>
<tr>
<td>------------------------</td>
<td>------------------------------------------------------------------------------</td>
<td>---------------------------</td>
</tr>
<tr>
<td>Reference material</td>
<td>literature, instructions on self-care, poison control</td>
<td>Moen &amp; Brennan, 2005</td>
</tr>
<tr>
<td>Phase of care</td>
<td>grouping cancer experience around point in the treatment process, e.g.,</td>
<td>Pratt, Unruh, Civan &amp; Skeels, 2006</td>
</tr>
<tr>
<td></td>
<td>such as surgery, chemotherapy, radiation, or hormonal therapy</td>
<td></td>
</tr>
<tr>
<td>Prominent events</td>
<td>e.g., consultations, treatment episodes, and personal events with</td>
<td>Pratt, Unruh, Civan &amp; Skeels, 2006</td>
</tr>
<tr>
<td></td>
<td>implications for their cancer care</td>
<td></td>
</tr>
</tbody>
</table>

This section discussed the overarching concept of personal information management, as well as information needs and the solution for an information need, i.e., an information item. These items may be simply put to immediate use or kept, whereby the activities of information keeping storage, organization and management take place. Furthermore, the result of these activities is a compilation of items that are collectively called a PIC. The next section discusses the PIM concepts in terms of a study’s health context, i.e., personal health information management, diabetes and the relationship to this study and within the context of the American health care system. This chapter concludes with a discussion of relevance.

2.2 PIM in Context of Health Focus: Personal Health Information Management (PHIM)

As discussed previously, this study is positioned within the overarching context of a personal health information management (PHIM), which is a subset of personal information management (PIM). PHIM is considered as the organization of health information and ensuring its accessibility (Agarwal, Khuntia, & Insight Policy Research Inc., 2009; Jacobs, 2009), and is an inclusive information framework, which includes information management activities, e.g., acquiring, managing, and communicating information that occurs in the home as part of personal health maintenance (Moen, 2007). These activities serve to “support consumers’ access, integration, organization, and use of their personal health information” (Civan, Skeels, Stolyar, & Pratt, 2006). The goal of these PHIM activities can include “prevention, self-care,
surveillance, symptom management, seeking providers’ advice, making treatment choices, or coordinate care” for purposes of “wellness, maintenance [or] desired health outcomes” (p. 222), while the goal of providing health information to individuals is to promote personalized health and wellness management (NCVHS, 2001). This direction toward a consumer’s view of health information is important as health care is historically provider-centric and recorded information about a patient is frequently created by the provider (Tang & Lansky, 1998). In order to develop a patient-centric system, wherein patients actively record and control information as part of interaction with the health care system, developers of personal health information systems aim to include information entered by the patient about daily symptoms, over-the-counter medicines taken, personal exercise programs, special diets, or data from home monitoring devices. By combining this personal health information with knowledge about diseases and their treatment, as well as knowledge of information behaviors that occur as part of disease diagnosis and treatment, future personal health information systems can provide tools that help patients understand and actively engage in their own health care and management.

PHIM activities include methods and procedures for handling, managing, organizing, and maintaining information personally encountered for the purpose of future retrieval (Jones & Teevan, 2007a). Naumer and Fisher (2007) broadly define collective behaviors as encompassing information needs, seeking, sharing, managing, organizing, and using behaviors that occur on a daily basis during the course of a day, month, year, lifetime, illness, etc., with regard to “information communicated and stored in multiple formats, including verbally, in print, and in digital format” (p. 76). The purpose of major PHIM activities is to meet the aim of three important goals: monitoring and assessing health, making health-related decisions and planning preventive or treatment actions, and performing these health-related actions (Civan, Skeels, Stolyar, & Pratt, 2006). These goals drive the need for several sub-activities, e.g., documenting history, making lists, bundling together related information, and setting reminders (Civan et al.). In order to support these activities, many tools and technologies used by the individual to keep up with health information management have been identified and categorized by type, form, need, and timing (Civan et al.; Moen & Brennan, 2005).

Although, saving and storing records is fairly common, consumer’s practice of health information management often arises from health concerns and focuses on goals for prevention and health problem management (Moen & Brennan, 2005). Information specific to timing, such
as appointment dates, are considered useful and routine information and may include time
critical events that are preventive or “in response to emergent health events” (Civan et al., 2006,
p. 157). Given the importance of time and health management, tools are used in the process of
health information management and include: calendars, phonebook, medical history or separate
sheets of paper with information of procedures, medication side effects, and, less commonly, as
personal digital assistants or personal computers (Moen & Brennan). Other types of health
information that are kept in the home include contacts, medical bills and receipts, calendars,
explanation of benefits, online chat logs, medication and self-care logs, first aid, health-related
articles and web pages, immunizations, medication and appointment schedules, diaries, medical
records (including x-rays, labs, etc.), referrals, educational materials, prescriptions, family
history and genealogy, cancer surveys, and insurance cards. Note that health information “forms”
minimally cross over with “types” to include: electronic (spreadsheets, lists, contacts, email,
calendar), paper (business cards, to do lists, printouts, file folders), images (paper and
electronic), devices (computer, cell phone, personal digital assistant (PDA), glucose monitor, pill
box), memory (remembering when you had your last physical), sensory-observation (attention to
weight scale readings) (Civan et al.; Moen & Brennan). Interestingly, these lists are quite
extensive and contain information pertaining to lab results (e.g., cholesterol and triglycerides),
immunization and health care provider records as these represent personal health information to
consumers (Jacobs, 2009). However, some potentially important health information was not
reported, including menstrual cycle dates, weight, blood pressure, and mood. This type of
information is as important as medical information and may fall under the category of
information scraps that could get lost in information keeping studies (Bernstein, Kleek, Karger,
& Schraefel, 2008). Despite the current research, Agarwal, Khuntia, and Insight Policy Research
Inc. (2009) contend that “the key gap that needs to be addressed is comprehensive and situated
understandings of what individuals actually do when they manage their personal health
information, and what challenges they face in doing so effectively” (p. vii). As such, this study
sought to determine what information items are deemed pertinent to management of life Type 2
diabetes exist, to what means individuals with diabetes consider their relevance, and how these
items are specifically used with regard to managing diabetes.

This section has provided a discussion of PHIM and discussed components of PIM, i.e.,
information seeking and storing behaviors that are tangential to the current research study. The
design of this investigates information items that are kept. It does not seek to elaborate on the seeking or management processes, other than whether the item was given or self-found and whether the item is electronic or paper based. The next section presents, in broad strokes, the context of this study with respect to the American health care system, wherein the federal government has established priority goals with regard to populations and technology.

2.2.1 The Study’s PHIM Context within the American Health Care System

This study of Type 2 diabetes is positioned within the larger confines of the American healthcare system. As such, this section provides a basic discussion of the American health care system and the context of the study’s population, the adult living with Type 2 diabetes. In doing so this study’s purpose are demonstrated relative to the gaps in the PHIM literature, i.e., knowledge of health information items that are kept in the home PHIM has become critical within healthcare in that Americans are increasingly encouraged to take personal responsibility for one’s health. This change from a patriarchal model of health care to one of personal responsibility is steadily promoted in federal reports, e.g., the National Committee on Vital and Health Statistics (NCVHS) (2001) and the Institutes of Medicine (IOM) (2001), laws (Executive Order 13335, 2004; H.R. 1, The American Recovery and Reinvestment Act, 2009), and funding opportunities. At the larger level, these reports and laws strive to promote goals of improving healthcare and moving the healthcare system to an “interoperable health information technology infrastructure,” which is referred to as a digital National Health Information Network (NHIN) (Brailer, 2005). The vision of a NHIN is that it will meet the health care needs of the primary stakeholders, i.e., the community (“population health”), the healthcare provider, and the general consumer (“personal health”) (NCVHS) and serve to promote the health care and the health information technology (HIT) agendas and address the various goals that exist for all stakeholders, including priority populations living with chronic conditions, e.g., diabetes. According to the Centers for Disease Control and Prevention (2009) chronic diseases are “non-communicable illnesses that are prolonged in duration, do not resolve spontaneously, and are rarely cured completely” (p. 2), e.g., heart disease, cancer, stroke, diabetes, and arthritis. Although, all chronic conditions warrant priority attention, this study focused on Type 2 diabetes.
Changes taking place in the American health system include the ability of individuals to have continual, 365 days-a-year/24 hours per day/7 days-a-week, access to medical and health information by technological means of Personal Health Records (PHRs). PHRs are defined as “an electronic record of health-related information on an individual that conforms to nationally recognized interoperability standards and that can be drawn from multiple sources while being managed, shared, and controlled by the individual” (National Alliance for Health Information Technology (NAHIT), 2008). These records are envisioned to benefit all consumers, but especially parents, patients with chronic illnesses, caregivers for elderly and disabled consumers, persons who travel, and consumers living in areas prone to disasters. The potential benefits of a PHR to patients, their physicians and the health care system are numerous and include: patient empowerment, improved patient-provider relationships, increased patient safety, improved quality of care, more efficient care delivery, better safeguards on health information privacy, and cost savings (Endsley, Kibbe, Linares, & Colorafi, 2006; Tang & Lansky 2005).

2.3 The Population: Adults with Type 2 Diabetes in their Homes

The context, i.e., “frame of reference” (Case, 2007; Courtright, 2007, p. 276) of this study has been set to that of individuals with Type 2 diabetes who keep in their homes and use health information items – electronic or paper based – that are related to their personal experience with the disease. The reasons for selecting this context, further discussed herein, include personal interest, federal attention, population need in order to promote positive outcomes, and population access.

Diabetes, more precisely called diabetes mellitus, is a chronic disease that is characterized by high glucose levels in the body that occur because of inadequate insulin supplies that are result of either the pancreas’ failure to produce enough insulin, or the body’s ineffective use of insulin that is produced and available (Centers for Disease Control and Prevention, 2007, 2010; Kishore, 2008, World Health Organization, 2006). The diagnosis of diabetes and the specific type, e.g., Type 1 or Type 2, is made based on plasma glucose estimation (World Health Organization) and a combination of features, such as age of onset, obesity, etc. (Crandall, 2007). The two primary types of diabetes are distinguished by the presence of insulin: non-insulin-dependent diabetes mellitus versus insulin-dependent diabetes mellitus. Whereas insulin-dependent diabetes mellitus is more commonly known as Type 1
diabetes, and formerly considered juvenile onset, the majority of individuals diagnosed with diabetes mellitus (90-95%) are non-insulin-dependent, which is more commonly known as Type 2 or adult onset diabetes. Note that the timing of onset does not determine the type of diabetes, as Type 1 can be identified in individuals well past their teen years and Type 2 can be diagnosed in youth. However, Type 2 diabetes is primarily associated with older age, obesity, family history of diabetes, history of gestational diabetes, impaired glucose metabolism, physical inactivity, race, and ethnicity (Centers for Disease Control and Prevention, 2010). Note that there are other types of diabetes that occur as a result of pregnancy (gestational), surgery, medication, genetics, etc. (Centers for Disease Control and Prevention, 2007). This study focused on adults who were living with Type 2 diabetes, however, as it is the most prevalent type.

Diabetes garners much attention in the U.S., as the Centers for Disease Control and Prevention (CDC) (2010) estimates that 23.6 million people, or 7.8% of the population, ages 20 years and older in the United States have diabetes, although only approximately 17.9 million are diagnosed. This disease strikes men and women of all ages and races. The CDC (2007) reported that as of 2007 diabetes, Types 1 and 2 combined, was most prevalent in adults, age 60+ years, accounting for nearly one-quarter of the diagnosis rate (23.1%). Adults, ages 40-59 years, account for 10.8% of the diagnoses, whereas those 20-39 years account for 2.6%. The majority of adults aged 20 years or older that were diagnosed with diabetes are non-Hispanic whites have diabetes (14.9 million, or 9.8%). However, African American, Hispanic, American Indian, and Alaska Native adults are twice as likely as white adults to have diabetes (CDC, 2010). According to 2004 to 2006 national survey data for people ages 20 years or older diabetes affects 7.5 percent of Asian Americans, 10.4 percent of Hispanics, and 11.8 percent of non-Hispanic blacks (National Diabetes Information Clearinghouse, 2008).

Additionally, diabetes was the seventh leading cause of death from disease according to death certificates issued in 2006, shortens the average lifespan by up to 15 years, and is the main cause of: new blindness, i.e., retinopathy (Crandall, 2007); kidney failure, i.e., nephropathy (Crandall, 2007); and amputations in the United States (CDC, 2010). Diabetes may also increase the possibility of experiencing a myriad of complications such as heart disease or nervous system disease (CDC).
2.3.1 Self-management and Perspectives of Individuals Diagnosed with Type 2 Diabetes

Living with diabetes can be considered a burden or a gift (Paterson, Thorne, Crawford, & Tarko, 1999). This dual view of the disease is evident in forum posts, such as those in DiabeticCommunity.com (n.d.) and blogs, including those of Mendosa (2011) and Pitt (2011). These blog writers specifically focus on living with Type 2 diabetes. However, they seem to start their blogs several years after their diagnosis, thus allowing them space and time for adjustment so they are able to focus on successful management strategies. While their posts provide guidance across various topics, including medication, education, life style changes, and need for support, posts to discussion forums indicate concerns of individuals trying to achieve successful self-management. Medication is often a concern.

In order to effectively manage diabetes, individuals may be prescribed medication, such as Metformin (DiabeticCommunity.com post, 2008; Pitt, 2011) or Byetta (DiabeticCommunity.com post, 2006, 2009), which is an injectable medicine. However, medications like Byetta may have side effects, including nausea, vomiting, heartburn; loss of appetite; weight loss; or dizziness, headache, or feeling jittery (Drugs.com, 2010). Diabetes self-management may also include, or fully depend on, diet and exercise changes. However, in order to make these changes and achieve effective control, i.e., self-management, patients often require education and training on self-care behaviors, such as healthy eating, being active, and monitoring blood sugar in order to improve health outcomes and quality of life (CDC, 2007; Funnell et al., 2009). Whatever the self-management strategy that is undertaken, patients increasingly turn to condition-related, social Internet forums, such as DiabeticCommunity.com, to seek advice from fellow patients.

Sometimes diabetes-related blogs portray pure optimism, as is expressed by Mendosa (2011) who embraces the lifestyle changes that were required. Postings in the diabetes forum, DiabeticCommunity.com, however, stand in contrast and indicate more of the difficulties of living with diabetes. The various posts and comments document difficulties of medication side effects, finding new ways to eat as indicated by recipe requests, discussion of diets, and personal tales of amputations. The differences portrayed by these two medium, blogs and discussion sites, indicate very different experiences. Although, Nagelkerk, Reick, and Meengs (2006) find it important to pay attention to the ability of individuals to “restructure the illness experience,” because the implications of the individual’s outlook of their future and their perception of
themselves as individuals with a chronic illness influence the individual’s ability to “control the disease and its impact on one’s life” (p. 788), attention to the topics of posts in the diabetes forum is important in that they show the areas of self-management that trouble the posters. In lieu of posts, this study seeks to provide insight into self-management concerns using kept items as a signifier and foundation for discussion about information needs.

The diagnosis of diabetes often necessitates individuals and families to major lifestyle changes in diet and exercise, and is accompanied by strong emotions of anxiety, shock, anger or denial, with younger respondents responding more strongly (Beeney, Bakry, & Dunn, 1996). Early changes experienced by diagnosed individuals are viewed as the “the most dramatic and significant in the participants’ experience of living with diabetes…in that the individuals experience new and enhanced awareness of self in relation to the disease and to caregivers” (Paterson et al., 1999, p. 792). This change is characterized by the individual’s realization that the individual, as the person with diabetes, “knows best what works for him or her” (p. 792). This mental shift is considered the initial “conscious decision to assume control of the self-management of the diabetes” (p. 792). Individuals continue to experience change throughout their experience with diabetes, but these are processes of “preserving and renegotiating balance” (p. 792) in order to “maintain good overall glycemic control” (p. 790). Modifications in diet and medication are considered “cornerstones of treatment and the most difficult components of self-management” (Nagelkerk, Reick, & Meengs, 2006, p. 152); therefore, it is critical that the individual with diabetes learns to manage these. Individuals experience diabetes as an “ongoing process, entailing growth and learning as new experiences occur” (Paterson, et al., p. 787). Barriers to care, e.g., financial, time, or knowledge, are encountered and pose major challenges in adhering to self-management programs (Nagelkerk, Reick, & Meengs). Therefore, informed and active patients are crucial to the adoption of healthy behaviors and the improvement of clinical outcomes (Bodenheimer, 2005). A patient’s pro-active health behavior enables him/her to manage diabetes as a life-long endeavor. This is not a lone endeavor, though. The majority want their families to be involved in order to be well informed about their diabetes, and therefore include them in training.

Means of support for individuals following a diabetes diagnosis include support groups, educational courses or workshops, written and audiovisual materials, and discussions with doctors (Beeney, Bakry, & Dunn, 1996). These sessions are important in that information
pertaining to diabetes self-care and possible complications are provided. These sessions also serve to provide support for the “transformative process” necessary to successfully manage diabetes, even when faced with any life challenge or change in life goals (Nagelkerk, Reick, & Meengs, 2006, p. 792). Unfortunately, self-management education is not reimbursable under Medicare, Medicaid, and most policies offered by private health insurance companies (Bodenheimer, Lorig, Holman, & Grumbach, 2002); therefore, education frequently needs to occur during visits with physicians. However, physicians frequently lack time or provide inadequate information for collaborative decision-making and goal setting. Patient planning for chronic care visits can help, but patients and physicians also value information provision from diabetes educators (Boddenheimer, 2005). Individuals with diabetes seek information and education in various formats, primarily 1-2 weeks after diagnosis compared to immediately after diagnosis, and also attend workshops that promote a family education format (Beeney, Bakry, & Dunn, 1996).

According to the National Standards for Diabetes Self-Management Education (Funnell et al., 2009) individuals with diabetes were provided training according to the nine content areas listed below. These areas provide a means to categorize information needs that are deemed important for self-managing life with diabetes and were used to assess situational relevance. These categories are deemed as “situationally relevant” to diabetes from a professional perspective.

1. Describing the diabetes disease process and treatment options
2. Incorporating nutritional management into lifestyle
3. Incorporating physical activity into lifestyle
4. Using medication(s) safely and for maximum therapeutic effectiveness
5. Monitoring blood glucose and other parameters and interpreting and using the results for self-management decision making
6. Preventing, detecting, and treating acute complications
7. Preventing detecting, and treating chronic complications
8. Developing personal strategies to address psychosocial issues and concerns
9. Developing personal strategies to promote health and behavior change
2.3.2 Barriers and Effective Strategies for Self-Management/Diabetes Education

The World Health Organization (WHO) (2006) encourages health care providers to facilitate patient identification of strategies to reduce barriers and facilitate integration of self-care into daily activities. According to Nagelkerk, Reick, and Meengs (2006), the greatest perceived barrier to self-management for adults with Type 2 diabetes in rural America is a lack of knowledge and understanding of the necessary diet plan, especially if it was too general or not individualized. Other identified barriers include: behaviors related to medication regimen included adherence; attendance to educational group meetings or classes; negative emotional responses; and limited resources.

Many of the identified barriers can be minimized by promoting good communication, and a crucial communication strategy is to follow up care with reminders, pamphlets, etc. The current study’s design provided insight into whether participants kept and used these informational items. Nagelkerk, Reick, and Meengs (2006) found that all patients who participated in focus groups preferred information delivery within two weeks of diagnosis, but individuals preferred the information to be delivered by a diabetes educator or from an educational course, rather than a doctor. These findings and recommendations make clear that in order to provide support for patients’ health behavior change health care providers need to know specifics about the individual’s behaviors so providers can help with “information giving, decision-making, problem solving and goal setting” (Boddenheimer, 2005, p. 327). This need highlights the type of information that patients may have and could provide a diabetes educator or physician in advance of a health appointment, promoting efficient and productive appointments.

Those patients who successfully self-manage their life with diabetes have demonstrated several strategies, in addition to discipline, that are useful for future education and tool development. According to Nagelkerk, Reick, and Meengs (2006) effective strategies identified during their exploratory focus groups include:

- finding and developing a collaborative relationship with a healthcare provider who listens to their concerns, assists them in making adjustments to their plan of care, and gives concise, simple instructions;
- maintaining a positive attitude that prompts proactive learning;
- having a support person who gives encouragement and assistance and facilitates self-management;
- acquiring adequate resources for self-management; maintaining routine medication administration times and routines;
- and participating in group education that encourages questions and discussion of feelings and fears.

Topics of strategies and barriers to self-management serve as foundations for development of diabetes education (Nagelkerk, Reick, & Meengs, 2006), which is incorporated into the holistic approach to treating diabetes, in that it is perceived that the result of education can be measurable behavior change. This change is sought in seven self-care behaviors, specifically healthy eating, being active, monitoring, taking medication, problem solving, reducing risks and healthy coping. Diabetes educators target these behaviors by providing training related to these concepts, including making healthy food choices, understanding portion sizes, gaining knowledge about the effect of food on blood glucose, sources of carbohydrates and fat, appropriate meal planning and resources reading labels, planning and preparing meals, identifying and addressing barriers to activity, learning to regularly check blood pressure, urine ketones and weight; demonstrating how to inject insulin or explain how diabetes pills work and when to take them; and learning to understand, seek and regularly obtain an array of preventive services. These specific activities and lessons are guided by the national standards set forth for diabetes education (Funnell et al., 2009).

An important part of the diabetes educator’s work is identifying the individual’s motivation to change behavior, then helping set achievable behavioral goals and guiding the patient through multiple obstacles. The implicit assumption underlying teaching and offering means to support a behavior change is that the material can be matched to the need. This notion of coordinating supportive material with the information need underscores the direction of this study. The results of this study provide insight regarding kept information items that support self-management skills and knowledge taught by diabetes educators. Only through further research, however, could it be determined if a lack of information items serves as a barrier to adequate self-management skills or knowledge.

2.3.3 Information Needs Relevant to Health and Diabetes

Health information studies have garnered much attention in the literature, including general studies of seeking and appraisal of online health information (Eysenbach & Kohler,
2002) and information behaviors across time of patients with cancer (Hesse, Moser, Rutten, & Kreps, 2006). However, Lambert and Loiselle (2007) contend that the concept of health information seeking behavior (HISB) is only partially mature. This is assessment it based on its broad definition, i.e., the process of obtaining information, which includes information about health, “health promotion activities, risks to one’s health, and illness” (Lambert & Loiselle, 2007, p. 1008), and that various scales, e.g., that of monitors, i.e., information seekers, and blunters, i.e., information avoiders (Miller 1987) measure “preference for information rather than HISB” (p. 1012) and conceptualize HISB as a dichotomy of seeking behavior or not, rather than as a process. According to Lambert and Loiselle historical investigations of HISB have primarily focused on two distinct aspects: the process of seeking information, and the information that is acquired. Studies of information behavior processes served to illuminate various facets, such as antecedents - e.g., information needs, personal factors, contextual factors, and situational factors; each factor is reported to have different influences (e.g., situational factors can influence what type and quantity of information sought) – or outcomes or consequences of seeking information, i.e., “the influence of HISB on individuals’ health-related outcomes” (Lambert & Loiselle, 2007, p. 1014). Studies that focused on the type of information sought investigated information within various contexts, including “(a) coping with a health-threatening situation, (b) participation and involvement in medical decision making, and (c) behavior change and preventive behavior” (p. 1009). Results from each of the model used in the various HISB studies contribute knowledge of specific actions or strategies that serve to inform a grander, holistic view of the HISB. While each model offers a contribution, “together, all models provide important insights into the study of HISB” (Lambert & Loiselle, 2007, p. 1011).

Early interest in HISB may have been to increase “understanding of why certain individuals might choose to seek available information, whereas others do not to the same extent” (Lambert & Loiselle, 2007, p. 1011). However, recent interest seems to be driven by concern of an individual’s HISB impact on the shared decision making process (Longo, 2005; Longo et al., 2010). Medical doctors find it useful to know what materials are relevant to patients for purposes of informed shared decision making (Godolphin, Towle, & McKendry, 2001). As such, Longo (2005) proposed a simple general model of HISB, based upon experience that includes antecedents of seeking behavior and information use, phases of active information seeking and use and passive receipt of information. These behaviors are modeled to result in
patient/consumer outcomes that include empowerment, satisfaction, activities of daily living, and health outcomes. This medical-specific HISB model has been used to provide insight into relationships between types of information sought and health self-assessments (Weaver et al., 2010) by a general population of adults in an urban area in the Northwest.

In an HISB investigation of how patients with diabetes seek and use health care information (Longo et al., 2010), patients were found to self-manage their health depending on their current needs. Patients followed a nonlinear process of health information-seeking behavior, wherein they sought and incorporated diverse information sources not traditionally viewed as providing health information. Information was sought from “a diverse and comprehensive range of information sources,” (p. 335), including traditional and electronic sources that were gleaned from media resources, friends, and health care professionals. The authors contend that the diversity of the specific information sought “reflects the nature of diabetes, which touches all aspects of daily living, including relationships… medications, cooking and portion control, exercise, and food shopping” (p. 335).

Although, Longo’s (2005) model is informative, it demonstrates the implications of disciplinary research silos and fails to address the broad information management and keeping literature pertinent to LIS. Lambert and Loiselle (2007) posed that a “more comprehensive understanding of HISB might lie in examining individuals’ patterns of HISB, that is, the particular ways in which individuals sequence components of the information and method dimensions within a given situation (and over time) to satisfy their information needs” (p. 1015), and to heed the notion that “typical categorizations of seekers or avoiders do not optimally capture differential patterns of HISB and might contribute to the misclassification of individuals” (p. 1015).

Therefore, although the HISB models inform this study, the current study drew upon LIS INSU literature as its framework, and added Wilson’s (1973) situational relevance in order to focus on individuals in context and to examine information needs as dependent on an individual’s knowledge and readily available sources. This study posed that the knowledge of what items are readily available in a home serves to inform diabetes education literature and personal health information management literature. Specifically, this study aimed to provide knowledge of diabetes related informational items that are kept in the personal information collections of adults living with Type 2 diabetes. Additionally, this study sought to identify the
information need associated with the item and the use associated with the item. This knowledge can serve to inform diabetes educators as to the use of materials that are provided or the use of readily available information that is stored in insulin pumps. The insights gathered from this study may further be used in the development of digital means of information provision, such as resources that online health applications, e.g., WebMD, make readily available for its users. The specific research question that extended from the literature presented herein, include:

What personal health items do individuals keep with regard to living with diabetes?
- What types of items (e.g., book, internet site) are kept?
- Are certain types of items kept more frequently than others?

What use was made of the kept personal health items?
- How was each item used?
- Is an item related with multiple uses?

What information needs are associated with kept personal health items’?
- What specified need is associated with kept personal health items?
- Are multiple needs associated with an item?

What does the kept health item say about the needs of individuals?
- What are the relationships that exist between the participant’s information need and the kept health item?
- How do the information needs map to current diabetes category schemes (taxonomies)?

2.3.4 Information Technology Tools and Systems in Use with Diabetes

Diabetes is a focal chronic condition for much health-related information system development (Dorr et al., 2007). In order for information systems to be successful, many conditions need to be in place, including an appropriate non-IT system of care and the use of specialized IT components that fit with “systems of care” (Dorr et al., p. 162). According to Piette, Kerr, Richardson, and Heisler (2008) health information technology research projects that are currently in development or in use for patients with diabetes include: patient-to-patient interactive voice response (IVR) calling systems used within Veterans Affairs (VA); IVR assessments with feedback to informal caregivers; information supports for clinical pharmacists
based on medication refill data; and enhanced pedometers. Additionally, the VA is developing a “My HealtheVet” program, a patient-accessible version of its electronic medical record. Information access, management extends beyond that of “medical information,” as demonstrated by Stepping Up to Health (Piette et al., 2008); this is a service whereby special pedometers upload data to personalized Web sites with tailored information promoting physical activity. The ability to offer tailored information can be improved upon if a system has knowledge of what information the patient currently maintains, as proposed by the current research. It is important to note, though, that requirements of each system change with quality of care and patient safety concerns for patients with chronic illness. Therefore, while “the most effective utilization of HIT for chronic disease care [remains] unclear,” (Dorr et al., 2007, p. 162) research continues into the software elements that are necessary “to facilitate best practices and which bring the highest likelihood of successful implementation in a broad network” (p. 157).

This section provided a discussion of diabetes, the importance of self-management, barriers and strategies to promote self-management, information behaviors associated with diabetes, and the tools that are in development or existence. As Piette et al. (2008) concludes development of “effective, patient-centered HITs should focus on bolstering the full array of diabetes patients’ supportive relationships and include a complement of observational, developmental, interventional, and implementation research” (p. 21). The next section pertaining to relevance strives to demonstrate the usefulness of this study to inform diabetes educators and health information management tools with information pertaining to the information items that adults with diabetes keep in their home. Godolphin et al. (2001) demonstrated that information items that were kept in a doctor’s office informed the shared decision making process; items kept in the individual’s home serve to do the same. In addition to identifying the specific information items that are kept, this study serves to illuminate the information needs that are associated with the items, to show how participants used the items, and to identify the relevance of the item to the participants self-management of their diabetes.

2.4 Relevance

This study is framed by the concept of situational relevance (Wilson, 1973), which is a specific type of relevance. Relevance is an important notion in both information retrieval (IR) and information science (IS) and has been the subject of much literature and several reviews.
(Jansen & Rieh, 2010; Mizzaro, 1997; Saracevic, 1975, 2007; Schamber, Eisenberg, & Nilan, 1990). It is a central construct for both fields; specifically, it is one of seventeen theoretical constructs (Jansen & Rieh, 2010) that are shared by both research streams of information searching and information retrieval. It is important to note, however, that relevance is treated differently in each area, i.e., has “different sets of assumptions and associated models” (p. 1518), and, therefore, should not readily be compared across fields (Jansen & Rieh, 2010, p. 1525). This notion of relevance as non-transferable across literature is underscored by the various types of relevance recognized in the literature, including: system/algorithmic relevance, topical relevance, cognitive relevance/pertinence, situational relevance/utility, motivational/affective relevance, and socio-cognitive (Cosijn & Ingwersen, 2000; Saracevic, 1996). As introduced in this section, the study utilizes the specific type of relevance, situational. This is discussed in more detail herein, but a general overview of relevance is first offered to provide context for this study.

While it is readily agreed that relevance is a critical construct to the IR and IS fields, a central definition of relevance is elusive, if it exists at all (Schamber, Eisenberg, & Nilan, 1990). While a grounding definition of relevance is lacking, there is no limit to the notions of the boundaries of relevance. Schamber, Eisenberg, and Nilan offer the perspective that relevance pertains to people more than systems, and that it must be considered using a multidimensional approach and the dynamic process. Cosijn and Ingwersen (2000) contend that the nature of relevance simply comprises three elements or role players – “systems, users, and the environment” (p. 535), while Jansen and Rieh (2010) offer that it is both a relation and a measure. In a means to further bind the concept, however, they further identify relevance as “a foundational criterion for evaluating the performance of searching or retrieval” (p. 1522). Mizzaro (1997) offers a more general, albeit circular definition: a relevance judgment is an assignment of a value of relevance by a judge at a certain point of time.

Mizzaro’s definition, however, over-simplifies the complexity of relevance research as is demonstrated by the different research streams. The vast scope of relevance is signified by Mizzaro (1997) in his proposed framework of the history of relevance, which is divided into several categories, including: kinds, surrogate, criteria, dynamics, subjectiveness, and expression. This choice of presentation was based on the framing of the literature reviewed, thus allowing the reader to gain insight in the vast division in the literature. The relevance literature offers
many studies that differ in perspective and the relationship that is portrayed by the concept of relevance. This portrayal of relevance provides insight into specifics of relevance studies, but as demonstrated by Mizzaro’s (1997) compilation of 13 foundational articles, studies of relevance generally fall within “two main classes: objective, or system-based relevance, and subjective, or user-based relevance” (Harter, 1992, p. 602). In addition to the two frameworks, system vs. user-based, relevance is also recognized as a foundational framework (Mizzaro, 1997). These categories and concepts were further discussed in this section.

2.4.1 Physical versus Cognitive

This section serves to provide a brief review of the two primary frameworks used to study questions of IR and IS: physical and cognitive. This section further provides an overview of classification methods used in relation to relevance and ends with recent relevance literature. These sections are meant to develop the link between this study and its grounding in situational relevance and to demonstrate how relevance was operationalized for this study. This section begins with comparative overview of both physical and cognitive streams in order to ground discussion of situational relevance in the larger context of relevance literature.

The study of relevance has followed within LIS two different frameworks (Borlund, 2003; Harter, 1992): objective, i.e., system-based, whereby research is conducted by bounding information as a physical object, i.e., “thing” or “physical information object” (Buckland, 1991) and subjective, i.e., human (user)-based (Schamber, Eisenberg, & Nilan, 1990; Harter, 1992; Park, 1994). The application of the physical metaphor to information research assumed that, information is a “physical, tangible object that…can be controlled by means of technology,” such as the book, the data byte, or the photograph (Buckland, 1991; Raber, 2003, p.51). The strength of the physical metaphor is that it provides a framework in which information, such as documents, texts, words – electronic or physical - can be defined. This framework provided for the ability to develop an information (retrieval) language that included detailed lists of relationships and characteristics (Soergel, 1967). This language provided a means for texts to be organized, stored, retrieved, processed, and communicated, thus allowing for stored texts to be retrieved for a request (Buckland). Additionally, the physical metaphor is critical to conduct information retrieval research, such as the Cranfield studies conducted by Cleverdon (1970) where text representation was measured against retrieval. The potential negative implication of
the physical metaphor, wherein all physical items serve to inform given the appropriate situation, occurs when the idea is universally extended to the point that “if everything is information, then information is nothing special” (Buckland, p. 356).

The early emphasis on information retrieval system development promoted studies of relevance within the objective framework and considered relevance as a “static and objective concept” (Borlund, 2003, p. 914). However, grounded in the belief that despite the identification of 40+ criteria that precede relevance judgments (Borlund, 2003), little was known of the criteria used by end-users in real information need situations. Cooper (1971) considered “relevance” a “vague” concept, albeit much researched. Unfortunately, it remains poorly defined, i.e., researched using multiple definitions. It continues to serve as a foundation of IR research in that it "expresses a criterion for assessing effectiveness in retrieval of information, or to be more precise, of objects (texts, images, sounds…from now for simply called ‘texts’) potentially conveying information" (Saracevic, 1996, p. 202). Fortunately, although many questions posed were about a retrieval system, the importance of users remained part of the equation. Therefore, discussion and research of the four key issues of relevance, i.e., nature, manifestation, behavior, and effects, often resulted in controversy, specifically in consideration of the user effect (Saracevic, 1996).

2.4.2 Classification of Relevance

It was noted earlier that relevance is perceived to be composed of several attributes (Saracevic, 1996). It is also posed that the existence of relevance “always indicates a relation,” while “different manifestations of relevance indicate different relations” (Cosijn & Ingwersen, 2000, p.533). Therefore, given that relevance is studied within different frameworks, e.g., system versus user-based, it is understandable that relevance is further categorized and classified according to many concepts. The first is multi-dimensionality (Park, 1997), wherein three dimensions were determined using different orientations: toward the problem, the use, or the value. Relevance may also be categorized by types that refer to the different possible relationships that may exist between two categories (Saracevic, 1996; Mizzaro, 1997; Borlund 2003). Based on these relationship relevance is said to consist of five types (Saracevic, 1996), discussed below.
The first group contains three entities: a document, a representation of a document (i.e., surrogate, such as a title), and information, which is the intangible use the user receives upon reading a document. The second group includes four entities: the problem, the information need, the request, and the query. The five basic types of relevance as defined by the possible relationships among entities include:

1. **System or algorithmic relevance** which is also considered objective. It describes the relation between the query (terms) and the collection of information objects expressed by the retrieved information object(s); this type of relevance is also sometimes called logical relevance (Borlund, 2003).

2. **A topical-like type**, which is associated with aboutness and is defined as “...how well the topic of the information retrieved matches the topic of the request. A document is objectively relevant to a request if it deals with the topic of the request” (Harter, 1992, p. 602); “direct matching” is generally assumed and plays an important role (Huang & Soergel, 2006).

3. **Pertinence or cognitive relevance**, which is related to the information need as perceived by the user. This relevance type poses that to resolve the relationship between item and need, topicality is not enough; a judgment requires an elusive subjective component (Swanson, 1977).

4. **Situational relevance**, which is dependent on task interpretation.

5. **Motivational and affective relevance**, which is goal-oriented.

Note that Cosijn and Ingwersen (2000) added an additional model of relevance, socio-cognitive. This type of relevance “typically takes place within the organisational environment or community” (p. 544). The authors also posed that the affective type was modeled as interacting with the other types of relevance, except that of system. The only implication of these additional relevance types with regard to the posed study is to note that emotions and motivation can have an effect on relevance judgments.

In addition to viewing relevance according to a classification scheme, each type of relevance is judged based on many criteria variables, such as instance style, specificity, level of difficulty of documents (Cosijn, & Ingwersen, 2000; Cuadra & Katter, 1967; Vakkari & Hakala, 2000) and time (Moen & Brennan, 2005). Whereas the latter category of time has more to do with storage means, the timeliness judgments, e.g., just-in-time or just because, may also play
into a decision for information selection or keeping. While Cuadra and Katter offer 38 criteria variables in their study of article abstracts within different document use situation, Vakkari and Hakala (2000) found that participants make judgments based on 56 variables within the five categories. The difference in these studies is that Cuadra and Katter had participants evaluate abstracts within a manipulated, i.e., experimental, situation, whereas Vakkari and Hakala conducted a longitudinal, naturalistic study, wherein students provided judgment feedback with regard to material selected for personal class projects. Similar to the work of Barry (1994) who found content to be the primary criteria for evaluation of academic material selected for a self-generated task, content also served as the major predictor of the usefulness of the document at each stage of the project (Vakkari & Hakala, 2000), as opposed to the categories of author, full text, journal/publisher/source, and oneself/participant/user. Their results support the notion that “motivated users evaluating information within the context of a current information need situation base their evaluations on factors beyond the topical appropriateness of documents (Barry, 1994, p. 444).

This section of literature pertaining to relevance has presented historical literature pertaining to the two paradigms of study, i.e., physical and cognitive, and has presented that relevance is considered to be a “system of manifestations” that is multidimensional and is determined based on numerous sets of categories and attributes.

2.4.3 Physical View of Relevance: System-centered

Research conducted within the system/physical framework recognizes the limitations set forth by the paradigm in that the states of an information need are bounded (Cooper, 1971) to the following foci: 1) a psychological state that is not directly observable, 2) the user’s query as an attempt to formulate the need, 3) the request which is the actually stated need, and 4) the representation of the need. Thus, Cooper set to define relevance, albeit “logical” relevance, also called “topic-appropriateness,” as a relationship between stored information and the users’ “information needs formulated as information need representations” (p. 22). This method implicitly assumed that relevance is answerable under the paradigm of the physical metaphor. Within this lens, however, the initial, operable definition for relevance had three restrictions: 1) the search query is of a yes-no type, 2) data stored in the system is in the form of sentences, and 3) the retrieval system can deduce the answer. Thusly, “a stored sentence is logically relevant to
an information need if and only if it is a member of some minimal premises set of stored sentences for some component statement of that need” (p. 24).

Leading into the late 1970’s there was a growing presence from the one side, of user-oriented, cognitive approaches and, from the other side, of attempts to define a logic for IR (Mizzaro, 1997). Most research conducted during the 1970’s and ‘80s was conducted within the objective, or system-centered framework, although different views were emerging. Saracevic (1975) noted these different views of relevance that resulted from the different approaches, i.e., the destination's view which concentrates on judgment; the pertinence view which concentrates on the stock of knowledge at hand; and the pragmatic view which focuses on an immediate application or on the problem at hand. During this time Wilson (1973) offered the concept of situational relevance, which built upon the concept of logical relevance (Cooper, 1971) and posed that an individual’s beliefs and knowledge had bearing on relevance judgments. Note that Saracevic’s (1975) pragmatic view is quite utilitarian and often associated with situational relevance (Cosijn & Ingwersen, 2000). However, Wilson’s (1973) notion of relevance differed from the pragmatic view in that it made a distinction between psychological and logical relevance. While the former concept, psychological relevance, deals with actual uses and actual effects of information, the latter, logical relevance, is a double concept "of a relation between an item of information and a particular individual's personal view of the world and his situation in it. It is a concept in which relevance depends on logical bearing on some matter on which [an individual] has preferences” (Wilson, 1973, p. 458).

Subjective, user-centered studies (Harter, 1992) continued to slowly emerge until Schamber et al. (1990) called for studies of relevance judgments made by “real” users, i.e., individuals who provide self-generated questions using personally defined queries. This naturalistic approach, as called for by Park (1994), leads to “a more complete and useful understanding of the dimensions of relevance” grounded in “…an understanding of relevance criteria, or the reasons underlying relevance judgments, as observed from the user’s perspective” (Schamber et al., p. 771). Relevance studies, thereafter, promoted the cognitive user-oriented approach which views relevance as a “subjective individualized mental experience that involves cognitive restructuring” (Borlund, 2003, p. 914), thereby supporting the assumption that “relevance is intimately related to thought processes and criteria used in the evaluation of
citations retrieved in an IR situation” (Park, 1994, p. 136). The cognitive paradigm and its benefits were further discussed in the next section.

2.4.4 Cognitive View of Relevance: User-centered

The cognitive metaphor provides a lens in which to study information as an interaction between text and reader texts, whereby information may only be judged as informative through a cognitive act. The extension of the cognitive metaphor provided relevance to be viewed as a multi-faceted concept, consisting of several attributes: relation, intention, context, inference, and interaction (Saracevic, 1996). Additionally, application of this metaphor provides a means to:

- study user-centered questions such as, a user’s need for information and the use of that information, e.g., interrelationships among concepts in the field (Wilson, 1981);
- focus on issues of sensemaking, i.e., information needs, item use, and sense individuals make of used information items (Dervin, 1977);
- consider information seeking relative to an individual’s cognitive state of uncertainty (Kuhlthau, 1993) or their anomalous state of knowledge (ASK) (Belkin, 1978);
- and consider relevancy when users can interact through “dialogue” with a retrieval system (Ofori-Dwumfuo, 1984).

According to Park (1994), a user’s view of relevance cannot be isolated from an individual's particular situation and is concerned with the topic of the problem but also includes much more, such as an “individual's goal and task in terms of one's information need in that particular situation (moment)” (p. 136). These goals and tasks may include: the catalyst of the information need, its purpose, and steps to find the information. In addition, user’s relevance is concerned with subjective contexts and assumptions, such as the individual’s current knowledge, experience, stage of “research” or information “solving” progress, the time frame, the expected form of the solution, etc. However, it also includes context in which information is sought, and the cognitive processes that take place before, during and after the encounter (Park, 1994; Saracevic, 1999). This comprehensive framework assumes that “information is intangible [and] depends on the conceptualization and the understanding of a human being” (Tague-Sutcliffe, 1995, p. 11).
2.4.5 Situational Relevance and Recent User-Centered Research

Situational relevance is recognized as another foundational view of relevance (Mizzaro, 1997). Wilson (1973) offered this logical, “influential,” and “personal” concept as a means to consider the user’s information needs in terms of their personal background and in light of system centered information retrieval studies (Nolin, 2009). Wilson’s notion of situational relevance is not that of a psychological concept, although he seems to broach it as such (Nolin, 2009). Instead, it is offered to extend Cooper’s (1971) definition of logical relevance by considering the individual’s particular view of his or her world with regard to their current situation (Wilson, 1973). Although, the focus begins to shift to the user, the concept was still focused on the intent to connect an information need with an information query as part of the information retrieval focus. As such, Wilson’s concept of situational relevance is considered a bridge between the cognitive and physical views (Borlund, 2003). Whereas the cognitive view, i.e., psychological relevance (Harter, 1992), investigates actual uses and the effects of the information, predicting that the use results in a change in perspective or view, situational relevance, in contrast, is an abstract and static view of the relationship between an information item and the individual’s context.

Whether a bridge or separate entity, situational relevance offers an important lens with which to view information and is therefore, an important concept for LIS. It offers a means to connect IR and information studies literature. Budd (2004) contends that this focus on relevance in LIS needs to be embraced as it offers a unique means to investigate the concepts of information needs and item use. Budd offers that there are historical alternative definitions, uses, and implications that need to be re-considered, e.g., Wilson’s (1973) approach to situational relevance, because it offers a view of relevance that is a “melding of deduction and induction …and thus stresses that the ultimate judgment of relevance in all but the most simple instances is a nonlinear and rich process” (Budd, 2004 p. 451).

Situational relevance provides a logical approach to consider the knowledge, beliefs, information needs and the individual with regard to the information item and draws upon inductive logic to determine if an item is situationally relevant. Information that is situationally relevant informs an individual’s context and can either strengthen or weaken a “case” (Wilson, 1973), e.g., a cookbook with diabetic recipes can promote the notion that an individual is self-managing diabetes. Wilson further poses that “situational relevance is a relation between items in
a particular individual’s stock of information and questions of concern to him” and that “items of information are situationally relevant if they answer, or help answer, questions of concern. Answers to all one’s questions of concern taken together constitute a situation description” (p. 463).

Considering the amount of attention paid to relevance as a foundational concept of LIS, the attention paid to Wilson’s (1973) notion of situational relevance is minimal in comparison to the attention paid within the bounds of IR (Budd, 2004; Mizzaro, 1997). This slight to situational relevance is further demonstrated in a literature search conducted Summer 2010 using the Thomson Reuters (formerly ISI) Web of Knowledge for articles that cite Mizarro’s (1997) or Wilson’s (1973) articles. Many articles that cite Wilson (1973) pertain to studies of partial relevance (Greisdorf & Spink, 2000) or to call for a shift to user-centered studies, e.g., Budd (2004) and Hjorland (2010). Both Budd and Hjorland contend that a subject-dependent/ situation specific understanding of information is best suited to fulfill the needs in information science. As questions and needs of information storage change, so does the perspective of relevance. Theoretical insights into new conceptual models serve to inform the development of relevance logical models. Such insights include that of Hjorland who offers a view of relevance from a social point of view and that of Crystal and Greenberg (2006) who in their study of content selected following an Internet search, conceptualize relevance as usefulness to an individual’s information need in the context of their background and interests, i.e., “situational relevance” with regard to situation and task. The key categories the individual identify include: research, topic, scope, data, influence, affiliation, Web characteristics, and authority/person.

User studies conducted within a lens of situational relevance serve to provide a view, albeit perceived as utilitarian (Cosijn & Ingwersen, 2000), that can support information management and system design (Petrelli, 2008). The insight that situational can provide is most prevalent during the first cycle of the four cycle design–evaluation process involved in system development, wherein a system is planned and system requirements are gathered. User-centered research conducted within the framework of situational relevance serves to provide an understanding of the “broad context of use,” which encompasses “users, tasks and environment” (p. 26). This understanding can inspire the design, which is made possible in that the “user-centered approach starts with a cycle of observing and understanding the user context in order to define an appropriate set of user requirements for an effective design” (p. 27). Additionally,
situational relevance is a useful lens in that it offers a dynamic view of relevance judgments (Cosijn & Ingwersen; Wilson, 1973), which are considered context dependent and “highly personal and subjective” (Cosijn & Ingwersen, p. 539). The judgment process is considered dynamic in that “interpretations of the other four attributes of relation, intention, context and inference of the relation towards the information objects may change as cognition changes” (Cosijn & Ingwersen, p. 543). According to Tan, Foo, Goh, and Theng (2009), Saracevic (1996) argued that context should be used to consider the relevance of information and that context can be used to measure the relevance of information such that only appropriate information is presented (Mizzaro, 1997; Wilson, 1973). This view supports the development of a device that can deliver “the right content for the right context” (Tan et al., 2009, p. 565). The usefulness of the content, however, is deemed largely dependent on the users’ judgment. This dynamic view of situational relevance is attributed to Borlund (2003) (Jansen & Rieh, 2010), wherein “the same user’s perception of relevance may change over time” (p. 1525).

Recently, user studies have recognized the applicability of Wilson’s situational relevance (1973) to investigate an individuals’ contextual personal background with regard to the development of information systems (Petrelli, 2008) and during user-centered evaluations of an information retrieval application or the development of location based tourism applications, such as TILES (Tan, Foo, Goh, & Theng, 2009). Note that TILES stands for the tourism-related categories, temporal, identity, location, environmental and social (Tan et al.). In previous application studies researchers used situational relevance to propose different context “types” in their definitions of context, including location, temporal elements, identity and activity, descriptions on identity and environment, social aspect, proximity, device and physiology social (Tan et al.). These “types” may also be considered “situational attributes” (Byström & Hansen, 2005), which are “of a transient nature, creating temporary conditions for task performance processes” (p. 1053). Situational context is important in the design of mobile devices, and that design of context-aware mobile applications can be improved through a clear and in-depth understanding of context and how it can be used to meet users’ requirements. Using tourism as a case application, Tan et al. (2009) develop a model that helps gather information needs that are situationally relevant to the tourist for tasks commonly executed, such as “selecting places of interest,” determining “how to get to places of interest,” or taking weather into account when making plans (p. 580). This study poses that the situational relevance lens serves as an equally
useful tool to provide insight regarding the situationally relevant information items to adults with Type 2 diabetes.

To conclude this section, it is important to note that similar to Tan et al. (2009), this study used situational relevance as a lens to view the information items, their uses, and the precursory information needs within the context of living with Type 2 diabetes. Additionally, it draws upon Taylor, Cool, Belkin, and Amadio, (2007), who used Wilson’s (1973) situational relevance lens, to develop a better understanding of how users’ perceptions of relevance change as they move through the information seeking process. This study differs from that of Taylor et al. (2007), however, in that this study looked at a judgment of relevance in a snapshot of time, rather than investigating changes in relevance made across time. The results from this study, however, did draw upon participants who had been diagnosed at different times and who had different past experiences, e.g., family history, with diabetes. Given the contextual differences, this study provided data from different stages of information needs.

2.4.6 Conclusion to Relevance: Use of Situational Relevance to Inform this Study

The concept of relevance emerged much as the notion of information storage and databases became center stage when Vannevar Bush (1945) offered his notion of a “memex,” a mechanical memory aid wherein “an individual stores all his books, records, and communications, and which is mechanized so that it may be consulted with exceeding speed and flexibility (p. 12). This notion of increasing amount of potential material that may be beneficial in supporting an individual’s life remains today, be it financial, household, or health related, e.g., personal health information management tools. As during the times when Bush proposed his Memex idea, individuals today continue to be limited in time to 365 days, 24 hours/day, and 7 days/week. However, it seems that individuals currently are expected to manage information of increasing types, stored at more locations, for multiple purposes. Therefore, although relevance seemed to become a critical issue for early information retrieval (IR) research in the 1960’s (Cooper, 1971; Saracevic, 1975; Schamber, 1994), it is as critical, if not more so today, as predicted by Bush (1945). Additionally, the demand for online tools is growing in many life areas and electronic storage media continues to become increasingly affordable, allowing for storage of increasing amounts of content. The skill and ability of individuals to effectively use the media to find information stored in the advancing databases may not be keeping pace with
the technological changes. Therefore, there is a need for equal focus on the means to connect the information to a user, the activity that defines the notion of relevance.

The process to connect a user and an object stored in a database requires input from both technical (IR) and user-centered (LIS) perspectives. The goal of the interaction of these parties is to develop conceptual models that serve to represent “real-world objects in the most realistic way possible” (Coronel, Morris, & Rob, 2009, p. 655). These conceptual models are later operationalized as logical database models, i.e., software-dependent objects that serve as the program for data storage with the purpose if information retrieval as result of the design process (p. 663). These two objects demonstrate the technical side of determining how to model data storage, as does the myriad of literature pertaining to relevance, model development, and information retrieval, e.g., Brooks (1998) who poses a specific model for IR development. The personal side of the relevance equation is determined by the business rules that are defined as the “restriction or limitations on certain aspects of a database based on the ways an organization perceives and uses its data” (Hernandez, 2003, p. 584). This definition provides a distinct view that databases serve “organizations”; however, the explosion of programs that provide databases for personal use demonstrates the need to expand this definition by eliminating the restriction to “organizations.” LIS has considered the importance of a user perspective of relevance since the development of the cognitive notions in the early 1990’s (Mizzaro, 1997), but its focus is less than that garnered in IR studies (Budd, 2004).

This study is grounded in Wilson’s (1973) notion of situational relevance, which is bracketed between two different frameworks, the objective and the subjective (Borlund, 2003; Harter, 1992) and bridges information studies conducted within information searching and information retrieval (Jansen & Rieh, 2010). Situational relevance serves as a foundation for this study in that it considers the knowledge, beliefs, and information needs of individuals and offered a lens by which to study individuals in context. This study posited that information items purposely kept and used can indicate the background for their knowledge, beliefs, and information needs. This situation relevance, i.e., a dynamic decision based on a holistic evaluation of the item, thereby defines an individual’s context. This study posed that an individual’s context is partially represented by the items that they choose to keep and use. Given that self-management is critical to successfully managing one’s life with diabetes, the items and their use represent the individual’s constructed situational context from which further
information needs develop. The specific research questions that flowed from the literature include:

What role does personal context play in the presence of kept personal health items?

- Are factors of personal context associated with kept personal health items?

What relevance decisions are attributed to the kept health item?

- What relationship (situational relevance) is attributed to the kept item with regard to a specific component of living with diabetes?

- Are there relevance decisions that are attributed to the kept health item, but that do not relate to either the information need or items use?

2.5 Information Need

The concept of an information need is central to the objectives of this study. The study specifically aimed to examine explicitly stated information need associated with kept health information items that adults living with Type 2 diabetes keep in their homes to help manage their life with diabetes. Additionally, the lens of situational relevance served to inform the existence of implicit information needs that were expressed during narratives of item use and context. Cooper (1971) in his foundational article defining logical relevance identifies an information need as “a psychological state… [that is] not directly observable” (p. 21); a user may be able to verbalize an information need, but the utterance is not the same thing as the need. Information needs have been investigated in user-centered studies within LIS using different concepts, including uncertainties (Kuhlthau, 1993), an “anomalous states of knowledge” (ASK) (Belkin, 1978), or information gaps (Dervin, 1982). Each offers a unique perspective on information needs and offer a framework to information needs as precursors to an information search process. However, this study departed from historical methods for investigating needs and focused on kept information items that may have been acquired as a result of a search process that proceeded an information need. Rather than readily dismissing the historical concepts of information need, however, each is briefly described herein and rationale for not using them is provided. Kuhlthau’s (1993) constructivist notion of uncertainty is not suitable in that it views the concept as a means to investigate psychological processes associated with the information seeking process. The focus of this study is not of information seeking or of the cognitive changes that take place during the process. Dervin’s (1992) notion of the information gap, i.e., the
individual’s questions, serves as the starting point to investigate the information use process. The concept of an “information gap” simply aims to describe the communicating moment and explain that moment as seen by the actor. The notion of an information need posed by Dervin is similar to the investigated concept; however, Dervin’s focus is on the subsequent verbing behaviors that focus on how an individual gets from the event of an information need to a point of knowledge or use. This study investigated information needs and item use, but not the information seeking process.

Information needs are a central concept in LIS research (Courtright, 2007) in that they are modeled as the precursor to information seeking behavior (Wilson, 1999). However, information needs are infrequently directly studied (Case, 2007) other than in specific question-negotiation investigations. The concept of information needs have also begun to draw attention from the health care community, wherein, an information need is a subjective and unique, “personal item about which individuals require information” (Timmins, 2006, p. 377) and is perceived as a reaction to a stimulus, such as “major life changes, other events or life-threatening or incapacitating illness” (p. 377). Just as individuals experience information needs, the medical community anticipates that certain information is required, i.e., needed, in order to self-manage life with diabetes, hence the development of curriculum standards (Funnell et al., 2009). This study seeks to draw upon these expectations as a baseline to explore situational relevance of information items that participants keep. Additionally, though, this study assumes the position that “a person’s idiosyncratic expression of need is not a singular, isolated expression” (Chatman, 1996, p. 204); information needs were inductively determined based on categorization of the items and the participants’ statements of information needs with regard to the items.

2.6 The Naturalistic Paradigm

The naturalistic framework is perceived by some authors (Naumer & Fisher, 2007) to be an appropriate lens to investigate behavior that is performed in a natural setting for the simple reason that “it is carried out in a natural setting (hence the term naturalistic), that it uses a case study format, and that it relies heavily on qualitative rather than quantitative methods” (Lincoln & Guba, 1982, p. 233). Park (1994) contends that the application of the naturalistic framework is appropriate “if we believe that the nature of users-based relevance is involved with individuals’ mental processes and involves cognitive changes” (p.137). The positioning of this study involves
more than this, however. The application of the naturalistic paradigm to this study was chosen in that it offers “holistic and contextual” (p.76) information about personal information management (PIM) (Naumer & Fisher, 2007). Additionally, “it offers a contextual relevance and richness unmatched by any other paradigm … [and it] takes full advantage of the not inconsiderable power of the human-as-instrument” (Guba & Lincoln, 1982, p. 235). It should be noted that research conducted within the naturalistic paradigm grounds it in the following five specific axioms (Lincoln & Guba, p. 237-239):

1. **Axiom 1**: The existence of “multiple, intangible realities” which need to be studied holistically.
2. **Axiom 2**: The existence of a relationship between inquirer and object wherein they interact and influence each other. The researcher must take steps to minimize “reactivity.”
3. **Axiom 3**: Importance is placed on “truth statements” that promotes the development of a “body of knowledge” that starts as "working hypotheses." Therefore, generalizations are impossible since the phenomena are temporal and context dependent.
4. **Axiom 4**: Actions are attributed and explained relative to the context and, and thus must be considered holistically.
5. **Axiom 5**: Inquiry is value laden and is further considered in corollaries of: problem framing/focus; paradigm selection; driving substantive theory; values inherent in the context; and the juxtaposition, i.e., either resonant (reinforcing or congruent) or dissonant conflicting), of the nature of the problem to the previous corollaries.

The implications of these axioms with regard to this study are:

1. **Axiom 1**: Adults with Type 2 diabetes have distinct realities of information needs, information keeping, and information use. A holistic picture of information behaviors of adults living with type 2 diabetes is informed by distinct narratives.
2. **Axiom 2**: The researcher conducted each face-to-face, semi-structured interview using a standard set of questions as a guide. Given the personal nature of the topic, living with diabetes, and the face-to-face contact, the researcher aimed to balance rapport with objective professionalism.
3. Axiom 3: Generalizations are not drawn from this study. The findings are discussed in relation to the sample used for the study, but possible larger implications are drawn.

4. Axiom 4: Information keeping and use behaviors are tied to each other and are associated with information needs. These cumulative behaviors occur within the grand context of living with Type 2 diabetes, but also within specific situations. Findings of these behaviors and context are investigated and discussed in conjunction with each other.

5. Axiom 5: This study offers value to historical INSU and HISB literature in that it provides insight into kept information items and associated information behaviors of adults living with Type 2 diabetes. Furthermore, this study demonstrates that these behaviors may be investigated using a lens that focuses on a kept item, rather than a process associated with an information need.

This study built upon previous naturalist health research conducted by Moen and Brennan (2005). Their insights into the organizational methods of keeping health materials at home provide taxonomies of storage placement and timing of use for maintained items. This naturalist study served to validate the list of health information sources that individuals living with diabetes reported during focus groups (Longo et al., 2010) and to identify health information items adults keep in their homes that may show that they have material to support knowledge that is deemed important in diabetes education (Funnell et al., 2009).

2.7 Conclusion

This study explored the health information items which adults with Type 2 diabetes keep in their homes to manage their life with diabetes. In particular, the study identified the uses and information needs that the participants attribute to these items, in addition to the “situational relevance” that is further identified with these items. This attribution can then be used to compare to the national standards set forth by the National Diabetes Association (Funnell et al., 2009) to determine if participants recognize the same priorities as signified by the kept items and attributions of relevance. This chapter provided a discussion of the literature that supports the conducted research. Additionally, a discussion of relevance was provided. Relevance has a vast historical underpinning in IR and IS research; it is frequently studied using different lenses, e.g.,
objective and subjective, and is studied as different types. The specific type of relevance, situational relevance, was used to frame this study. Historical categories that have informed previous relevance studies, and that were used to inform this study, were presented.
CHAPTER THREE

RESEARCH DESIGN

This study used semi-structured interviews to address the focus of this study: information needs portrayed by health information items that adults with Type 2 diabetes keep in their homes to manage life with diabetes. Interviews were chosen as the study’s primary method for two reasons: in order to encourage discussion about the responses and to allow participants the ability to expand upon responses given to the basic questions. The interviews used the kept health information items as the focus in order to spark memories that would allow the researcher to address the overarching question of what the items may indicate with regard to information needs of the participants. Although, the health information items kept in the participants’ homes served as the emphasis of data collection, the questions focused on identifying information needs, item uses, and item relevance. Additionally, questions pertaining to health history and demographics served to identify the overall context of living with diabetes of the information behaviors. Rich narratives provided during the interviews provided additional insights in specific bounds of situational relevance.

In Chapter 1, the primary purpose of this research was outlined as being to explore these personal health items that individuals living with diabetes keep with regard to this diagnosis and what information needs and usages are associated with the items. Chapter 2 addressed the literature that is relevant to this study’s objective of exploring kept health information items to support managing life with Type 2 diabetes. This chapter provides details of the research approach and procedures that were used to address the research questions. The key methodological issues addressed in this chapter include: research design, data collection, study participants, data analysis, and issues of quality, including credibility, validity and reliability. Prior to commencing official data collection, the researcher conducted a pre-test using three participants for the purpose of validating the data collection process and providing insight into necessary method changes.

3.1 The Research Questions

This study set out to address the research questions which were developed from and supported by literature presented in Chapter 2. Specifically, this study aimed to address the
overarching question: What do kept health information items say about the participant’s situation relative to their life with diabetes? Subsequently, the study sought to illuminate:

- The specific items kept within an individual’s context of living with diabetes.
- The use made of these items with regard to the individual’s life with diabetes.
- The cohesiveness of the information needs stated and the items’ usage.

Specifically, the questions addressed by this study are:

RQ1. What personal health items do individuals keep with regard to living with diabetes?
   1.A. What types of items (e.g., book, internet site) are kept?
   1.B. Are certain types of items kept more frequently than others?

RQ2. What role does personal context play in the presence of kept personal health items?
   2.A. Are factors of personal context associated with kept personal health items?

RQ3. What use was made of the kept personal health items?
   3.A. How was each item used?
   3.B. Is an item related with multiple uses?

RQ4. What information needs are associated with kept personal health items’?
   4.A. What specified need is associated with kept personal health items?
   4.B. Are multiple needs associated with an item?

RQ5. What is the relevance of kept health information items to living with diabetes?
   5.A. What relationship (situational relevance) is attributed to the kept item with regard to a specific component of living with diabetes?
   5.B. How does the framework of the national standards for education curriculum categories map to the information needs and item uses?
   5.C. What is the congruency of information needs, item use, and relevance decisions that are attributed to kept health information items?
   5.D. What do kept health information item attributed with incongruent information needs or uses say about the needs of individuals?

3.2 Pre-Test

A pre-test was conducted March - April 2011 using three participants in order to determine the suitability and understandability of all study material, including the marketing flyer (Appendix A), Letter of Introduction (Appendix B), the completeness of interview
questions, and the usefulness of the print versus digital data collection sheets. Specifically, the following considerations were used to review the study’s feasibility:

- if the material presented in the Letter of Introduction and consent form were understandable and complete
- if the pre-determined questions were understandable
- if additional questions needed to be asked
- if additional answer options needed to be offered
- if data were collected easier using paper questionnaires or electronic survey tools.

The individuals who participated in the pre-test were recruited using the same means as that planned to be used for the study. Diabetes educators with the local diabetes center announced the study during a support group meeting using the script provided by the researcher. They provided a sign-up sheet and handed out flyers that described the research study and gave the researcher’s contact information. Five individuals from the class provided their contact information on the sign-up sheet during the support group meeting.

### 3.2.1 Pre-test Methods

The researcher called the first three individuals who signed the sign-up sheet to inform them that a letter describing the study and a consent form would be placed in the mail. The researcher called back in a few days to answer any questions they had and scheduled an interview if they were still willing to participate. During the follow-up call process the researcher was unable to connect with a participant who did not want messages left. The researcher contacted the next individual on the sign-up sheet and they chose to participate in the pre-test. The names of the two individuals who signed up during this first recruitment, but were not used during the pre-test, were retained to ask to participate in the full study.

The pre-test participants were interviewed in their homes, using a semi-structured interview format that was intended for the study. This format did not change as a result of the pre-test, and is described in detail in the section below pertaining to the study’s methods.

The demographics of the three participants showed some variability (male = 2; Caucasian = 2, African American = 1; Leon county resident = 2, Wakulla county resident = 1; married = 2, widowed = 1; graduated high school = 1, graduated college (4 year degree) = 1, completed
graduate degree = 1) (Table 2). However, the three were similar in that they all were referred to the diabetes center by their primary physician, owned their homes, and were 73 years of age.

Table 2. Pre-test participant demographics.

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Age</th>
<th>Race</th>
<th>Occupation</th>
<th>Education</th>
<th>Marital Status</th>
<th>Diabetes Family History</th>
</tr>
</thead>
<tbody>
<tr>
<td>Flo</td>
<td>73</td>
<td>Black/African American</td>
<td>Retired</td>
<td>Completed high School</td>
<td>Widowed mother</td>
<td>Yes</td>
</tr>
<tr>
<td>Mark</td>
<td>73</td>
<td>White/Caucasian</td>
<td>Retired</td>
<td>Completed graduate degree</td>
<td>Married father</td>
<td>No</td>
</tr>
<tr>
<td>James</td>
<td>73</td>
<td>White/Caucasian</td>
<td>Self-employed</td>
<td>Completed college degree</td>
<td>Married</td>
<td>Yes</td>
</tr>
</tbody>
</table>

With regard to their diabetes, as shown in the table depicting diabetic specific context (Table 3), two had been diagnosed with Type 2 diabetes 4 months prior to the interview. The other had lived with the Type 2 diabetes diagnosis for 4 years. The pre-test participants rated their health status fairly high, with two of the three indicating excellent health. Although, all pre-test individuals managed their diabetes with diet and exercise, one participant also took medication.

Table 3. Pre-test participant context of life with diabetes.

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Length of time living with diabetes</th>
<th>Overall Health (1 = poor, 7 = Excellent)</th>
<th>Means of Control</th>
<th>Insurance?</th>
<th>Referral Source</th>
</tr>
</thead>
<tbody>
<tr>
<td>Flo</td>
<td>3 months</td>
<td>7</td>
<td>Diet &amp; exercise</td>
<td>yes</td>
<td>physician</td>
</tr>
<tr>
<td>Mark</td>
<td>4 months</td>
<td>7</td>
<td>Diet &amp; exercise</td>
<td>yes</td>
<td>physician</td>
</tr>
<tr>
<td>James</td>
<td>4 years</td>
<td>5</td>
<td>Diet, exercise, metformin (medication)</td>
<td>yes</td>
<td>physician</td>
</tr>
</tbody>
</table>
3.2.2 Changes Made Following the Pre-test

Data were collected during the pre-test using the procedures posed for the study. The data were not analyzed, but simply reviewed to see if the procedures provided a means to collect data that could be analyzed. Based on the interviews of the three pre-test participants changes were made to the study’s design. The specific changes included:

- The diabetes educators were asked to announce the study using a script provided by the researcher.
- The researcher, when available, was present at the support meetings during the announcement or announced the study herself. This step was added per the request of the diabetes educators. They wanted the researcher available to answer any immediate questions that potential participants may have.
- Data sheets were implemented using Microsoft Excel spread sheets, in which the researcher made notes and record data throughout the interview. The researcher had tried to record data into a questionnaire that mirrored the data sheets using LimeSurvey, a survey design application, that was running locally on the researcher’s computer using a WAMP server, but the process was too cumbersome and forced data to be entered in a specific format, whereas the flow of an the interviews could jump. The researcher determined that using LimeSurvey slowed data collection and note taking, in that the paginated survey forced the interview in directions that were not taken naturally by participants.

These changes were submitted as a modification to the institutional review boards for Florida State University and the hospital that was providing access to potential participants. The modification further stated that the researcher had received a dissertation research grant which was used to fund compensations for four participants. In order to receive reimbursement, the researcher had to have the participants initial a receipt that had their subject ID on it. The FSU graduate office was provided a list of subject IDs and copies of the receipts, but was not given any means to determine the identification of the participants by using the list of subject IDs. Approval for the modification (Appendix D) was received before further data were collected.
3.3 Study Data Collection Methods

In order to meet this study’s overarching research purpose - to explore what the kept and used health information items of adults living with Type 2 diabetes indicate with regard to information needs and usage associated with the kept items - and the specific research questions that were posed, this study employed methods that are congruent with the research questions and the exploratory focus. Foremost, this study was conducted within the naturalistic framework, in that the researcher conducted data collection in participants’ homes. A naturalistic study was undertaken as it was the most suitable for addressing the questions of this study. Specifically, naturalistic designs are structured in order to study actors in their natural settings (Naumer & Fisher, 2007). The use of the natural setting, in this specific instance, allowed participants to participate in a setting in which they were surrounded by the items of interest, providing opportunity for visibility of items to trigger memories. This naturalistic design was coupled with semi-structured interviews. Semi-structured interviews allowed the researcher to systematically guide each interview similarly across subjects, while allowing individuals to flexibility in the items that were discussed and the amount of information that was shared. The use of semi-structured interviews provided dialog that led to rich descriptions of personal context, items, information needs associated with the items, and explanations of item usage. The first part of the interview was guided by questionnaire that the participant completed in the presence of the researcher. The questionnaire included items pertaining to health history, demographics, and information technology in the home. These questions were asked using a paper-based questionnaire to promote a sense of privacy. The questions pertaining to the kept items, the item usage, and information needs were guided by a data sheet, but the researched conducted this part of the interview orally. The researcher often had the participants expand upon responses given to the questions, thus rich qualitative data pertaining to the context of living with Type 2 diabetes.

3.3.1 Recruitment

This study utilized purposive sampling. Purposive sampling is “a non-probability sampling method in which elements are selected for a purpose” (Schutt, 2006, p. 155), and thus curtails any ability to generalize to the general population. The sampling was purposive in that recruitment specifically targeted adults living with Type 2 diabetes who keep personal health items. During recruitment it was specifically stated that consideration for participation required
keeping of health information items in the home to help manage life with diabetes. In order to maximize the benefit of recruitment resources, recruitment was done in a diabetes center. This process ensured verification of a diabetes diagnosis, be it any type. After the study began, the researcher also recognized that the recruitment from diabetes education classes also ensured that participants had been given diabetes related material, thus ensuring the presence of diabetes related information in the home. After analysis was competed, the researcher realized that participants may have adjusted information items they personally acquired as a result of receiving information items, but some participants specifically acquired items, such as the book *The Calorie King*, as a result of the classes.

Participants (pre-test: n = 3; study: n = 21) were recruited from a diabetes center associated with a regional, non-profit teaching hospital. The center was chosen as the source to target the sample, because the number of individuals served by the center was thought to be substantial enough to provide an adequate sample size. Specifically, in 2010, the center provided diabetes education for 1798 adults with Types 1 and 2 diabetes. According to the center’s director in a private message (February 22, 2011) the majority of individuals who visit the center come through physician referral, but they are also referred by the associated hospital. Hospital patients who have elevated A1C levels or are newly diagnosed with diabetes are sent a letter asking them to contact the center if they would like to receive follow up education. Further assistance is offered once the patient calls. In instances where self-referrals contact the center, the individuals are encouraged to contact their primary care physician for referral before beginning services, for purposes of insurance, billing, assessment, health history, and communication.

This study specifically recruited individuals who were English-speaking, age 18 or older, and diagnosed with Type 2 diabetes. The researcher did not verify the diagnosis, but the recruitment process ensured that the participant did indeed have a diagnosis of diabetes of some sort. Additionally, the study limited participation to only one member per household. This limit on household participation was placed in order to prevent any cross over in data. The limit was placed on language, because the researcher does not have non-English speaking skills and did not plan to bring an interpreter or record the conversations for subsequent translation.

Recruitment was conducted over the course of four months, during which participants were recruited from 16 separate diabetes course sessions (Table 4). These sessions were nearly
evenly dispersed across morning (n = 5), afternoon (n = 6), and evening (n = 5) times. The evening sessions were attended by more people (n = 54; morning n = 36; afternoon n = 40), yet more people from the afternoon sessions chose to participate in the study (n = 10, 48% of study sample; morning participation n = 4, 19% of study sample; evening participation n = 7, 33% of study sample) (Table 5).

<table>
<thead>
<tr>
<th>Date</th>
<th>Class period</th>
<th># in class</th>
<th># Recruited</th>
<th># Participated Pre-test</th>
<th># Participated Study</th>
<th># Opted Out</th>
</tr>
</thead>
<tbody>
<tr>
<td>19-May-11</td>
<td>morning</td>
<td>8</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>16-Jun-11</td>
<td>morning</td>
<td>10</td>
<td>6</td>
<td>1</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>7-Jul-11</td>
<td>morning</td>
<td>9</td>
<td>1</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>18-Aug-11</td>
<td>morning</td>
<td>4</td>
<td>4</td>
<td>1</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>13-Sep-11</td>
<td>morning</td>
<td>5</td>
<td>3</td>
<td>1</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>13-Apr-11</td>
<td>afternoon</td>
<td>8</td>
<td>5</td>
<td>3</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>11-May-11</td>
<td>afternoon</td>
<td>9</td>
<td>1</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8-Jun-11</td>
<td>afternoon</td>
<td>8</td>
<td>5</td>
<td>4</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>13-Jul</td>
<td>afternoon</td>
<td>8</td>
<td>3</td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>15-Aug-11</td>
<td>afternoon</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>14-Sep-11</td>
<td>afternoon</td>
<td>5</td>
<td>1</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>17-May-11</td>
<td>evening</td>
<td>12</td>
<td>2</td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>21-Jun-11</td>
<td>evening</td>
<td>10</td>
<td>2</td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>19-Jul-11</td>
<td>evening</td>
<td>8</td>
<td>2</td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>23-Aug-11</td>
<td>evening</td>
<td>7</td>
<td>0</td>
<td>0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>13-Sep-11</td>
<td>evening</td>
<td>17</td>
<td>1</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Totals</strong></td>
<td><strong>130</strong></td>
<td><strong>36</strong></td>
<td><strong>3</strong></td>
<td><strong>21</strong></td>
<td><strong>12</strong></td>
<td></td>
</tr>
</tbody>
</table>

Initially, recruitment was solicited by diabetes educators at the outset of diabetes education classes. The educators announced the study in education classes using the IRB approved script (below).

A local doctoral student at Florida State University is conducting a study of the information items that you keep in your home you help you manage your diabetes. She asked that we pass out a flyer that has more information about the
study. If you are interested in participating in her study you may sign-up on the sign-up sheet or contact her. Her information is on the flyer.

Table 5. Participation Percentages from Class Sessions.

<table>
<thead>
<tr>
<th>SESSION</th>
<th># in class</th>
<th>% of class total (n = 130)</th>
<th># Recruited</th>
<th>% of class (n = 36)</th>
<th># in Study</th>
<th>% of session total</th>
<th>% of TOTAL in study (n = 21)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Morning</td>
<td>36</td>
<td>28%</td>
<td>14</td>
<td>39%</td>
<td>4</td>
<td>11%</td>
<td>19%</td>
</tr>
<tr>
<td>afternoon</td>
<td>40</td>
<td>31%</td>
<td>15</td>
<td>38%</td>
<td>10</td>
<td>25%</td>
<td>48%</td>
</tr>
<tr>
<td>evening</td>
<td>54</td>
<td>42%</td>
<td>7</td>
<td>13%</td>
<td>7</td>
<td>13%</td>
<td>33%</td>
</tr>
</tbody>
</table>

The educators also handed out flyers (Appendix A) with the researcher’s contact information and provided a sign-up sheet during the class as a means to get contact information of potential participants. The educators forwarded the sign-up sheet to the researcher following the education class. Following the pre-test, the researcher personally presented the research opportunity to the diabetes class participants.

The researcher contacted by mail those individuals who signed up as potential participants. The individuals were sent a packet that included:

- a letter of invitation and introduction, referred to as the Letter of Introduction (Appendix B)
- a copy of the consent form

The Letter of Introduction included a brief biographical sketch of the researcher and a description of the study. This letter, in addition to the consent form, was written in the simplest language possible and was checked for readability using the Microsoft Word Flesch-Kincaid Readability factor and outside review. The consent form scored of Flesch-Kincaid Readability factor of 11.3, whereas the letter scored 8.3. The goal was to make both documents readable at the eighth-grade level, but the institutions require that consent forms contain certain text that could not be adjusted. The participants were asked to clarify their understanding of the study, though, to ensure that the material contained in the documents was understood.

Within a week of sending the Letter of Introduction the researcher called each potential participant to discuss the study in more detail, to ensure that the individual was willing to participate in an interview in the participant’s home, and to let the participant know that the
compensation was $30/interview. Appointments were made once an individual confirmed they were interested in participating.

3.3.1.1 The recruitment site: Description of the diabetes education classes. The diabetes center offers different education classes, for individuals with different diabetes education needs, e.g., Type 1, Type 2, and gestational diabetes. The center’s diabetes education program, from which the study participants were recruited, has received national recognition by the American Diabetes Association (ADA) since 1994, per the organization’s website (for confidentiality purposes, the citation is disclosed upon request only). The diabetes center contends that this recognition is an acknowledgement that “the education program meets the national standards for diabetes self-management education (DSME) programs.” The program, however, is not listed by the American Association of Diabetes Educators (AADE) as an accredited diabetes education program. According to AADE (n.d.), accredited diabetes education programs offer curriculum that is specifically tailored for the practice setting. The material included in the curriculum is to pertain to topics defined by the AADE7™ Self-Care Behaviors: healthy eating, being active, monitoring, taking medication, problem solving, reducing risks and healthy coping. The goal of the curriculum and material is to promote behavior change strategies; therefore accredited diabetes education programs also take steps to evaluate patient outcomes.

Diabetes education offered by the center includes both personal training and class sessions. Prior to the diabetes education class sessions, patients meet with diabetes educators for personal counseling. These personal sessions often occur within a week of a patient’s referral to the diabetes center. During these sessions, they are given glucose logs, given instructions in using their glucose meter, and instructed as to how to enter their glucose readings into the paper logs. Many glucose meters have memory chips to record readings, but participants are encouraged to also keep a paper log. The diabetes educators can download the data from the glucose meters if needed.

The Type 2 diabetes education classes offered by the diabetes center used for recruitment occur during a three session series that are offered monthly. The classes are held in the diabetes center and are set-up with a traditional class-room style, wherein patients sit at conference tables facing the educator and screen for presentations. Class sessions are offered in the morning, afternoon and evening, and each session lasts three hours. Each class session includes time for
the educators to review and make copies of the glucose logs, and to answer questions. Topics covered during the sessions include blood sugar testing, managing high- and low-blood sugar, making healthy food choices, and insulin and nutrition therapy. During the first session, diabetes educators present the basics of diabetes, including diagnosis criteria, risk factors for Type 2 diabetes, and symptoms of hyperglycemia, i.e. high blood sugar. The session also covers food groups and digestion, diabetes complications, medications and insulin, important numbers relevant to diabetes control (e.g., A1C and daily blood glucose), testing, target values, and monitoring activities (e.g., foot exam and vaccines). Handouts, such as Good Foot Care, Medications, and Fat Facts (Appendix F) are provided during this session. The second session, during which recruitment was often conducted, focused on the topics of nutrition. The diabetes educators discussed portion sizes, foods to avoid, nutrition content (e.g., carbohydrates and fats), and ranges to target. The session also covers carbohydrate counting and learning to read a nutrition label. For insight into the nutrition label discussion, view the information provided by the American Diabetes Association (n.d.) at the webpage, Taking a Closer Look at Labels. This content provides a description of the various label elements and includes a video that further discusses this information. This second session is when the book, The Calorie King, was introduced. This class session includes an activity where the participants created a meal plate, and also encourages participants to develop a self-management support plan that includes determining a source of support. A template plan is provided in order to encourage participants to identify and connect with resources that will help them change eating and activity behaviors as needed. The participants begin keeping a food record after this class. The final session is used to schedule a follow-up visit with the diabetes educators and to review food labels and the participants’ food records. The educators also present information about how to deal with low blood sugar and when sickness arises. While the second session dealt with creating meals at home, the final session discusses eating out. The slides show the differences between historical restaurant menu item, and those offered today. The portions are larger and filled with more calories today. The participants are encouraged to check restaurant websites for nutrition information, especially prior to visiting the restaurant. The book, The Calorie King, is also a useful reference. During this session, the diabetes educators lead the participants through a five-minute exercise session to demonstrate the effect activity has on blood sugar. Finally, the
participants develop an Action Plan. They are encouraged to determine what they will do, for how long, at what time, and on what days.

For further insights into the specific information items that were provided during the class sessions, refer to Appendix F. All items that were included in the diabetes education packets are described. The items included handouts of the slides that were presented during class and several handouts. Specifically, the packet included handouts that pertained to: A1C relationship to glucose readings; diabetes medications; foot care; stress; routine problems; and fat facts. Additionally, the educators provided a Community and Resource List that offered names and addresses for various national organizations, e.g., Needy Meds, dLife, Healthy Dining Finder, America on the Move, Spark People, and American Dietetic Association. While the majority of the items in the packet were informational, three items included in the packet were interactive. These interactive items include: a Glucose Log that the participants were encouraged to use to record their glucose readings; a Daily Meal Planning Guide; and a Diabetes Self-Management Support Plan and Action Plan.

3.3.2 The Study Participants

This research studied adults who are living with Type 2 diabetes and who use health information items that they keep in their homes to help manage life with diabetes. The sample for this study was drawn from a local diabetes education center associated with a not-for-profit community health care system. According to the center’s director in a private message (February 22, 2011), the individuals who receive services from the center reside primarily in three counties: County A is predominantly metropolitan and is home to the diabetes center; counties B and C are both rural areas that surround county A. All but one participant came from metropolitan County A (n = 20). The participant who did not reside in the metropolitan area came from an area outside the rural counties that usually send clients to the diabetes center. Specifically, this participant came from Liberty County, which is another rural county that borders the metropolitan area. Further description of these counties is presented herein.

County A is located in the panhandle of Florida and is home to a medium sized metropolitan area. According to 2010 census data (U.S. Census Bureau, 2010), County A has a population greater than 275k and is primarily female (52.4%). Liberty County has a population greater than 8k and is primarily male (60.9%). The number of adults, over the age of 18 years,
diagnosed with diabetes in County A (CDC, 2009) is 9.8% CI [8.3, 11.3], while Liberty County has an adult diagnosis rate of 11.5% CI [10.0, 13.2].

The demographic characteristics of the participants are presented in the Results chapter.

3.3.3 Data Collection: The Interviews

Data were collected using semi-structured interviews conducted in the participant’s homes. The semi-structured approach to the interviews provided more focus than a conversational approach, but still allowed flexibility in adjusting an interview to elicit the information from participants. Part of the interview was conducted using a paper-based questionnaire that contained items pertaining to demographic information, presence of technology in the home, basic diabetes diagnosis and management information, and personal assessments of current health and life conditions. Questionnaires can be used to obtain information about “individuals through their responses of questions about themselves” (Schutt, 2006, p. 234) and serves to produce quantitative or numerical descriptions about a group (Fowler, 2009). The use of the questionnaire in this study to inquire about demographics and diabetes history and treatment offered participants opportunity to take their time in considering each question, as well as providing privacy if they did not want to answer a question, such as income or diabetes treatment. The questions asked during the verbal portion of the semi-structured interviews centered on the kept information items, both electronic and textual, that were used and associated with the participant’s Type 2 diabetes. Before the participants filled out the questionnaire or were interviewed, the researcher obtained written consent (Appendix C).

Note that during the interviews, several participants (n = 6, 28.6%) had spouses present. The participation of the majority of spouses was minimal and many only added various small details. In this regard, in most cases, the presence and contribution of spouses did not appear to be an undue influence on the participants and their responses. However, the researcher specifically noted the impact on two participants. In the case of Adam, the researcher made the following note indicating that his spouse played a significant role in the interview and in helping manage his life with diabetes:

Adam was not very talkative, but that may have partly been due to his wife's presence. His wife was quite participatory. Adam's wife commented that class has seemed to get him more involved. Before the classes, his wife had to learn
how to use the glucose meter [“machine”], by going to the pharmacy for help, and tried to teach him. She also tracks his food intake in separate log to see what might be elevating the sugars.

Alan’s spouse also participated strongly in the interview, but merely at the outset. The researcher specifically noted that Alan deferred to his wife “for answers of health quality activities, etc.”

During the interviews descriptions of the items were documented and the items were categorized, when possible, according to lists found in the literature. The information needs, uses, and assessments of situational relevance were also assessed. If categorization was quickly apparent during data collection, the researcher also took copious notes so the item types, uses, and information needs could be categorized upon completion of the interview.

The interviews were conducted at the participant’s homes and included:

- Purpose of the interview.
- Terms of confidentiality.
- Estimated minimum time for interview (1-2 hours).
- Interviewer’s contact information.
- Time for participant to ask questions.

The questions asked during the interview used the kept items as the focus of questioning. The interviews included open ended, neutral questions posed to examine the participant’s use of a kept health item and their perceptions of the precipitating information need. The participants determined which items they would discuss by self-selecting the health information items they had in their home and used to help manage their life with diabetes. The questions asked during the interviews fall under four categories: 1) questions about the participants’ demographics, personal context, and diabetes related context - via questionnaire; 2) background questions to determine if digital items are kept - via questionnaire; 3) questions describing the item and its acquisition; and 4) questions about information behavior relative to the item. During the interviews, participants provided rich descriptions that added to the depth of the context obtained from the questionnaire.

Data sheets (Appendix E) were used to record information pertaining to the information items’ use, associated information need, and situational relevance. These data sheets provided a
systematic, semi-structured blueprint that was used to guide each interview. The data sheets included: an informational sheet of each participant; an item description sheet; an acquisition data sheet that serves to identify the timing or instance when an item was acquired, as well as to identify the source of the item; a sheet that ascertains information use and need; a sheet that identifies the reasoning for keeping the item; and a sheet that ascertains the participants perspective of “situational relevance” as well as the relevance with regard to national standards for diabetes education. Specific data that were gathered during the interviews include the following:

Personal background information (discussed further below under Context):
- demographic data
- personal life descriptions
- diabetes related life descriptions

Technology background information:
- indication if health information is kept on a home computer
- indication if they have access to the Internet
- indication if health information is bookmarked on a home computer

Kept health item information:
- To assess information about the item
  1. An initial checklist of descriptions provided on the data sheet was used to categorize the type of item.
  2. Furthermore, the researcher took copious notes to describe the document; the information noted varied depending on the item in questions. Items, such as books or articles, were documented using typical citation metadata, i.e., first author, title, journal title, year, volume number, and pages. Electronic items, such as spreadsheets were described by its purpose and last modification date, whereas website bookmarks were simply documented by the specific verbiage used for the bookmark, whether it is the URL or simple a given title. Items such as lab results, pamphlets, calendars, etc. were described relative and given a unique title, e.g., blood result 1, blood result 2, etc.
Information behavior associated with kept item:

- To assess acquisition of the item and the participants’ reasons for keeping the item, the participants were asked:
  1. Did you get this information in the: past week, past month, past year, more than a year ago, don’t recall?
  2. What do you remember about the time you found the item or it was given to you?
  3. Did you get the information by yourself or did someone give it to you?
  4. If the information was given to you, by whom? Please select an option from the list that best describes where the health information came from.

- To assess the information need associated with this item, the following questions were posed to the participants:
  1. Tell me about what information you needed that prompted you to search for or to use this item.

- To assess the uses, participants were asked to answer the following questions:
  1. Did you use the item: yes / no
  2. Is there a time that you used the item in a different way? Please tell me about it.
  3. Please indicate how useful item was using a scale of 1-10, whereby 1 is of no use at all to 7 meaning maximum usefulness

- To assess the relevance of this item to the individual’s use, participants were asked:
  1. How would you say this item relates to your life with diabetes?

During the interviews there were times when participants indicated that they had more items in the home that might have been used at some point or may be used in the future. The interviewer asked to see the item if it was readily available, in order to document details about the item. However, if the participant described it as not currently used and it was not readily available, the researcher merely made a note of its presence in the home. For example, John thought he had earlier editions of books pertaining to nutrition and medications, but he was not sure where the books were currently stored. These items were replaced by current items that were discussed and included in data collection. The new items were discussed with regard to
John’s information needs and item usage. The previous editions were simply noted as items in the home, but not used. Sometimes participants showed items that had the potential to inform diabetes management, but the researcher chose to simply generally note their presence, and otherwise exclude the item from data collection. For example, Renee had a plateful of clipped recipes that could possibly inform nutrition management. She had not used any of these recipes, though, and she also had not sorted them to determine if she would use them. Therefore, the researcher excluded the items from the study as it could not be clearly determined that the items informed her diabetes management. Therefore, although there were possibly an estimated additional 100 items that could possibly be counted as “kept,” these items were determined to be outside the bounds of “kept health information items” that are used to help manage life with diabetes.

3.4 Ethical Considerations

Ethical considerations that are necessary to consider (Schutt, 2006, p. 318) include: voluntary participation; description of the study, including discussion of benefits; subject well-being; identity disclosure, i.e., privacy and confidentiality. Additionally, consideration of how informed consent is obtained, the researcher’s role, and compensation (Kvale & Brinkman, 2009) must be considered. The steps taken to address each of these criteria are discussed herein.

3.4.1 Voluntary Participation

Participation in the study was voluntary and participants were informed that they could withdraw at any time without jeopardizing the relationship with the investigator, the investigator’s university, or the diabetes center where they received diabetes education. The participants were instructed in the consent form what would happen to any data collected prior to their withdrawal. Specifically, they were told:

- We will no longer use information about you.
- We may continue using the information obtained prior to your withdrawal if it is necessary for the soundness of the overall research.

Participants were recruited and encouraged to participate by providing $30 in compensation for their time. This amount of compensation was determined based on estimating potential interview duration and time’s value for possible participants. For a working
professional who made themselves available for a 2 hour interview, the compensation was well below hourly wage and was thus, not considered a possible form of coercion. For participants who were unemployed, the compensation may have helped motivate them, although no statements were made during data collection that would have indicated this. Some participants actually were surprised to receive the compensation at the end of the interview, although it had been disclosed on the recruitment flyer and in the Letter of Introduction, others tried to refuse it, and others simply accepted it quietly. An indication that the compensation served as the motivation could have included specific comments or inquiries about the compensation during recruitment or at the beginning of the interview. Neither of these occurred.

Of the number of individuals who signed up as potential participants (n = 36), one-third (n = 12, 33%) did not participate in the pre-test or study (Table 5 provided above). The individuals who opted out of the study did so by either specifically stating that they were not interested during the recruitment process, or by not accepting communication from the researcher after the study’s Letter of Introduction (Appendix B) was sent. One participant specifically stated during the follow-up process that they had signed the volunteer form thinking it was a class sign-in form (Appendix A), although the sign-up form clearly stated it was for the study, so it is possible that this happened for others.

3.4.2 Communication of Study’s Purpose and Benefits of Participation

The researcher sent a letter to potential participants prior to formal selection, in which an overview of the study and a copy of the consent form were provided. The researcher called the potential participants within a week of sending the letter to answer questions and provide further details about the study. If the individual agreed to participate in the study, an interview was scheduled. To further ensure the participant understood the purpose of the study, before the interview began, the researcher again described the study and answered questions. The consent form specifically stated the purpose of the study and the benefits of participation. The participant attested to their understanding of the study by signing the consent form (Appendix B).

3.4.2.1 Study’s Purpose. The consent form included a specific statement of the study’s purpose. Note that the statement, included herein, was purposely simplified in order to be readable.
The purpose of this study is to learn about the items that are kept in the home and that are used to help manage life with diabetes. This study is specifically focused on the use of these items and the associated information needs. This study focuses on the type of item and is not concerned with the specific information that is in the item, such as sugar levels.

Additionally, the participants were told what would occur during the interview. Specifically, they were instructed that

During the meeting, I may take occasional notes using an audio recorder. I will only use the recorder if you give permission. The only purpose of the recording is to help me with written notes taken during our meeting. The recording will not include any information that can be used to identify you.

All participants agreed to the potential use of audio recordings, but none were made. The researcher took time to type extended notes as needed.

3.4.2.2 Benefits. This study offers three primary benefits: 1) the opportunity to discuss experiences of living with diabetes and personal health items that are kept and used to manage information needs related living with diabetes; 2) the indirect benefit of sharing the results of this study with the community of diabetes educators in order that they may gain insights about what information is available in homes and what types of information they could provide; and 3) the indirect benefit of sharing the results of this study with developers of technology, such as personal health records in order that they may provide tools and services that users want as reflected by the habits and needs of potential users must first be understood.

3.4.3 Subject Well-being: also known as Unanticipated Harm

This study posed no specific health risk to its participants, but there were minor possibilities that were documented in the consent form. Primarily, there was a possibility that a participant could become emotional about their health or their situation during discussions. Attention to one's health can cause psychological stress and the diagnosis of diabetes, as well as the retelling of this time period, can cause strong emotions. This consequence could not be eliminated, but the researcher was watchful for signs of emotional distress and listened to concerns.
During the study, no further steps, such as directing participants to appropriate health care providers, were necessary. No participants reported or displayed any indications that the interviews caused undue stress, although some participants displayed tears when talking about family members who had been affected by diabetes. During these times, the researcher continued to listen and moved the interview back to the topic of the kept health information items. The participants quickly regained their composure and the researcher did not perceive that the interview left emotion distress.

3.4.3.1 Risk Mitigation. The greatest concern stemming from the study’s design was that participants could reveal personal health information, e.g., glucose readings or cholesterol levels, which were not pertinent to the study. To reduce participants concern for divulging personal information, the researcher reminded the participants that they did not need to disclose any specific about their health and that they could decline to answer a question during any part of the interview. When the participants displayed any resistance to a question, the researcher moved on and reassured the participants that they could decline comment at any time.

3.4.4 Privacy and Confidentiality

Researchers are obligated to ensure protection of research participants and their interests by keeping their identities private and confidential. While privacy pertains to the need to protect participants from intrusion, and is often associated with anonymity, confidentiality pertains to keeping secret all responses provided by the participant, unless explicit consent was provided permitting disclosure (Babbie, 2007). All information recorded during the volunteer process and home interviews were maintained as private and confidential. Additionally, the data were encrypted. The steps that were taken with regard to privacy and confidentiality were described in the informed consent form signed by each participant. These steps are discussed herein.

3.4.4.1 Privacy. Privacy refers to the expectation for an individual to control the access of others to themselves. Privacy issues were addressed during the recruiting and data collection processes. During the recruiting process, the researcher obtained mailing addresses for the potential participants using a sign-up sheet (Appendix A) provided during recruitment. The sign-up sheet included a box for potential participants to indicate if the researcher could leave a phone message. The researcher did not leave details about the study in a phone message unless the individual had indicated approval. In these instances, the researcher simply requested a return
call. During the recruiting phone conversations, the researcher offered further details of the research process, talked conversationally with the participants if they wanted to begin to discuss personal stories, and verified the interview time and location. Notes taken during these calls were kept private and confidential. During data collection, the interviews were conducted in the individuals’ homes and the researcher went alone. The participants had control over who was present during the session. Given that the researcher attended the interviews alone, for security purposes, prior to entering the participants’ homes, the researcher texted their location to a trusted individual. These texts did not contain names and were subsequently deleted.

### 3.4.4.2 Confidentiality

Anything that the researcher saw or recorded was kept confidential. The researcher disclosed that any evidence of abuse, neglect, or exploitation of any vulnerable person, such as a child or elderly would be reported. The researcher did not encounter any such situations. Several confidentiality measures were put in place in order to ensure identifiable private information were kept private. The collected data, including contact information and interview sheets are stored safely in the researcher’s password-protected personal computer and in locked drawers. No one has access to the notes or consent forms, except the researcher and the Human Subject’s Committees of the researcher’s university and the health care organization serving as the source for participants. All collected data associated with a participant were de-identified with the use of a subject ID code. The subject ID was created using the date of the interview and the individual’s initials, e.g., Jane doe interviewed on November 1, 2010 was coded as 110110JD.

In order to further protect participants’ confidentiality, their identities are not disclosed in the results, although the results do include rich descriptions. These descriptions are associated with pseudonyms that the researcher chose at random. Details that could potentially lead to participant identification have been omitted.

### 3.4.4.3 Protected Health Information and HIPAA

Data were collected using participants who were recruited from a hospital diabetes education center. As such, the participants were associated with a covered entity and therefore, adherence to Health Insurance Portability and Accountability Act (HIPAA) policies covering protected health information (PHI) was required. The elements that were collected during the study using a volunteer sign-up form that were considered within the realm of the eighteen PHI elements are: name, address, phone number, email address, and dates. The researcher obtained separate approval from the

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hospital’s Institutional Review Board and adhered to the principles of maintaining privacy as stipulated by HIPAA (U.S. Department of Health and Human Services, 2003).

3.5 Data Analysis

The items kept by the study’s participants served as the “focal point” about which data pertaining to types of information, information needs, item usage, and relevance attributions were made. For some research questions, the item served as the unit of analysis. Analysis conducted at this level provided insight into questions about the frequency of items kept according to categories. Other research questions addressed assessments of information needs, item usage, and relevance. Participants could make multiple assessments per item, and thus the item was not suitable as the unit of analysis. Therefore, the assessments of information needs, item usage, and relevance serve as the as the units of analysis for other research questions addressed by this study.

Analysis consisted of coding the data, performing tabulations that address the specific research questions, determining themes across the data, and providing narrative evidence. Specifically, data pertaining to information item type, information needs, information use, usefulness and situational relevance were coded according to code sheets included in Appendix E. The codes listed in these initial coding categories were pulled from literature sources (Table 6). New categories were created during the coding process for instances where existing categories were not appropriate. During data coding, responses that required multiple codes were coded and analyzed accordingly to reflect these multiple responses. Therefore, the results reflect more information needs and uses than the number of kept items. Further details pertaining to the specific methods used to analyze data for each research questions are discussed herein.

Table 6. Sources for categories used to code data for information needs, and information use.

<table>
<thead>
<tr>
<th>Data Variable</th>
<th>Coding Source</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information type</td>
<td>Longo et al. (2010); Moen &amp; Brennan (2005)</td>
</tr>
<tr>
<td>Information needs</td>
<td>Song (2007); Google Top Health, WebMD</td>
</tr>
<tr>
<td>Item use</td>
<td>Song (2007)</td>
</tr>
<tr>
<td>Relevance/usefulness</td>
<td>Crystal &amp; Greenberg (2006)</td>
</tr>
<tr>
<td>Situational relevance</td>
<td>Funnell et al. (2009)</td>
</tr>
</tbody>
</table>
3.5.1 Operationalization of Observations of Interest

The concepts central to this study are the kept item, personal context, information need, item use, and situational relevance. Definitions of these concepts were presented in Chapter 1. The working definitions are presented herein.

3.5.1.1 Context. Overall, the general context under investigation is that of individuals with Type 2 diabetes who keep in their homes health information items - electronic or paper based- that are related to their personal experience with the disease. The specific context personal to each participant, however, is operationalized using demographics, insurance coverage of care, and length of time living with the diagnosis, and treatment methods. The specific demographic information chosen to be gathered for this study is based on the literature (Longo, 2010; Moen & Brennan, 2005). Specifically, the demographic, socio-economic, and diabetes-related information that were collected includes:

1. gender
2. birth year
3. education level
4. occupational status
5. marital status
6. income
7. home ownership or renter
8. race
9. number of children under the age of 18
10. indication of family history of diabetes
11. hobbies or activities
12. diagnosis date or duration of disease
13. controlled or non-controlled diabetes status
14. means of diabetes control
15. insurance availability for diabetes coverage
16. diabetes center referrer
17. overall evaluation of one’s health
18. description of life with diabetes
Furthermore, note that additional insight of a participant’s specific context emerged throughout the interview as they discussed their personal stories, family history, information needs, and the ways in which they used kept items. The needs that a participant experiences and the choices they make about using items says as much about their context as does the demographic information. The notes taken during the interview are used to supplement the categorical data that were recorded.

3.5.1.2 Kept health information item. Information items of interest in this study are those items that participants consider relevant to managing their life with Type 2 diabetes. An information item is an item “that can be acquired, created, viewed, stored, grouped (with other items), moved, given a name and other properties, copied, distributed, moved, deleted, and otherwise manipulated” (Jones & Teevan, 2007b, p. 7). Examples include journals, diaries, calendars, news clippings, cholesterol reports, weight, blood pressure readings, etc., to support their health information management behaviors (Moen & Brennan, 2005). This study used the term “health item” or “health information item” to refer to electronic or paper-based items that the individuals deem relevant to managing their life with diabetes. These kept items may include items, such as books, news clippings, journal articles, printouts from an Internet site, or notes of references that are maintained in the home. Electronic items that are maintained on the individual’s computer are also considered kept items; this is inclusive of spreadsheets, bookmarked URLs, etc. The bookmarked URLs are similar to the concept of a book title written on a paper scrap. Just as the paper scrap would serve as the kept item, so does a bookmarked URL. Given this physical connotation of “kept,” excluded items included: a website or file not stored on a computer in the home; a reference source not maintained in the home; items that are kept in memory, such as or a website address or title of reference material. Note that although National Research Council: Ticker (2011) identified the notion of Facebook group memberships as possible sources for information, these associations or links to them are not maintained directly on the computers in individual homes. This study used a working definition of kept items as “maintained in the home.” Therefore, the notion of Facebook group and page memberships, wherein no link is stored locally in the home, falls outside the bounds of this study.

3.5.1.3 Information need. An information need is generally accepted within the library and information studies (LIS) literature as the precursor to information seeking behavior
Harter (1992) poses that an information need is dynamic with regard to the “current cognitive state or context of a user (rather than the initial state)” and encompasses “not only a topical statement of the subject of the inquiry and why it is of interest to the individual, but also all other assumptions that comprise the current context” (p. 606).

Historically, information needs were investigated in terms of the information that was missing from an information retrieval system relative to the information desired by a user; studies of this discrepancy were focused on “objective” differences and were conducted within a system framework. Beginning in the late 1970s (Mizzaro, 1998) studies began to investigate information needs as subjective measures from the perspective of the user, i.e., what information is missing from the user’s knowledge base (Dervin & Nilan, 1986) or as “a hypothesized state brought about when an individual realizes that they are not comfortable with their current state of knowledge” (Case, 2007, p. 333). Studies of information needs conceptualized this state as “internal mental states” e.g., an "anomalous state of knowledge” (Belkin, 1978), or as situations that are addressed through “verbing” behaviors within a sensemaking framework (Dervin, 1992).

The concept of an “information need” has also begun to draw attention from the health care community, wherein an information need is perceived as a reaction to a stimulus, such as “major life changes, other events or life-threatening or incapacitating illness” (Timmins, 2006, p. 377). These information needs are considered to be subjective and unique “personal item[s] about which individuals require information” (p. 377). This study employs this health care view of an information need in that it is a personal situation regarding life with Type 2 diabetes that serves to benefit from information.

3.5.1.4 Situational relevance. Relevance is historically conceptualized in the LIS literature in terms of information retrieval. It is broadly conceptualized objectively as “an evaluation of the match between a question (or search statement) and the answer (or text) retrieved by that statement” (Case, 2007, p. 336). The evolution of relevance studies led to considering subjective relevance judgments as perceived by a user. An early subjective view of relevance, situational relevance, was offered by Wilson (1973). This posed dynamic relationship relates an individual’s “stock of knowledge or information” to “questions of concern to him” (p. 463); it as an individual’s assessment of an item regarding “relevance to [the concerns of] a particular [aspects of an] individual situation” from the individual’s perspective (p. 406). Wilson
further posed that situational relevance is inclusive of practical relevance, which examines a relationship between goals and plans of action. Situational relevance may offer little to resolve the questions of information retrieval (Saracevic, 1975). However, it is useful in considering context of information seeking or use (Chatman, 1996; Crystal & Greenberg, 2006).

3.5.2 Addressing the Research Questions

In order to address the research questions posed by this study, the data were analyzed according to the methods described in Table 7. In general, much of the data were analyzed using cross-tabulations. Generally speaking, the results of this study provide a general description of participants with regard to information keeping and kept items, rather than a statistical analysis of predictor variables associated with these items. As such, the data provide rich insights into specific stories, but do not provide the ability to generalize or extrapolate to discussions, such as an information need of XX will lead to the presence of the health information item YY to be used for the purpose of ZZ. The analysis procedures used to address the study’s research questions include frequency analysis and cross-tabulation. An example of the outcome of a frequency analysis is a list of categories generated for RQ3.

<table>
<thead>
<tr>
<th>Research Question</th>
<th>Form of Finding</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>RQ1. What personal health items do individuals keep with regard to living with diabetes?</strong></td>
<td></td>
</tr>
<tr>
<td>1.A. What types of items (e.g., book, internet site) are kept?</td>
<td>A list of items by category</td>
</tr>
<tr>
<td>1.B. Are certain types of items kept more frequently than others?</td>
<td>The frequency of items by category</td>
</tr>
<tr>
<td><strong>RQ2. What role does personal context play in the presence of kept personal health items?</strong></td>
<td></td>
</tr>
<tr>
<td>2.A. Are factors of personal context associated with kept personal health items?</td>
<td>Presentation of demographics, as well as a cross-tabulation of demographic data and kept item categories</td>
</tr>
</tbody>
</table>
### Table 7 – continued

<table>
<thead>
<tr>
<th>Research Question</th>
<th>Form of Finding</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>RQ3. What use was made of the kept personal health items?</strong></td>
<td></td>
</tr>
<tr>
<td>3.A. How was each item used?</td>
<td>A list of item uses according to categories</td>
</tr>
<tr>
<td>3.B. Is an item related with multiple uses?</td>
<td>The frequency of item uses associated with the items</td>
</tr>
<tr>
<td><strong>RQ4. What information needs are associated with kept personal health items?</strong></td>
<td></td>
</tr>
<tr>
<td>4.A. What specified need is associated with kept personal health items?</td>
<td>Tabular comparison portraying information needs matched the category of items</td>
</tr>
<tr>
<td>4.B. Are multiple needs associated with an item?</td>
<td>The frequency of information needs associated with the items</td>
</tr>
<tr>
<td><strong>RQ5. What is the relevance of kept health information items to living with diabetes?</strong></td>
<td></td>
</tr>
<tr>
<td>5.A. What relationship (situational relevance) is attributed to the kept item with regard to a specific component of living with diabetes?</td>
<td>Table of the situational relevance category from the national diabetes self-management education standards matched to the categories of kept items</td>
</tr>
<tr>
<td>5.B. How do the information needs map to current diabetes category schemes (taxonomies)?</td>
<td>Table of comparisons showing the information need categories to the national diabetes self-management standards</td>
</tr>
<tr>
<td>5.C. What is the congruency of information needs, item use, and relevance decisions that are attributed to kept health information items?</td>
<td>Cross-table showing the relevance decisions, information need categories, and item use categories that are reported for each item</td>
</tr>
</tbody>
</table>
Table 7 – continued

<table>
<thead>
<tr>
<th>Research Question</th>
<th>Form of Finding</th>
</tr>
</thead>
<tbody>
<tr>
<td>5.D. What do kept health information item attributed with incongruent information needs or uses say about the needs of individuals?</td>
<td>Discussion of specific items that were associated with information needs or uses that map outside the national diabetes education standards or that are attributed to information needs other than what item may portray.</td>
</tr>
</tbody>
</table>

3.6 Evaluating Study’s Quality: Credibility, Reliability, Validity, and Other Measures

In order to assess the level of contribution that can be made by this study, criteria that can be used to assess it need to be considered. Measures of validity and reliability are important constructs in research in that they provide a means to estimate credibility of the study. These measures are primarily associated with quantitative studies, however (Golafshani, 2003; Silverman, 2006). This study employed a naturalistic and qualitative design, specifically using a semi-structured interview format that was guided by a questionnaire comprised of a standard set of questions (Appendix E). Measures of reliability and validity can be applied toward qualitative studies, as will be discussed herein, but they are implemented differently in order to assist in determination of the study’s “quality” (Golafshani, 2003). Historically, though, qualitative studies are for truthfulness, or confidence in the study’s findings, using four criteria: credibility, transferability, dependability, and confirmability (Lincoln and Guba, 1985). Descriptions of these four criteria are included herein and are followed by a discussion of reliability and validity as applied to qualitative studies.

3.6.1 Credibility and Other Measures

Credibility requires that all important factors in the research question are accurately and completely described and clarified as to how the factors are reflected in the data gathered (Lincoln and Guba, 1985), but is also assessed based on “the extent to which any research claim has been shown to be based on evidence” (Silverman & Marvasti, 2008, p. 507). The potential for the study to demonstrate credibility was assessed at the surface level during the prospectus approval process. In attempt to further demonstrate credibility, participants’ quotes are offered as
evidence of conclusions drawn as a result of analysis. While brevity would direct the selection of few well-chosen exemplars, several examples are provided in attempt to demonstrate scientific rigor as opposed to “anecdotalism,” i.e., the use of entertaining stories or anecdotes that fail to demonstrate credibility. According to Trochim (2006) the final assessment of credibility of the results, however, can only be assessed by the participants. This study’s design did not include a process wherein the participants reviewed the final product.

Dependability addresses the notion of replicability and pertains to whether findings are consistent and repeatable (Lincoln and Guba, 1985). The study was pre-tested in order to develop methods and a questionnaire that guided the semi-structured interviews so that the same data were recorded for each item across every participant. These methods, questionnaire (Appendix E), and analysis procedures are specified herein, so that the study could be repeated by this or any researcher using other adults with Type 2 diabetes.

Confirmability refers to a level of researcher objectivity and neutrality (Lincoln and Guba, 1985) and indicates the “degree to which the results could be confirmed or corroborated by others” (Trochim, 2006, para. 7). This measure of quality may be evaluated by looking at the data to ensure it supports the conclusions, or other more substantial methods may be implemented, including establishing procedures for checking and rechecking the data throughout the study, or documenting a process of checking or using an outside party to double-check the results may be used to demonstrate confirmability. The researcher may also demonstrate confirmability by including in results cases that contradict observations, or by conducting an audit post- data collection and analysis in order to document potential biases (Trochim, 2006). This study implemented a limited evaluation for confirmability by documenting potential biases that may occur as a result of data collection and analysis methods, and is providing results that include many examples in order to discussion conclusions with the research oversight committee.

3.6.2 Reliability

The remaining criteria for assessing quality of research, validity and reliability, historically apply to quantitative studies, as these concepts are rooted in a positivist paradigm (Golafshani, 2003). However, these measures are increasingly adopted as a means to assess qualitative studies. Some authors contend that qualitative studies cannot be assessed for
reliability of a qualitative study (Golafshani, 2003), while some view it as similar to the quality criteria, replicability. However, others contend it is critical, and note that it is dependent on trustworthiness. In quantitative studies reliability is considered an indication of consistent results across different observations (Schutt, 2006). A measurement technique that is considered reliable is consistent in its reports of the same value for an observation that is not changing. For example, as an adult who stand 5’8” today as measured by ruler, the technique of eye-ballng may yield unreliable results, whereas a ruler will consistently (reliably) measure 5’ 8”. Note that it is possible for a measure to be reliable, but consistently wrong (inaccurate). For example, an adult could be repeatedly measured as 5’6” when they are 5’8”; the measurement technique yields a consistent measurement, but it is incorrect. Reliability may be demonstrated through several means, including: test-retest, intra-rater (or intra-observer), inter-observer, or alternate forms.

The concept of reliability when asking questions of individuals, as was done in the current study, is more difficult to determine (Babbie, 2007). The methods that can be used in quantitative studies to assess reliability in quantitative studies do not apply. Instead, methods to evaluate trustworthiness are necessary, and may include intercoder assessments or “low inference descriptors,” wherein observations are recorded as concretely as possible and include direct quotes (Silverman & Marvasti, 2008). This study made use of low inference descriptors in order to demonstrate reliability.

3.6.3 Validity

Validity, in terms of quantitative studies, is defined as an assessment of whether a “measure adequately” represents the theoretical concept which it attempts to measure” (Babbie, 2007, p. 146). Silverman and Marvasti (2008) refer to validity as “truth” when applying it to qualitative studies. In either type of study, it is a complex assessment that includes many different measures and is difficult to determine, because it frequently depends on method design. While quantitative studies have many assessments that may be used to determine various levels of validity, e.g., construct validity, face validity, and external validity. This study’s design depended upon semi-structured interviews that were guided by a standard set of questions for each participant and item. Given the importance of the questions in order to collect data that adequately measured the activities of interest, the notion of face validity and its assessment was critical to this study. Face validity is a form of external validity and is evaluated by obtaining
expert opinions from outside evaluators, e.g., investigator, judges, respondents, or research oversight members as occurred during this study’s prospectus stage, before a study is conducted or a questionnaire is used in a study. Ideally, experts review a study and conduct a pre-test to determine if the study or questionnaire appears to measure the constructs adequately relative to the question and theory. The methods of the current study were evaluated and a pre-test of the data collection process was conducted. External validity is further determined by measures included in the following three categories: content validity, criterion validity, and construct validity. The concept of content validity applies to this study, so is further discussed.

Content validity “refers to the degree to which a measure covers the range of meanings included within a concept” (Babbie, 2007, p. 147). This concept is similar in nature to that of measurement validity, which is the “extent to which measures indicate what they are intended to measure” (Schutt, 2006, p. 117). There are other forms of validity, such as criterion validity and construct validity but these are not relevant to this study. Threats to validity are relevant in the questionnaire and interview question portions of the study. The primary threat stems from the modification of the questionnaire that was used from tested historical questions. The possibility exists that modifications made may change the meaning of the items and the variable measurements. To ensure rigor of the study, however, validity was specifically addressed in the current study in the following manners:

- The majority of items contained in the questionnaire were based on other instruments found in literature (Longo, 2010; Moen & Brennan, 2005).
- The study’s questionnaire and interview questions were examined by a committee to determine face validity.
- The survey instrument was pilot tested during data collection methods.

To conclude, the rigor and quality of the current study was evaluated during the approval process. Data collection methods were detailed and reviewed, the proposed questionnaire was evaluated by experts for face validity. It was further pilot tested. Steps were taken to ensure data were consistently obtained and that the data were reliable. In order to ensure the interviews were consistent across participants, the researcher used a set of boiler plate questions tailored to address the research question (Appendix E). The descriptions of categories that were used for data analysis were described and are presented in Appendix E. The results include several quotes in order to substantiate reliability of coding, as well as to provide a means to assess
confirmability. Additionally, reliability checks of frequency counts were made during analysis by double- and triple-checking the Microsoft Excel count and sum functions. Furthermore, the findings are considered in light of the literature in order to provide a comparison that may be used to signal possible needs for additional inspection.

3.7 Limitations and Assumptions

The study’s design aimed to ensure that the results are valid and reliable. However, several assumptions are inherent to the study and the results are not without limitations. These assumptions and limitations are discussed herein.

3.7.1 Assumptions

The inherent assumption of this study of kept items is that a conscious decision was made to keep an item. This assumption was evaluated across participants using the question “What made you keep this item?” Additionally, the study assumed that participant’s identification of information item acquisition, need, and use was consistent across time. The use of a naturalist setting promotes reliability of the recall of an information item that the individual keeps; it is hoped that this methodology further prompts participants’ recall. However, it is recognized that future events could impact participant interpretations of information item acquisition, need, and use.

This study further assumed that participants could have personal reasons for keeping and using an item that may not be predicted. For example, it was not uncommon in the 1970’s to use a thick retailer’s catalog, e.g., the quarterly JC Penney’s catalog that was approximately 2” thick, as a window-prop or as a seat booster for children. This catalog-usage example shows that a presumed linkage of an information need (e.g., to purchase clothing or home goods), an item (e.g., catalog of available items for purchase), and the item’s use (e.g., window-prop or seat-booster), as opposed to a purchase, may not follow expected connections. This study assumed that similar disconnects in information need - information item - item usage could also exist with regard to health information items kept to manage life with diabetes. For example, the study provided opportunity to find instances, e.g., an individual may have a diabetic cookbook that was given to them and, by placing it in a visible place in the house, use it to remind themselves to take oral medication. In this example of the diabetic cookbook, the information need and use are not connected to the conventional notion of an information need for nutritional meals or used for
recipes. This linkage would thus break from conventional expectations. This assumption supports the combination of questions which are asked pertaining to information need, item usage, and situational relevance.

Additionally, the researcher assumed that the participants indeed had obtained a diagnosis of Type 2 diabetes. Patients are referred to the diabetes center with various diabetes diagnoses, including gestational, Type 1, and pre-diabetes, so there is a possibility that a participant incorrectly self-identified their diagnosis. The researcher did not attempt to verify participants’ diagnoses, as this would require access to the participant’s medical record.

3.7.2 Limitations

This study was bounded by several limitations. Primarily, given this study is exploratory and used purposive sampling methods, the results are limited and may not be generalized to a larger population. Specifically, this study focused on individuals who use health information items kept in their homes to help manage life with Type 2 diabetes. This bound thereby excluded information that participants found using Internet searches and potential participants who rely on this information seeking-use process. The results of the study are further limited in that the participants were drawn solely from a diabetes center associated with a regional teaching hospital. According to the diabetes center director, the majority of individuals who attend the diabetes classes are referred by physicians and have insurance. The cost of the three diabetes education sessions is $720 without insurance, per the participant Louis who paid for the classes out of pocket. The remaining participants had insurance which paid this fee. The results of this study, therefore, are biased toward those who have insurance. While attendance at the diabetes classes ensured that these individuals had information items in their homes while attending the class, it is possible that individuals may not keep information items upon class completion. Therefore, this study does not provide insight into the prevalence of information keeping within the population of individuals with Type 2 diabetes outside of diabetes class attendees.

Additionally, serving to further limit the study’s results, data collection depended upon the participants’ memories. The participants frequently recalled triggers that surrounded the acquisitions and use of an item, but they were also often vague about specific details. The information needs and item uses, therefore, may be biased by perceptions rather than grounded in fact. Questions were framed using a technique of telescoping to attempt to focus the participant’s
attention to a specific time. They were asked to describe what they recall about the time an item was acquired or used, but some of the incidents were not memorable or critical.

This study only included adults with Type 2 diabetes who spoke English. The results of this study cannot be generalized to individuals with gestational or Type 1 diabetes, or those individuals with diabetes who do not speak English.

The results of this study are also limited in that the majority of participants had been diagnosed within the past year. Although, data from participants (n = 2) who had lived with Type 2 diabetes more than 5 years indicates greater item keeps, further study is needed.

The results are limited in that more participants were recruited from afternoon sessions, although more people attend evening sessions. The results of this study are therefore not equally representative of individuals who attend evening versus afternoon classes.

Furthermore, this study is limited in that it is a snapshot in time. It does not provide the means to view the changes of a personal item collection that may occur over time. Items that may have previously been kept and considered useful may have been discarded by the time of the study. This snapshot also does not provide any insight as to a change from paper-based to electronically kept items.

3.8 Schedule & Budget

The completion of this study included periods for a pre-test, data collection, and a prolonged time period for data analysis and final write-up. The study began with pre-test recruitment in March 2011 and interviews of study participants were completed September 2011. The complete schedule afforded this study process is presented in Table 8.

Table 8. Dissertation schedule.

<table>
<thead>
<tr>
<th>DATE</th>
<th>ACTIVITY</th>
</tr>
</thead>
<tbody>
<tr>
<td>DATA COLLECTION</td>
<td></td>
</tr>
<tr>
<td>PREPARATION</td>
<td></td>
</tr>
<tr>
<td>December 2010</td>
<td>Submitted IRB application to FSU &amp; TMH; submitted prospectus to committee</td>
</tr>
<tr>
<td>February 1, 2011</td>
<td>Prospectus Defense – passed with requested revisions</td>
</tr>
</tbody>
</table>
### Table 8 - continued

<table>
<thead>
<tr>
<th>DATE</th>
<th>ACTIVITY</th>
</tr>
</thead>
<tbody>
<tr>
<td>February 2, 2011</td>
<td>Attended staff meeting at the diabetes center to introduce study to the diabetes educators and to discuss their role</td>
</tr>
<tr>
<td>By Feb 28, 2011</td>
<td>Made requested changes and submitted final prospectus to the department’s front office</td>
</tr>
</tbody>
</table>

**DATA COLLECTION BEGINS**

<table>
<thead>
<tr>
<th>DATE</th>
<th>ACTIVITY</th>
</tr>
</thead>
<tbody>
<tr>
<td>March 2011</td>
<td>Began recruitment</td>
</tr>
<tr>
<td>March 2011</td>
<td>Contacted volunteers for pre-test</td>
</tr>
<tr>
<td>March - April 2011</td>
<td>Conducted pre-test interviews, revised instrument, and sought IRB modification</td>
</tr>
<tr>
<td>May 2011- September 2011</td>
<td>Conducted study interviews. Progressively reviewed data and ended data collection when relevance categories became saturated</td>
</tr>
</tbody>
</table>

**DATA COLLECTION ENDS**

<table>
<thead>
<tr>
<th>DATE</th>
<th>ACTIVITY</th>
</tr>
</thead>
<tbody>
<tr>
<td>October – November 2011</td>
<td>Finished analyzing data</td>
</tr>
<tr>
<td>November 2011 - January 2013</td>
<td>Wrote Results, Conclusion &amp; Discussion chapters</td>
</tr>
<tr>
<td>September 2012</td>
<td>Applied for graduation – resubmitted as needed</td>
</tr>
</tbody>
</table>

**DISSERTATION DRAFT SUBMITTED**

<table>
<thead>
<tr>
<th>DATE</th>
<th>ACTIVITY</th>
</tr>
</thead>
<tbody>
<tr>
<td>March 28, 2013</td>
<td>Submitted completed draft to Advisor, committee, and library</td>
</tr>
<tr>
<td></td>
<td>Submitted the manuscript through the ETD Administration site</td>
</tr>
<tr>
<td>April 2, 2013</td>
<td>Submitted Defense Announcement to University’s system</td>
</tr>
<tr>
<td>April 25, 2013</td>
<td>Dissertation defense</td>
</tr>
<tr>
<td>July 8, 2013</td>
<td>FSU deadline: final submission of manuscript &amp; forms</td>
</tr>
<tr>
<td></td>
<td>Revised manuscript submitted to UMI ETD Admin site.</td>
</tr>
</tbody>
</table>

A breakdown of the costs associated with this study, totaling $1,602.12, is presented in Table 9. This total cost includes travel and $30 compensation per participant. The researcher received and used a Florida State University dissertation research grant to help defray the out of pocket expense.
Table 9. Expenses associated with this dissertation.

<table>
<thead>
<tr>
<th>Item</th>
<th>Qty</th>
<th>Cost</th>
<th>Subtotal</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>DATA COLLECTION</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mileage for researcher</td>
<td>1722 miles</td>
<td>$0.50</td>
<td>$861</td>
</tr>
<tr>
<td>Postage: letters (used 2 stamps/letter)</td>
<td>24 @ 0.88</td>
<td></td>
<td>$21.12</td>
</tr>
<tr>
<td>Reimbursement: 3 people for a pre-test</td>
<td>3</td>
<td>$30</td>
<td>$90</td>
</tr>
<tr>
<td>Reimbursements: 21 participants</td>
<td>21</td>
<td>$30</td>
<td>$630</td>
</tr>
<tr>
<td><strong>GRAND TOTAL</strong></td>
<td></td>
<td></td>
<td><strong>$1,602.12</strong></td>
</tr>
</tbody>
</table>

### 3.9 Conclusion

This study sought to determine information items that are kept by adults living with Type 2 diabetes to help them manage their life, and to explore the influence of personal context on keeping, the information needs and item uses associated with these kept items and the situational relevance attributed to these items.

To meet the aims of this study, semi-structured interviews were conducted using participants (n = 21) recruited from a local diabetes center associated with a regional teaching hospital. It was assumed that the adults who participated did indeed have Type 2 diabetes, but the participants were not asked to verify this. A pre-test was conducted (n = 3) and minor changes were made to interview questions and the data collection process. All participants were compensated $30 per interview. Initial paper-based data sheets or data collection using survey software were abandoned for the study. Instead, the researcher made notes and record data throughout the interview directly into Microsoft Excel spreadsheets. The specific study variables noted include: the items’ details, the participants’ use of the item, the participants’ information need associated with the item, and the relevance of the item with regard to their life with diabetes. The health information items kept by the adults living with Type 2 diabetes served as the “critical incident” used to guide the interviews, but the participants’ descriptions of item details, the individual’s use of the item, the individual’s information need associated with the item, and the item’s relevance served as the data points.

This chapter provided additional information with regard to the recruitment process, the informed consent procedures, the schedule and budget, and the planned methods for data
analysis. Supporting material, such as the consent form, coding sheets, and letter of introduction, are presented in the Appendix.
CHAPTER FOUR

RESULTS

The purpose of this study was to explore what health information items are kept and used by individuals with Type 2 diabetes and to investigate what these information items say about the participants’ information needs. Additionally, the study examined the relationship among the kept personal health information items (items), information needs, and item uses with regard to the context of the participants’ lives as they manage living with Type 2 diabetes. The background for this study was provided in Chapter 2, and details of the study design and analysis methods were provided in Chapter 3. This chapter aims to provide the results of the analysis set forth by the earlier chapters. Specific data analysis conducted to address each question put forth by this study is described herein, alongside the subsequent results. The data used in this analysis were collected during semi-structured interviews of adults living with Type 2 diabetes (n = 21), which were conducted in participants’ homes. This chapter serves to provide the results of the study, but the research questions that guided this study are also presented herein, as are descriptions of the sample and the interviews. Conclusions and implications associated with the results presented herein are discussed in Chapter 5.

4.1 The Sample and the Interviews

Over the course of four months (April – September, 2011), participants (n = 21) were recruited and interviewed. The participants’ general health profile and basic demographic characteristics are presented in Tables 10 and 11 respectively. The participants were 38-79 years old (mean = 60 years, SD = 9.5). The majority of the participants lived in the metropolitan County A (n = 20, 95%). They were primarily female (n = 15, 71%), white/Caucasian (n = 17, 81%), and insured (n = 18, 86%). The majority were new to diabetes (diagnosis < 3 months n = 15, 71%) and generally considered their health as above average (mean = 4.75, SD = 1.3, median and mode = 5 on a 1 (low) – 7 (high) scale). With regards to their health, the majority report that they have others in the family, living or deceased, with diabetes (n = 12, 57%) and that their diabetes is controlled (n = 19, 90%). Control is primarily maintained using medication (n = 13, 62%), although some do report using exercise (n = 8, 38%) and diet (n = 9, 43%).

98
Table 10. Participant basic demographics.

<table>
<thead>
<tr>
<th>Question</th>
<th>Mean / Range</th>
<th>Median / Mode</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>60 yrs / 38-79 yrs</td>
<td>59 yrs / 57 yrs</td>
</tr>
<tr>
<td>Sex</td>
<td>F</td>
<td>%</td>
</tr>
<tr>
<td>Female</td>
<td>15</td>
<td>71%</td>
</tr>
<tr>
<td>Male</td>
<td>6</td>
<td>29%</td>
</tr>
<tr>
<td>Ethnic background</td>
<td>F</td>
<td>%</td>
</tr>
<tr>
<td>African American/black</td>
<td>4</td>
<td>19%</td>
</tr>
<tr>
<td>White/Caucasian</td>
<td>17</td>
<td>81%</td>
</tr>
<tr>
<td>County of residency</td>
<td>F</td>
<td>%</td>
</tr>
<tr>
<td>County A (metropolitan)</td>
<td>20</td>
<td>95%</td>
</tr>
<tr>
<td>County B (rural)</td>
<td>1</td>
<td>5%</td>
</tr>
<tr>
<td>Time since diagnosis of Type 2 diabetes</td>
<td>F</td>
<td>%</td>
</tr>
<tr>
<td>&lt;= 3 months</td>
<td>15</td>
<td>71%</td>
</tr>
<tr>
<td>&lt;= 12 months</td>
<td>3</td>
<td>14%</td>
</tr>
<tr>
<td>&gt;5yrs</td>
<td>3</td>
<td>14%</td>
</tr>
</tbody>
</table>

Table 11. Participant health profile.

<table>
<thead>
<tr>
<th>Health Profile Question</th>
<th>F</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number who have others in the family, living or deceased, with diabetes</td>
<td>12</td>
<td>57%</td>
</tr>
<tr>
<td>Number who have insurance coverage for diabetes care (no response = 1)</td>
<td>18</td>
<td>86% (5%)</td>
</tr>
<tr>
<td>State their diabetes is controlled</td>
<td>19</td>
<td>90%</td>
</tr>
<tr>
<td>Means of Control (participant could indicate multiple means)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Exercise</td>
<td>8</td>
<td>38%</td>
</tr>
<tr>
<td>Diet</td>
<td>9</td>
<td>43%</td>
</tr>
<tr>
<td>Medication</td>
<td>13</td>
<td>62%</td>
</tr>
<tr>
<td>Overall Health Assessment: scale of 1 (low) to 7 (high)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean / SD</td>
<td>4.75 / 1.3</td>
<td></td>
</tr>
<tr>
<td>Median / Mode</td>
<td>5 / 5</td>
<td></td>
</tr>
</tbody>
</table>
Data pertaining to the extended demographics of the participants (Table 13) show that participants were: primarily homeowners (n = 17, 81%), employed (n = 13, 62%), and married (n = 11, 52%). Few had children currently living in the home (n = 5, 24%). The education level of the participants ranged between high school graduation (n = 3, 14%) to completing a graduate degree (n = 3, 14%) and the estimated annual household income also varied, with three participants (14%) in the lowest bracket ($15,000-$29,999), and the remaining 17 similarly split in the $30,000-$49,999 (n = 6, 29%), $50,000-$74,999 (n = 5, 24%) , and $≥$75,000 (n = 6, 29%) brackets. One participant (5%) chose not to report household income.

Table 12. Participant extended demographics.

<table>
<thead>
<tr>
<th>Question</th>
<th>F</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Marital status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>11</td>
<td>52%</td>
</tr>
<tr>
<td>Divorced</td>
<td>5</td>
<td>24%</td>
</tr>
<tr>
<td>Living as married</td>
<td>2</td>
<td>10%</td>
</tr>
<tr>
<td>Single, never married</td>
<td>3</td>
<td>14%</td>
</tr>
<tr>
<td><strong>Number with children under the age of 18 in household</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>5</td>
<td>24%</td>
</tr>
<tr>
<td><strong>Highest level of education</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Graduated high school</td>
<td>3</td>
<td>14%</td>
</tr>
<tr>
<td>Some college courses</td>
<td>4</td>
<td>19%</td>
</tr>
<tr>
<td>Completed 2 year degree</td>
<td>3</td>
<td>14%</td>
</tr>
<tr>
<td>Graduated college (4 year degree)</td>
<td>4</td>
<td>19%</td>
</tr>
<tr>
<td>Some Graduate classes</td>
<td>4</td>
<td>19%</td>
</tr>
<tr>
<td>Completed graduate degree</td>
<td>3</td>
<td>14%</td>
</tr>
<tr>
<td><strong>Current occupational status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employed</td>
<td>13</td>
<td>62%</td>
</tr>
<tr>
<td>Student</td>
<td>1</td>
<td>5%</td>
</tr>
<tr>
<td>Disabled</td>
<td>1</td>
<td>5%</td>
</tr>
<tr>
<td>Retired</td>
<td>6</td>
<td>29%</td>
</tr>
</tbody>
</table>
Table 12 - continued

<table>
<thead>
<tr>
<th>Question</th>
<th>F</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Estimated annual household income</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>$15,000-$29,999</td>
<td>3</td>
<td>14%</td>
</tr>
<tr>
<td>$30,000-$49,999</td>
<td>6</td>
<td>29%</td>
</tr>
<tr>
<td>$50,000-$74,999</td>
<td>5</td>
<td>24%</td>
</tr>
<tr>
<td>≥$75,000</td>
<td>6</td>
<td>29%</td>
</tr>
<tr>
<td>no response</td>
<td>1</td>
<td>5%</td>
</tr>
<tr>
<td><strong>Home ownership?</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Own</td>
<td>17</td>
<td>81%</td>
</tr>
<tr>
<td>Rent</td>
<td>4</td>
<td>19%</td>
</tr>
</tbody>
</table>

Interviews were conducted in the participants’ homes and lasted between 40 - 135 minutes (mean = 74 minutes, SD = 26.5; median and mode = 75 minutes). The interview durations are noted alongside the number of items kept in the home and the number of items that participants reported as used (Table 13). Note that the length of the interview did not necessarily correspond with the number of items found or used, e.g., Jack spent the most time speaking with the researcher (n = 135 minutes), but Sarah, who had a similar number of items (n = 24 vs. Jack’s n = 21) was interviewed for only 75 minutes. The variability in interview times is partially due to the number of items discussed, but also that some participants preferred to stay on topic and end the interview quickly, while others were very conversational, discussing general things, e.g., previous residences or their work experiences, and had to be prompted to move to another item. The interview length may also have varied, because only some of the participants had a family history of diabetes. These stories often came up at some point during the conversation. While these conversations did not shed light on the items per se, they did provide insight into the context in which the health information items were acquired, used, and kept.

The results for this study are based on the number of kept health information items (n = 300) that participants reported as using. The total number of health information items that the participants revealed that they kept in the home (n = 706) is nearly double that of the number of the items that were used. Many of the items in the homes kept in the home had been collected during participation in diabetes education classes, e.g., class slides and educational handouts.
This course specific material was presented during the classes or included for future information. Many participants commented that the information contained in the class packet helped them learn the material initially, but only the specific items that participants identified as personally using to help manage diabetes were discussed and analyzed. The diabetes education class items that were identified as “not used” were not discussed with the participants, although basic coding, such as book or details pertinent to diabetes course material, was done. Results pertaining to these items, i.e., class specific and any other materials that were kept but not used, are presented in Ancillary Findings. Analysis to address the study’s research questions was performed using only the items identified as “used” (n = 300).

The number of items kept in the home (Table 13) ranged from 16 - 118 items (mean = 33.6, SD = 22.5; median = 25, and mode = 22). This number of health information items kept in homes is under reported, however. Some items, such as the older edition items that John thought he had, but did not use, were not counted as he was not sure where they were located and was not precisely sure if he did have items or which items, specifically, were duplicated. This data loss, however, had minimal effect on the data collected as these items were not currently used and they were older editions of items that were discussed. Another possible source of under reporting of data, with regard to the total number of health information items kept in the home, is from Renee, who had a plateful of clipped recipes that she had not used or sorted through to determine what she would use. It was not clear if these items could or would be used to inform managing life with diabetes, and the focus of the study was on kept items that had been used, therefore the items were not included during data collection.

The number of kept health information items that were subsequently reported as “used” (n = 300, range = 2 - 94 items; mean = 14.3, SD = 19.9; median = 8, and mode = 6) is lower than the number of items that were kept (n= 706) and serves as the list of items used for analysis. Note that the counts of both kept and used items include data from one extreme collector, Renee. Renee is an outlier in that her values exceed the number of items reported by the participant who was the second highest in information item keeping and using, Kay. Kay had almost half the number of items in her home (n = 61) compared to Renee’s (n = 118), and used one-third (n = 28) of that reported by Renee (n = 94). If the data are considered outside of Renee’s data, the mean number of items kept in the home drops by 4.5 items (mean = 29.5, SD = 12.2), and the number of items reported as used drops by 3.5, which is a 25% reduction (mean = 10.4, SD = ...
However, Renee’s data illustrates a level of saturation in that obtained data included that from individuals who tended to keep and use many information items. Therefore, Renee’s data are included in all analysis.

Table 13. Interview durations and number of health information items maintained/used.

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Interview Duration (in minutes)</th>
<th>F Items Kept in Home</th>
<th>F Used Items</th>
<th>% Used Items / Kept</th>
</tr>
</thead>
<tbody>
<tr>
<td>Renee</td>
<td>105</td>
<td>118</td>
<td>94</td>
<td>79.7</td>
</tr>
<tr>
<td>June</td>
<td>90</td>
<td>45</td>
<td>28</td>
<td>62.2</td>
</tr>
<tr>
<td>Jack</td>
<td>135</td>
<td>42</td>
<td>21</td>
<td>50.0</td>
</tr>
<tr>
<td>Sarah</td>
<td>75</td>
<td>49</td>
<td>24</td>
<td>49.0</td>
</tr>
<tr>
<td>Kay</td>
<td>95</td>
<td>61</td>
<td>28</td>
<td>45.9</td>
</tr>
<tr>
<td>Louis</td>
<td>60</td>
<td>21</td>
<td>9</td>
<td>42.9</td>
</tr>
<tr>
<td>John</td>
<td>75</td>
<td>27</td>
<td>11</td>
<td>40.7</td>
</tr>
<tr>
<td>Emily</td>
<td>45</td>
<td>23</td>
<td>9</td>
<td>39.1</td>
</tr>
<tr>
<td>Janice</td>
<td>120</td>
<td>25</td>
<td>9</td>
<td>36.0</td>
</tr>
<tr>
<td>Sandy</td>
<td>60</td>
<td>29</td>
<td>10</td>
<td>34.5</td>
</tr>
<tr>
<td>Mary</td>
<td>60</td>
<td>24</td>
<td>8</td>
<td>33.3</td>
</tr>
<tr>
<td>Carla</td>
<td>75</td>
<td>24</td>
<td>8</td>
<td>33.3</td>
</tr>
<tr>
<td>Suzanne</td>
<td>65</td>
<td>18</td>
<td>5</td>
<td>27.8</td>
</tr>
<tr>
<td>Lisa</td>
<td>50</td>
<td>22</td>
<td>6</td>
<td>27.3</td>
</tr>
<tr>
<td>Mona</td>
<td>75</td>
<td>25</td>
<td>6</td>
<td>24.0</td>
</tr>
<tr>
<td>Adam</td>
<td>45</td>
<td>28</td>
<td>6</td>
<td>21.4</td>
</tr>
<tr>
<td>Dan</td>
<td>90</td>
<td>22</td>
<td>4</td>
<td>18.2</td>
</tr>
<tr>
<td>Alan</td>
<td>40</td>
<td>22</td>
<td>4</td>
<td>18.2</td>
</tr>
<tr>
<td>Kathy</td>
<td>50</td>
<td>19</td>
<td>3</td>
<td>15.8</td>
</tr>
<tr>
<td>Arlene</td>
<td>40</td>
<td>16</td>
<td>2</td>
<td>12.5</td>
</tr>
<tr>
<td>Sue</td>
<td>95</td>
<td>46</td>
<td>5</td>
<td>10.9</td>
</tr>
</tbody>
</table>
The percentage of the reported kept items (n = 706) that were used (n = 300) ranged from 10.9% to 79.7% (Table 13). The mean percentage of kept items that were used was slightly less than half (mean = 42.6%), while the median and mode show that the percentage of used items is less than one-third (median = 32.0% and mode = 27.3%). When Renee’s data is excluded from analysis, on average participants used approximately one-third of the items that were kept (mean = 35.3%, median = 32.7%, and mode = 27.3%). Renee’s data show that she used more of her kept items (79.7%) than other participants. June used the second highest percentage of kept items (62.2%) to manage life with diabetes.

Further details about the determination of kept and used health information item counts are provided further down in the Results chapter. The results subsequently reported herein are based on the number of kept health information items that participants reported as using (n = 300 of the 706 reported items). Given the difference in Renee’s data from that of the other participants, the results are discussed with and without Renee’s data in the sections pertaining to kept item types and uses. Note that the discussion of excluding Renee’s data does not intend to minimize the value of this contribution. Her data is important in that it demonstrates data

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Interview Duration (in minutes)</th>
<th>F Items Kept in Home</th>
<th>F Used Items</th>
<th>% Used Items / Kept</th>
</tr>
</thead>
<tbody>
<tr>
<td>TOTALS</td>
<td></td>
<td>706</td>
<td>300</td>
<td>42.5</td>
</tr>
<tr>
<td>Mean</td>
<td>74</td>
<td>33.6</td>
<td>14.3</td>
<td>42.6</td>
</tr>
<tr>
<td>Median</td>
<td>75</td>
<td>25</td>
<td>8</td>
<td>32.0</td>
</tr>
<tr>
<td>Mode</td>
<td>75</td>
<td>22</td>
<td>6</td>
<td>27.3</td>
</tr>
<tr>
<td>SD</td>
<td>26.5</td>
<td>22.5</td>
<td>19.9</td>
<td></td>
</tr>
<tr>
<td>Min</td>
<td>40</td>
<td>16</td>
<td>2</td>
<td>12.5</td>
</tr>
<tr>
<td>Max</td>
<td>135</td>
<td>118</td>
<td>94</td>
<td>79.7</td>
</tr>
</tbody>
</table>

Excluding Renee’s Data

<table>
<thead>
<tr>
<th>Excluding Renee’s Data</th>
<th>588</th>
<th>206</th>
<th>35.0</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean</td>
<td>72</td>
<td>29.5</td>
<td>10.4</td>
</tr>
<tr>
<td>Median</td>
<td>70</td>
<td>24.5</td>
<td>8</td>
</tr>
<tr>
<td>Mode</td>
<td>75</td>
<td>22</td>
<td>6</td>
</tr>
<tr>
<td>SD</td>
<td>26.1</td>
<td>12.2</td>
<td>8.1</td>
</tr>
<tr>
<td>Min</td>
<td>40</td>
<td>16</td>
<td>2</td>
</tr>
<tr>
<td>Max</td>
<td>135</td>
<td>61</td>
<td>28</td>
</tr>
</tbody>
</table>

The percentage of the reported kept items (n = 706) that were used (n = 300) ranged from 10.9% to 79.7% (Table 13). The mean percentage of kept items that were used was slightly less than half (mean = 42.6%), while the median and mode show that the percentage of used items is less than one-third (median = 32.0% and mode = 27.3%). When Renee’s data is excluded from analysis, on average participants used approximately one-third of the items that were kept (mean = 35.3%, median = 32.7%, and mode = 27.3%). Renee’s data show that she used more of her kept items (79.7%) than other participants. June used the second highest percentage of kept items (62.2%) to manage life with diabetes.

Further details about the determination of kept and used health information item counts are provided further down in the Results chapter. The results subsequently reported herein are based on the number of kept health information items that participants reported as using (n = 300 of the 706 reported items). Given the difference in Renee’s data from that of the other participants, the results are discussed with and without Renee’s data in the sections pertaining to kept item types and uses. Note that the discussion of excluding Renee’s data does not intend to minimize the value of this contribution. Her data is important in that it demonstrates data
saturation; it represents differences in information keeping and use behaviors. The unique symbolism of Renee’s data is discussed further in the next chapter, Chapter 5: Discussion.

4.2 The Research Questions

This study was designed to address six main questions related to the keeping and use of kept health information items relative to a participant’s management of their life with diabetes:

1) What personal health items do individuals keep with regard to living with diabetes?
2) What role does personal context play in the presence of kept personal health items?
3) What use was made of the kept personal health items?
4) What information needs are associated with kept personal health items’?
5) What relevance decisions are attributed to the kept health item?
6) What does the kept health item say about the needs of individuals?

The sub-questions asked within these main questions are presented in the individual sections discussed herein.

4.3 Kept Personal Health Items (RQ1)

The first research question aimed to address, “What personal health items do individuals keep with regard to living with diabetes?” Additionally, two sub-questions were asked: “What types of items (e.g., book, internet site) are kept?” and “Are certain types of items kept more frequently than others?” In order to address these questions, participants were asked about items they had which were paper versus electronic. These items, as the unit of analysis for this question, were then categorized and totals were used for comparisons.

Before discussing the items that were kept, the participants were first asked about electronics in the home, e.g., computers and smartphones, on which items could kept to determine if there were electronic and/or paper items to discuss. Specifically, participants were asked whether they had computers, smart phones, or e-book readers in their homes. Results (Table 14) show that the majority of participants had computers in the home with Internet access (n = 18, 86%). However, only some kept health information, e.g., lab reports or spreadsheets, (n = 2, 10%) or bookmarked health information on the computer (n = 7, 33%). As for personal information technology, e.g., smartphones and e-book readers, although it is quickly reaching more consumers, only four (19%) had e-book readers, while approximately one-quarter (n = 5,
24% of the participants had smartphones. The use of this technology to store health information items to help manage life with diabetes was limited, however. Three participants (14% of the sample, 60% of participants with smartphones) maintained diabetes related apps on the phone, but only one participant had and used an e-book (5% of the sample, 25% of participants with e-book readers).

Table 14. Home access to electronic health information items.

<table>
<thead>
<tr>
<th>Technology in Home used for Information Management</th>
<th>F</th>
<th>% of total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Computers</td>
<td>18</td>
<td>86%</td>
</tr>
<tr>
<td>Keep health information on home computer</td>
<td>2</td>
<td>10%</td>
</tr>
<tr>
<td>Internet access</td>
<td>18</td>
<td>81%</td>
</tr>
<tr>
<td>Have health information bookmarked on the computer</td>
<td>7</td>
<td>33%</td>
</tr>
<tr>
<td>Smart phone with Internet access</td>
<td>5</td>
<td>24%</td>
</tr>
<tr>
<td>Diabetes related apps on the phone</td>
<td>3</td>
<td>14%</td>
</tr>
<tr>
<td>eBookReader</td>
<td>4</td>
<td>19%</td>
</tr>
<tr>
<td>Diabetes related eBooks</td>
<td>1</td>
<td>5%</td>
</tr>
</tbody>
</table>

During data collection the researcher made a note about the investigated health information items’ type, e.g., book, log, etc. The typology used was initially developed using the literature: Longo et al. (2010) and Moen & Brennan (2005). These categories are listed in Appendix E, as part of the data collection sheets. During data collection, if an initial category could not be determined, notes were made and final categorization was left for the analysis phase. This process showed that these category types were insufficient to address each item. In order to adequately categorize the items, five new categories were created and added to the list originally created using the literature. These new categories are: log, meter, handouts, recipes, and prescription information. Although, this process of determining personal health information item category types resulted in a total of 24 possible categories, including “Other,” which was used as a placeholder until the researcher made further consideration during analysis, only 17 categories (Table 16) were used to categorize the items found during this study.
The results of the types of health information items kept and used (Table 15) show that participants keep and use various items to help manage their lives with diabetes, including: recipes; books (hardcopy and digital); glucose meters, wherein historical data is stored and used for review; and logs where readings of glucose levels are kept, sometimes in addition to notes of food, exercise, and medication dosage.

Table 15. The number of each type of item that is kept and used by adults with Type 2 diabetes. Listed by rank of most frequently kept.

<table>
<thead>
<tr>
<th>Type of Item</th>
<th>Notes</th>
<th>F</th>
<th>%</th>
<th>Excluding Renee's Data</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Recipes</td>
<td>These are cut-out from magazines or printed off from websites</td>
<td>89</td>
<td>29.7</td>
<td></td>
</tr>
<tr>
<td>2 Handout</td>
<td>Items given out by doctors at time of diagnosis or from the diabetes center as part of class. Includes a Letter of Introduction the center mailed to students prior to classes.</td>
<td>54</td>
<td>18</td>
<td>50 24.3</td>
</tr>
<tr>
<td>3 Books (other than phone book or cook book)</td>
<td></td>
<td>34</td>
<td>11.3</td>
<td>31 15.0</td>
</tr>
<tr>
<td>4 Cook book</td>
<td></td>
<td>19</td>
<td>6.3</td>
<td>19 9.2</td>
</tr>
<tr>
<td>5 Log</td>
<td>The format of the logs may be that provided by the diabetes educators, or log books provided with glucose meters.</td>
<td>19</td>
<td>6.3</td>
<td>19 9.2</td>
</tr>
<tr>
<td>6 Self-care brochure</td>
<td></td>
<td>17</td>
<td>5.7</td>
<td>17 8.3</td>
</tr>
<tr>
<td>7 Internet site (give name or address)</td>
<td>These are bookmarks</td>
<td>16</td>
<td>5.3</td>
<td>11 5.3</td>
</tr>
</tbody>
</table>
In order to address the research sub-question about the prevalence of kept health information item types, e.g., book, prescription information, etc., frequency was tabulated (Table 15) and compared. Before further discussing the results, the unique information keeping behaviors of two participants with regard to specific items are presented. This discussion is

<table>
<thead>
<tr>
<th>Type of Item</th>
<th>Notes</th>
<th>F</th>
<th>%</th>
<th>Excluding Renee's Data</th>
</tr>
</thead>
<tbody>
<tr>
<td>8   Diabetes specific</td>
<td>(e.g., Diabetes Forecast, Diabetes Self-Management)</td>
<td>14</td>
<td>4.7</td>
<td>11 5.3</td>
</tr>
<tr>
<td>Magazine</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9   Meter</td>
<td>Glucose meters used to test the blood</td>
<td>9</td>
<td>3</td>
<td>7  3.4</td>
</tr>
<tr>
<td>10  Nutritional information</td>
<td>Restaurants provide pamphlets that provide information about the</td>
<td>5</td>
<td>1.7</td>
<td>5  2.4</td>
</tr>
<tr>
<td>pamphlet, fast foods</td>
<td>nutrition in menu items. This information can sometimes be found in</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>books, such as <em>The Calorie King</em>.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11  Prescription information</td>
<td>Drug information sheets provided by pharmacists</td>
<td>5</td>
<td>1.7</td>
<td>4  1.9</td>
</tr>
<tr>
<td>12  Lab report</td>
<td></td>
<td>4</td>
<td>1.3</td>
<td>4  1.9</td>
</tr>
<tr>
<td>13  Popular magazine</td>
<td>Popular press magazines that contain content that is not specifically</td>
<td>4</td>
<td>1.3</td>
<td>4  1.9</td>
</tr>
<tr>
<td></td>
<td>geared toward diabetes.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14  Diet information</td>
<td></td>
<td>3</td>
<td>1</td>
<td>3  1.5</td>
</tr>
<tr>
<td>15  Exercise video</td>
<td></td>
<td>3</td>
<td>1</td>
<td>3  1.5</td>
</tr>
<tr>
<td>16  Notebook</td>
<td>Includes notebooks and loose notes</td>
<td>3</td>
<td>1</td>
<td>2  1.0</td>
</tr>
<tr>
<td>17  Calendar</td>
<td></td>
<td>2</td>
<td>0.7</td>
<td>2  1.0</td>
</tr>
</tbody>
</table>

**TOTALS** 300 206
presented, because the rank of kept items changes with the data of these participants. First, as shown in Table 16, Renee’s data are unique with regard to the number of recipes kept. The results show that Renee kept 120 health information items in her home, while 93 items (n = 77.5%) were reported as used. These used items were primarily recipes (n = 75, 80.6% of the kept and used items). If an adjustment is made to account for the large number of recipes kept by Renee (n = 75) as opposed to the number of items kept by others, handouts (n = 54, 18%; n = 50, 24.3% when excluding Renee’s data) are kept most frequently. However, the data show that Kay, whose data is not separated out in the table, kept a large number of handouts (n = 28, 51.9% of the handouts kept). These handouts were obtained when Kay’s husband was diagnosed with diabetes during a hospital stay. These KODI based print-outs were provided by a nurse per doctor’s instructions. Kay began to use the handouts for herself after her diagnosis. The stories of these women show that information keeping behaviors are influenced by different contexts, and although perhaps possibly considered atypical, these stories and keeping behaviors demonstrate the importance of data saturation. The results discussed henceforth will include the data of both Kay and Renee. The data thus informs results of different types of information keepers. To exclude the data would inflate or conflate other data.

As reported in Table 15, the most kept item type was the recipe (n = 89, 29.7%). Recipes were sometimes items that were cut-out from magazines, items that had been printed off from a website or newsletter, hand written cards, or stock recipe cards that had been provided by a publisher. The second most kept health information type was the handout (n = 54, 18%). The handout category contains items that were given out by doctors at time of diagnosis or from the diabetes center as part of class. This category includes a Letter of Introduction the center mailed to students prior to classes. Note that the diabetes educators provided at least eleven handouts, including five sets of slides covered during class, per participant, including a blank glucose log. Therefore, the participants kept at least 231 handouts (including slides = 105) in the home. Additionally, some physicians provided several handouts, while others offered none. The presence and use of the 54 handouts represents approximately one-quarter of the handouts provided to participants. These handouts cover various topics including: resources, stress reduction tips, foot care, and medication. The results of the handout data includes seven copies of slides (n = 7) that had been obtained as part of the diabetes education classes. This is 6.8% of the
number of slides that were provided. The number of slides found accounts for 13.0% of the total number of handouts that were kept.

The next most frequently used item type, excluding cookbooks, is books (n = 34; 11.3%). These 34 books include six copies of the book, *The Calorie King*, two copies of *Diabetes for Dummies*, and two copies of *The Complete Book of Food Counts*. This list further includes multiple copies of the same title kept by Sue in places like her car or office, e.g., *Tell Me What to Eat: If I Have Diabetes*. Results also show books with different copyright dates, e.g., *Diabetic Meals in 30 Minutes or Less*, copyrighted in 2007 and 2010.

The next item type found most frequently is Cookbooks. These are books specific to preparing food with a diabetic diet in mind (n = 19, 6.3%). Many cook book titles specifically identified them as target books for individuals living with diabetes, e.g., *The Healthy Kitchen: Delicious Recipes for People with Diabetes*, *Diabetic Microwave Cookbook*, *All New Cookbook for Diabetics and Their Families*, and the *American Diabetes Association (ADA) Diabetic Meals in 30 minutes or Less*. However, cookbooks that were not specific to diabetes, but contained relevant information were also found. For example, Mona also kept and used cookbooks that provide recipes specific to sugar substitutes, e.g.: *Splenda Life Cookbook* and *Sweet Ideas from Equal*. Other titles indicate that recipes that do not use sugar were contained within the book, e.g.: *Sugar free desserts: Naturally Sweetened with Fruits & Juices* and *Sweet Inspirations: A Sugar Free Dessert Cookbook*.

The topics of cookbooks and non-cookbooks highlighted above share a similar theme: food. Much of the content discussed with regard to the non-cookbooks is related to nutrition. Thus, it seems reasonable to consider a combined count of the cook book and other book items, including one eBook (n = 53, 18.6%). This combined count of books shows that books were kept and used nearly as often as handouts (n = 54, 18%). Books that are not cookbooks (n = 34, 11.3%) make up the majority (62%) of this combined count of books.

A list of 45 unique titles of books and cookbooks kept by the participants is provided in Appendix H. This list has fewer items than the number that were found, because duplicates were not listed repeatedly in the compiled list. The list is also shorter as it does not contain reference to books which were not presented to determine the true title. This omission in data occurred because some participants were unable to physically present a book that they believed they used quite a bit. For example, Emily usually keeps a book she received from the doctor's office in her
purse so she could look up nutrition content information. She recently cleaned her purse out, and could not find where she placed the book. She thought it was prepared by the American Diabetes Association. She described it as “basically a book that is like those calorie books, but it has a list of foods and their carb equivalents.” The book was coded and used in analysis despite the lack of item details. Emily was able to describe all other relevant information pertinent to the study.

The items contained within the categories of recipes, handouts, books, and cookbooks account for over half of the items discussed during data collection. However, other health information items that were used by at least 5% of the participants are noted here. These items which require active user interaction, such as glucose logs, were kept and used less frequently than books (n = 19, 6.3%). Frequently, the paper glucose logs that were found were filled-in versions of the template provided by the diabetes educators. However, participants also kept log books that were provided with glucose meters; composition books wherein participants kept notes of glucose reading and food intake; Microsoft Excel spreadsheets; and the digital meter recordings.

Other types of items that account for at least 5% of the reported kept and used health information items include self-care brochures (n = 17, 5.7%), bookmarked websites (n = 16, 5.3%), and diabetes specific magazines (n = 14, 4.7%). Many of the self-care brochures were kept by Kay who received a stack of print-outs of several from her husband’s health care provider when he was diagnosed with diabetes for an unrelated hospital visit. The titles of these brochures include: Diabetes: Activity Tips; Diabetes: Inspecting Your Feet; and Exercise to Manage your Blood Sugar. Some of self-care brochures found were provided by the diabetes center, including the brochure entitled Stress, as well as the packet of slides entitled Nutrition for Diabetes and Exercise for Diabetes.

Several participants reported that they use the Internet to search for information when needed, such as Suzanne who looks for recipes that include information about the number of carbohydrates. A few participants, such as John who uses the online version of The Calorie King, said they regularly access diabetes related websites directly by typing in the memorized address. However, although the Internet is becoming ubiquitous for information, only one-third (n = 7) of participants (Lisa, Jack, Renee, Dan, Emily, June, and Sarah) had bookmarked websites pertaining to diabetes. These sites include: WebMD; American Diabetes Association; Publix (a regional grocery store chain); Pharmacy Diabetes Management; InfoDiabetes, which contains a
Daily Food Guide; HealthTrioConnect, the website for Capital Health Plan, a regional health insurance company; dLife; DiabetesDaily; Cleveland Clinic; LifeScan; Kraftdiabetes; and Splenda. The only websites found bookmarked by multiple participants are dLife and American Diabetes Association. These are both resources that are included in the list of resources provided by the diabetes educators.

Items that were found but in limited quantities include digital glucose meters (n = 9, 3.0%), nutritional information pamphlets (n = 5, 1.7%), prescription information (n = 5, 1.7%), lab reports (n = 4, 1.3%), popular magazines (n = 4, 1.3%), diet information (n = 3, 1.0%), exercise videos (n = 3, 1.0%), notebooks (n = 3, 1.0%), and calendars n = 2, 0.7%). Note that the results show multiples in instances that were not expected, but not in others. Specifically, Renee had two digital glucose meters used for testing her glucose. She had recently acquired the second meter from her insurance company, but was slowly changing over from using her older meter. She still had testing strips that could be used with the older meter that she wanted to use up, but she was also testing a bit with the new meter to get used to it. Participants who kept lab reports and prescription drug information sheets mainly kept one copy of prescription drug information sheets: often the original document from when the prescription was first filled. As for lab reports, most of the participants were only recently diagnosed and had not had follow-up tests. The magazine titles found in participants’ homes that are specific to diabetes include: Diabetes Health Monitor; Diabetes Focus; and Diabetic Living: Diabetes What to Eat. Magazines that are not specific to diabetes, but are used for recipes and exercise advice include: Eating Well; Health Magazine; and Rachel Ray.

4.3.1 Ancillary Findings with Regard to Kept Personal Health Information Items

In addition to the data that were collected to address the posed research questions, data were collected regarding when the information items were acquired (Table 16) and where the participants acquired the items (Table 16). Although, participants did not recall when some of the items were acquired (n = 78, 26%) – specifically, recipes (n = 74) collected by Renee from various magazines and websites - slightly more than one-tenth of the items were collectively acquired in the week prior to data collection (n = 6, 2.0%) and the previous month (n = 29, 9.7%). The number of newly acquired items seems fairly low given the majority of participants (n = 15) were diagnosed fairly recently. Nearly as many items (n = 76, 25.3%) were collected in
the past year. Slightly more than one-tenth of the items were collectively acquired in the week prior to data collection (n = 6, 2.0%) and the previous month (n = 29, 9.7%).

Table 16. Acquisition time of information items.

<table>
<thead>
<tr>
<th>When</th>
<th>F</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>past week</td>
<td>6</td>
<td>2.0</td>
</tr>
<tr>
<td>past month</td>
<td>29</td>
<td>9.7</td>
</tr>
<tr>
<td>past year</td>
<td>76 (includes 28 handouts from Kay)</td>
<td>25.3</td>
</tr>
<tr>
<td>&gt; year ago</td>
<td>44</td>
<td>14.7</td>
</tr>
<tr>
<td>don't recall</td>
<td>78 (includes 74 recipes from Renee)</td>
<td>26.0</td>
</tr>
<tr>
<td>at diagnosis</td>
<td>30</td>
<td>10.0</td>
</tr>
<tr>
<td>in class</td>
<td>32</td>
<td>10.7</td>
</tr>
</tbody>
</table>

4.3.1.1 Source. As for the source of the kept and used health information items (Table 17), the majority of items (n = 179, 59.7%) were personally acquired. Note that Renee kept a large number of individuals recipes (n = 75). Taking this into account, the participants themselves still personally procured the majority of kept items. Participants selected these items from various locations, including book stores, racks of magazines in pharmacy aisles, check-out lines in grocery stores, and from storage of reference material at locations of work of participants who worked in healthcare. Equal numbers of items were provided by diabetes educators (n = 42, 14%) and health care providers, i.e., nurses and physicians combined (n = 42, 14%). Note that diabetes educators provided 15 items per participant (n = 21; total items = 315). This includes handouts (n = 210) and slide copies (n = 105). Participants frequently stated during the interviews that they found the materials supplied by the diabetes educators to be useful, especially during class. However, the results show that they used a fraction of the items (n = 42; 13.3%) outside of class.

Table 17. Acquisition source of information items.

<table>
<thead>
<tr>
<th>Source</th>
<th>Qty</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self</td>
<td>179</td>
<td>59.7</td>
</tr>
<tr>
<td>Diabetes educator</td>
<td>42</td>
<td>14.0</td>
</tr>
<tr>
<td>Nurse, nurse practitioner</td>
<td>27</td>
<td>9.0</td>
</tr>
</tbody>
</table>
4.3.1.2 Usefulness. Participants were asked to indicate on a score of one (low) through ten (high), the usefulness of each kept item with regard to managing life with diabetes. These scores were compiled and averaged for each category of item. Many participants made comments indicating that if an item were used, it was useful, and therefore had difficulty assigning a score. Many participants dealt with this difficulty by assigning mostly high scores. However, other participants provided scores that led to some range in usefulness of item categories (Table 18). The items that were considered most useful were lab reports (mean score, median, and mode = 10; SD = 0). This category was closely followed by recipes (mean score = 9.8, SD = 0.4, median and mode = 10), nutritional pamphlets (mean score = 9.6, SD = 0.9, median and mode = 10), calendars (mean score = 9.5, SD = 0.7, median = 9.5, no mode), notebooks (mean score = 9.5, SD = 0.9, median and mode = 10), meters (mean score = 9.25, SD = 1.8, median and mode = 10), and diabetes specific magazines (mean score = 9.1, SD = 1.3, median = 9, mode = 10). The least useful item was the exercise video (mean score = 6, SD = 3.5, median = 4, mode = 4).

Table 18. The usefulness of the information items kept in the homes of adults with Type 2 diabetes.

<table>
<thead>
<tr>
<th>Information Items</th>
<th>Usefulness Mean</th>
<th>Median</th>
<th>Mode</th>
<th>S.D.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Printed reports of lab report</td>
<td>10</td>
<td>10</td>
<td>10</td>
<td>0</td>
</tr>
<tr>
<td>Recipe</td>
<td>9.8</td>
<td>10</td>
<td>10</td>
<td>0.4</td>
</tr>
</tbody>
</table>

Table 17 – continued.

<table>
<thead>
<tr>
<th>Source</th>
<th>Qty</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physician</td>
<td>15</td>
<td>5.0</td>
</tr>
<tr>
<td>Friends, neighbors, coworkers, acquaintances, other patients,</td>
<td>13</td>
<td>4.3</td>
</tr>
<tr>
<td>Pharmacist</td>
<td>8</td>
<td>2.7</td>
</tr>
<tr>
<td>Information from insurance company</td>
<td>7</td>
<td>2.3</td>
</tr>
<tr>
<td>Family, including family members with diabetes</td>
<td>6</td>
<td>2.0</td>
</tr>
<tr>
<td>Information from pharmaceutical company, drugstore, medication supplier</td>
<td>2</td>
<td>0.7</td>
</tr>
<tr>
<td>Booklets, brochures, etc., from clinic or health professionals</td>
<td>1</td>
<td>0.3</td>
</tr>
</tbody>
</table>
Table 18 - continued.

<table>
<thead>
<tr>
<th>Information Items</th>
<th>Usefulness Mean</th>
<th>Median</th>
<th>Mode</th>
<th>S.D.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nutritional information pamphlet, fast foods</td>
<td>9.6</td>
<td>10</td>
<td>10</td>
<td>0.9</td>
</tr>
<tr>
<td>Calendar</td>
<td>9.5</td>
<td>9.5</td>
<td>-</td>
<td>0.7</td>
</tr>
<tr>
<td>Notebook</td>
<td>9.5</td>
<td>10</td>
<td>10</td>
<td>0.9</td>
</tr>
<tr>
<td>Meters</td>
<td>9.25</td>
<td>10</td>
<td>10</td>
<td>1.8</td>
</tr>
<tr>
<td>Diabetes specific magazines (e.g., <em>Diabetes Forecast</em>)</td>
<td>9.1</td>
<td>9</td>
<td>10</td>
<td>1.3</td>
</tr>
<tr>
<td>Log</td>
<td>8.7</td>
<td>10</td>
<td>10</td>
<td>2.1</td>
</tr>
<tr>
<td>Internet site (name or URL)</td>
<td>8.6</td>
<td>8.5</td>
<td>10</td>
<td>1.7</td>
</tr>
<tr>
<td>Medicine information sheet</td>
<td>8</td>
<td>8</td>
<td>10</td>
<td>2.1</td>
</tr>
<tr>
<td>Handout</td>
<td>7.8</td>
<td>8</td>
<td>8</td>
<td>1.7</td>
</tr>
<tr>
<td>Book (other than phone- or cook book)</td>
<td>7.7</td>
<td>8</td>
<td>10</td>
<td>2.2</td>
</tr>
<tr>
<td>Diet information</td>
<td>7.7</td>
<td>8</td>
<td>-</td>
<td>1.5</td>
</tr>
<tr>
<td>Self-care brochure</td>
<td>7.1</td>
<td>8</td>
<td>8</td>
<td>2.5</td>
</tr>
<tr>
<td>Cook book</td>
<td>6.9</td>
<td>8</td>
<td>8</td>
<td>2.1</td>
</tr>
<tr>
<td>Popular magazine</td>
<td>6.25</td>
<td>3, 6</td>
<td>6</td>
<td>2.9</td>
</tr>
<tr>
<td>Exercise video</td>
<td>6</td>
<td>4</td>
<td>4</td>
<td>3.5</td>
</tr>
</tbody>
</table>

4.3.1.3 Kept items not used. This study focused on the items that participants kept in the home and used. However, the study’s methods also provided insight into the items that were kept and not used. These items were categorized and counted for informational purposes (Table 19). The majority of items found that were not used (n = 126, 31.0%) were handouts and slides (n = 97, 23.8%) provided by the diabetes educators, as well as self-care brochures (n = 81, 19.9%) provided by health care providers. There were also items that tended to be personally obtained, including: diet information (n = 19, 4.7%); books (other than phone book or cook book), e.g., *The Merck Manual of Medical Information*; *Biggest Loser Calorie Counter*; and *The Carbohydrates Addicts Healthy Heart* (n = 18, 4.4%); nutritional information pamphlets (n = 16, 3.9%), e.g., *Prevention: Healing with Chocolate*; Supplement to Reader's Digest: Taking Control of Diabetes Meal Planning Guide; and *AmMedDirect: Diabetes Care*; Diabetes specific
Magazines (e.g., Diabetes Forecast and Diabetes Self-Management) (n = 12, 2.9%); and cookbooks (n = 12, 2.9%), e.g., The Diabetes Detour Diet; The Art of Cooking for the Diabetic; Desserts for Diabetics; American Dietetic Association: The New Soul Food; and Betty Crocker's Diabetes Cookbook.

Table 19. Count of the types of unused items kept in the homes of adults with Type 2 diabetes.

<table>
<thead>
<tr>
<th>Category</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Handout</td>
<td>126</td>
<td>31.0</td>
</tr>
<tr>
<td>Slides</td>
<td>97</td>
<td>23.8</td>
</tr>
<tr>
<td>Self-care brochure</td>
<td>81</td>
<td>19.9</td>
</tr>
<tr>
<td>Diet information</td>
<td>19</td>
<td>4.7</td>
</tr>
<tr>
<td>Book (other than phone- or cook book)</td>
<td>18</td>
<td>4.4</td>
</tr>
<tr>
<td>Nutritional information pamphlet, fast food</td>
<td>16</td>
<td>3.9</td>
</tr>
<tr>
<td>Cook book</td>
<td>12</td>
<td>2.9</td>
</tr>
<tr>
<td>Diabetes-specific magazine</td>
<td>12</td>
<td>2.9</td>
</tr>
<tr>
<td>(e.g., Diabetes Forecast or Diabetes Self-Management)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Log</td>
<td>6</td>
<td>1.5</td>
</tr>
<tr>
<td>Meter</td>
<td>4</td>
<td>1.0</td>
</tr>
<tr>
<td>Internet site (name or URL)</td>
<td>4</td>
<td>1.0</td>
</tr>
<tr>
<td>Printed report of lab report</td>
<td>3</td>
<td>0.7</td>
</tr>
<tr>
<td>Medicine information sheet</td>
<td>3</td>
<td>0.7</td>
</tr>
<tr>
<td>Smartphone app</td>
<td>2</td>
<td>0.5</td>
</tr>
<tr>
<td>Recipe</td>
<td>2</td>
<td>0.5</td>
</tr>
<tr>
<td>Audiotape</td>
<td>1</td>
<td>0.2</td>
</tr>
<tr>
<td>Diabetic alert bracelet information</td>
<td>1</td>
<td>0.2</td>
</tr>
<tr>
<td>TOTAL</td>
<td>407</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

4.4 The Role of Personal Context (RQ2)

The second research question aimed to address, “What role does personal context play in the presence of kept personal health items?” This question sought to identify whether factors of personal context are associated with kept personal health items. Prior to gaining information about kept items, participants were asked to provide demographic and descriptive information
(Appendix H), including items such as typical demographic questions, as well as information specific to their diabetes diagnosis and treatment. Demographics could be considered the context in which information behaviors occur. Given the qualitative nature of this study, demographic data available to address this question is limited to a small sample (n = 21). However, results with regard keeping behaviors based on gender, age, health status, and diabetes duration are provided herein (Table 20). Living with Type 2 diabetes is a personal experience, however. Therefore, the results also include participants’ descriptions of their lives. These descriptions offer rich context of individual stories that include information pertaining to hobbies and interest. Analysis of these descriptions show that several themes of context emerged from the self-descriptions: activity, level of challenge, and adjustment (Tables 21 and 22).

4.4.1 Context with Regards to Gender, Age, Diagnosis Duration, and Health Status

As presented previously in Table 13, the mean age of the participants was 60 years, and the majority of participants were insured, married, employed, white/Caucasian females who lived in Leon County and were new to diabetes. They also have others in the family, living or deceased, with diabetes and control their diabetes primarily using medication.

The results show (Table 20) that, overall, women (n = 15, 71.4%) kept and used more information items than men (n = 6, 28.6%). The participants’ self-reported health status, independent of gender, did not seem to have any bearing on the number of items that had been kept and used. Specifically, the results show that over half of the participants (n = 11, 52.4%, women = 8, 72.7%) kept and used five - ten items. Over half of these respondents (n = 7, 63.7%) were 55+ years and over half (n =6, 54.5%) described their health as average. Nearly one-quarter of the participants (n = 5, 24%), nearly equally divided between men (n = 2, 40%) and women (n = 3, 60%), kept and used less than five items. These participants varied in age and reported health levels ranging across the spectrum. The remaining participants (n = 5, 23.8%) kept and used 20+ items, including Renee and Kay, who could be considered “outliers” in that they kept many more items than other participants. Renee kept and used a large number of recipes (n = 54) and Kay kept and used a large number of handouts (n =28). As discussed earlier, Renee’s items were recipes that had been clipped from magazines and emails over a period spanning more than five years since her diagnosis. Kay had received her handouts during the previous year when they had been given to her husband who was diagnosed with diabetes during a hospital stay. The
other participant in this 20+ item category is Jack. He, like Kay, had been diagnosed less than three months prior to the interview. While Kay is married with her kids out of the home, Jack is divorced with children living in the home. Jack had personally sought the information items he kept, whereas Kay had received her handouts from her husband’s physician during a hospital visit.

Table 20. Number of items per gender/age/health status/diagnosis duration.*

<table>
<thead>
<tr>
<th>Health of Item: Range</th>
<th>≤5</th>
<th>6 - 10</th>
<th>11 - 20</th>
<th>21 - 50</th>
<th>&gt;50</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>FEMALE</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>35-44 years</td>
<td>1</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Avg ≤3mos</td>
<td>1</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td>2</td>
</tr>
<tr>
<td>45-54 years</td>
<td>1</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Avg ≤3mos</td>
<td>1</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td>2</td>
</tr>
<tr>
<td>55-64 years</td>
<td>1</td>
<td>6</td>
<td>1</td>
<td>1</td>
<td>9</td>
<td></td>
</tr>
<tr>
<td>L 6 - 12 mos</td>
<td>1</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td>2</td>
</tr>
<tr>
<td>Avg ≤3mos</td>
<td>3</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td>4</td>
</tr>
<tr>
<td>Avg 6 - 12 mos</td>
<td>1</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td>2</td>
</tr>
<tr>
<td>Avg &gt; 5 yrs</td>
<td>1</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td>2</td>
</tr>
<tr>
<td>H ≤3mos</td>
<td>2</td>
<td>1</td>
<td>1</td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>≥65 years</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>1</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Avg ≤3mos</td>
<td>1</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td>2</td>
</tr>
<tr>
<td>Avg &gt; 5 yrs</td>
<td>1</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td>2</td>
</tr>
<tr>
<td>H ≤3mos</td>
<td>1</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td>2</td>
</tr>
<tr>
<td>not stated</td>
<td>3 - 6 mos</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>MALE</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>45-54 years</td>
<td>1</td>
<td>1</td>
<td></td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Avg ≤3mos</td>
<td>1</td>
<td>1</td>
<td></td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>55-64 years</td>
<td>2</td>
<td>2</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Avg ≤3mos</td>
<td>1</td>
<td>1</td>
<td></td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>H ≤3mos</td>
<td>1</td>
<td>1</td>
<td></td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>≥65 years</td>
<td>1</td>
<td>1</td>
<td></td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Avg ≤3mos</td>
<td>1</td>
<td>1</td>
<td></td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Avg &gt; 5 yrs</td>
<td>1</td>
<td>1</td>
<td></td>
<td>1</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 20 – continued.

<table>
<thead>
<tr>
<th>Health</th>
<th>F of Item: Range</th>
<th>≤5</th>
<th>6 - 10</th>
<th>11 - 20</th>
<th>21 - 50</th>
<th>&gt;50</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>≥65 years</td>
<td>Avg ≤3mos</td>
<td>1</td>
<td>1</td>
<td>2</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Avg &gt; 5 yrs</td>
<td>1</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female Total:</td>
<td>3 (20%)</td>
<td>8 (53%)</td>
<td>3 (20%)</td>
<td>1 (7%)</td>
<td>15</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male Total:</td>
<td>2 (33%)</td>
<td>2 (33%)</td>
<td>1 (17%)</td>
<td>1 (17%)</td>
<td>6</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Grand Total:</td>
<td>5 (24%)</td>
<td>10 (48%)</td>
<td>1 (5%)</td>
<td>4 (19%)</td>
<td>1 (5%)</td>
<td>21</td>
<td></td>
</tr>
</tbody>
</table>

* Health Status: was scored on range of 1-7, and then categorized as Low (L) = 1&2; Average (Avg) = 3-5; High (H) = 6&7

4.4.2 Themes of Personal Context

During the analysis of the participants’ descriptions of their lives, which included descriptions hobbies, interests, and living with diabetes, several themes emerged, specifically: activity, adjustment, challenge of living with diabetes, and emotion. These themes are described herein, alongside statements that were used to develop the themes, as well as several examples.

4.4.2.1 Activity. Several participants (n = 8, 38.1%) indicated on their questionnaire that they managed their diabetes using exercise. Details of the participants’ descriptions of their life and interests support this. Specifically, the hobbies listed by participants (Table 21) show various activities, including: Rumba class (Arlene) or dancing (Mona); exercise (Dan); walking (Adam, Alan, Arlene, Jack, and Lisa); kayaking; and hiking (Emily). Other participants list less rigorous activities, but these activities help keep the participants moving, e.g., gardening (Mary and Sue) and yard work (Adam and Alan). Other participants list activities that are not as much exercise that work muscle or the cardiovascular system, but are gentle activities that would promote stress reduction, e.g., carpentry and woodworking (John and Louis); sewing (Sue); and fishing (Jack). The participants’ awareness of the importance of activity, or the lack thereof, was best summarized by Jack: He was

“in good health and active until ... [I was] injured and laid off in 2006. Lack of mobility has helped to ... bring this diabetes into my life.”
Mona, however, summarized the feelings of several when she described her life as a cycle of “food preparation, exercise time, difficult to discipline myself.” This statement reflects the difficulty experienced by those who had not been previously active; they often found it difficult to add activity to a routine that had to change in other ways.

Table 21. The theme of Activity which emerged from the rich self-descriptions that were provided by the study participants.

<table>
<thead>
<tr>
<th>Activity emerge as part of diabetes management</th>
<th>Participant</th>
<th>F Items</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>hunting, fishing, swimming, walking, &amp; hiking</td>
<td>Jack</td>
<td>21</td>
<td>7.0</td>
</tr>
<tr>
<td>gym, woodworking, garden</td>
<td>John</td>
<td>11</td>
<td>3.7</td>
</tr>
<tr>
<td>walk, yard work</td>
<td>Alan</td>
<td>9</td>
<td>3.0</td>
</tr>
<tr>
<td>carpentry, programming</td>
<td>Louis</td>
<td>9</td>
<td>3.0</td>
</tr>
<tr>
<td>kayaking, hiking</td>
<td>Emily</td>
<td>9</td>
<td>3.0</td>
</tr>
<tr>
<td>reading, gardening, cooking, and a little board games</td>
<td>Mary</td>
<td>8</td>
<td>2.7</td>
</tr>
<tr>
<td>walking, reading, yard work</td>
<td>Adam</td>
<td>6</td>
<td>2.0</td>
</tr>
<tr>
<td>dancing, sewing, reading</td>
<td>Mona</td>
<td>6</td>
<td>2.0</td>
</tr>
<tr>
<td>walking, Nascar, grandkids</td>
<td>Lisa</td>
<td>6</td>
<td>2.0</td>
</tr>
<tr>
<td>genealogy, sewing, quilting, reading, gardening</td>
<td>Sue</td>
<td>6</td>
<td>2.0</td>
</tr>
<tr>
<td>Exercise</td>
<td>Dan</td>
<td>4</td>
<td>1.3</td>
</tr>
<tr>
<td>walking, singing, rumba class</td>
<td>Arlene</td>
<td>2</td>
<td>0.7</td>
</tr>
</tbody>
</table>

**TOTAL**                                           | **97**      | **29.4** |

The theme of activity demonstrates a context in which information items were kept and used, but a participant’s lifestyle that includes activity does not seem to indicate the number of items that a participant kept (Table 22). Specifically, participants who were active were found to have anywhere between 2 and 21 (0.7% - 7.0% of total items n = 300) items in the home. The participants who stated they used activity to help manage life with diabetes kept less than one-third of the total number of items reported by all participants (n = 97, 29.4%). The activities listed by participants range in intensity level, from sewing and fishing to rumba (dance class) and hiking.
4.4.2.2 Adjustment. A second theme that emerged from participants’ descriptions of their context in living with diabetes is that the diagnosis of diabetes prompted some to simply view life as “different” (Kathy), while others were further compelled to act upon this changed view and recognize there was a need for life adjustments (Table 23). While participants did not make statements made about adjustments in activity, they did make comments about the diabetes education session where they had to walk for 5 – 10 minutes between blood tests. They were very surprised how much the activity had affected their sugar readings. The adjustment often discussed was the need to make changes to diet. Carla summarized this group consensus in her statement that “Not much has changed except diet.” Kay also indicated her need to make diet adjustments in that she found it to be “hard to give up sweets,” while Sarah clearly stated that food changes were her most challenging adjustment:

“My biggest challenge since my recent diagnosis has been knowing what I can eat...Learning to use the information on nutritional labels is literally a life saver.”

Participants also talked about adjustments when speaking about their life in general. Sue stated that she sees the need for adjustment is many aspects of her life and said that her life is “completely changed” and that she “can no longer be impulsive.” Sue had begun her journey post-diabetes diagnosis with this feeling, and it had led her directly to the book store. Her main thought that haunted her as she left the doctor’s office was that the next meal would kill her. She was looking for books to help figure out what to eat until she heard from the diabetes educators.

Others are making adjustments in changing life style with various goals in mind. For example, Arlene wants to be “medicine free,” while Lisa, a mother with a teenaged daughter and government project manager, currently views her life as “rough,” and wants to “learn everything about diabetes.” Lisa’s desire to learn much about diabetes is not readily apparent in the number of items she keeps in her home (n = 6, 2.0% of total items reported by participants), however. The participants may readily see that they need to make adjustments to manage life with diabetes, but they do not find it easy to make the adjustments. Louis demonstrates this difficulty in his description that “[it takes] lots of work right now to control it. [It is] a bit of a pain, but [I] hope things smooth out.” He shows determination in making adjustments though, as he stated the he wants to “kick diabetes in the butt.” Many participants talked about the changes they are making or the goals they have, but Sandy was at a place in treatment where she evaluated her life...
at its current state and compared it to the time before treatment. Before her diagnosis, she was “very tired and just felt bad before.” “She now feels “so much better.” She did not dwell on adjustments, but the juxtaposition of the pre-diagnosis and post-treatment evaluations indicate there was a change.

Table 22. The theme of Adjustment which emerged from the rich self-descriptions that were provided by the study participants.

<table>
<thead>
<tr>
<th>Need for Adjustment emerges as part of diabetes management</th>
<th>Participant</th>
<th>F Items</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Have a goal (in reference to being healthy), but struggle to get there</td>
<td>Renee</td>
<td>94</td>
<td>31.3</td>
</tr>
<tr>
<td>Hard to give up sweets, but try to eat in moderation and count carbs.</td>
<td>Kay</td>
<td>28</td>
<td>9.3</td>
</tr>
<tr>
<td>“Since being diagnosed and treated I feel so much better. I was very tired and just felt bad before.”</td>
<td>Sandy</td>
<td>10</td>
<td>3.3</td>
</tr>
<tr>
<td>“Lots of work right now to control it. [It is] a bit of a pain, but hope things smooth out.” He wants to “kick diabetes in the butt.”</td>
<td>Louis</td>
<td>9</td>
<td>3.0</td>
</tr>
<tr>
<td>“Not much has changed except diet.” She has a goal to be healthy, but struggles to get there</td>
<td>Carla</td>
<td>8</td>
<td>2.7</td>
</tr>
<tr>
<td>Completely changed.</td>
<td>Sue</td>
<td>6</td>
<td>2.0</td>
</tr>
<tr>
<td>Describes life as “rough,” but wants to “learn everything about diabetes”</td>
<td>Lisa</td>
<td>6</td>
<td>2.0</td>
</tr>
<tr>
<td>Seems like you have to always watch &amp; think about what you eat. Hate to see high #s on my meter.</td>
<td>Suzanne</td>
<td>5</td>
<td>1.7</td>
</tr>
<tr>
<td>Describes life as “different” She loves to cook...mostly desserts, cakes, and pies. “That is having to change.”</td>
<td>Kathy</td>
<td>3</td>
<td>1.0</td>
</tr>
<tr>
<td>I'm working on being medicine free</td>
<td>Arlene</td>
<td>2</td>
<td>0.7</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>171</strong></td>
<td><strong>57.0</strong></td>
<td></td>
</tr>
</tbody>
</table>

The number of health information items reported as used (Table 22) with regard to the theme of adjustment is fairly consistent across those who sense the need for adjustment and those who report very little. Participants (n = 9, 43%) who discussed learning to manage life with diabetes required adjustments in life, reported more than half of the items that were kept and
used (n = 171, 57%). The greatest number of items (n = 94, 31.3%) were kept by Renee, the
government worker who had lived with diabetes for 10+ years, but was recently sent for diabetes
education after experiencing complications. Renee’s sense of adjustment is implicit in her
statement that she struggles to reach her goals for health. Sandy, who focused on the current
improved status of health, reported that she used 10 items (3.3% of total items reported by
participants). Carla, who reported that she felt her life was unchanged, except for diet, reported 8
items (2.7%), while Sue who felt life was completely changed reported using 6 items (2.0%).
Lisa, who is goal-oriented and working to be medicine free, reported using 2 items (0.7%).

4.4.2.3 Living with diabetes: Challenge. Several participants described their personal
life following the Type 2 diabetes diagnosis with phrases that reflect challenge (Table 23).
Arlene clearly stated that she found living life with diabetes to be “very challenging.” Sue was a
bit more circumspect, but described life as “completely changed.” She further explained that she
feels “like I can no longer be impulsive.” Others took to describing their lives with diabetes in
terms that indicate they found it challenging, e.g., Alan called it “stressful;” Janice described her
life as “scary;” and Jack said that he finds his life to feel “upside down, scary.” Lewis also
described a challenge, in that “life is a bit of a pain,” but he continued with a sense of optimism
in that he “hopes that things smooth out.” He wants to “kick diabetes in the butt.” Sarah was also
aware of challenges facing her, but also expressed optimism:

“My biggest challenge since my recent diagnosis has been knowing what I can
eat. It is encouraging that nowadays, the patient makes their own choices.
Learning to use the information on nutritional labels is literally a life saver.”

In contrast, Dan said that he now thinks that life is boring, but he is taking an enlightened
view and thinks that the key to life is to “see beyond one’s vision.”

The theme of challenge was also implicitly expressed in descriptions of various life
activities. For example, Mona said that she now spends much of her time in food preparation and
exercising, and that she finds it “difficult to discipline” herself. Sue’s description of the time that
immediately followed her diagnosis demonstrated an initial response that showed action in the
face of challenge. Specifically, she reacted to her diagnosis so strongly that she left the doctor’s
office, terrified that her next meal could kill her, and immediately went to the bookstore and
picked up eight books. Mona has lived with diabetes for several years, so could talk about
challenges she faced in learning to cook when the guidance was to modify recipes, rather than
modify portion sizes. She had purchased different cookbooks and tried different –“diabetic” - recipes, but she had recently gone back to using her regular cookbooks. During those years of trial, she and her family missed the traditional recipes. For her, the traditional meals were an important part of family gatherings so she kept trying unsuccessfully to make adjustments so she could eat the favorite desserts. The challenge of meals was also described by Jack. He frequently commented that “it's not fun” now that he cannot eat what he wants. He also has a hard time with the fact that the portion dictates what is good; for instance, “fifteen grapes isn't worth it.”

Table 23. The theme of Challenge which emerged from the rich self-descriptions that were provided by the study participants.

<table>
<thead>
<tr>
<th>The notion of the Challenge of living with diabetes emerges as part of diabetes management</th>
<th>Participant</th>
<th>F Items</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hard to give up sweets, but try to eat in moderation and count carbs.</td>
<td>Kay</td>
<td>28</td>
<td>9.3</td>
</tr>
<tr>
<td>Stated that her “biggest challenge since my recent diagnosis has been knowing what I can eat. It is encouraging that nowadays, the patient makes their own choices. Learning to use the info on nutritional labels is literally a life saver.”</td>
<td>Sarah</td>
<td>24</td>
<td>8</td>
</tr>
<tr>
<td>Lots of work right now to control it. A bit of a pain, but hope things smooth out. I want to kick diabetes in the butt.</td>
<td>Jack</td>
<td>9</td>
<td>3</td>
</tr>
<tr>
<td>Stated that it is “difficult to discipline myself.”</td>
<td>Mona</td>
<td>6</td>
<td>2</td>
</tr>
<tr>
<td>Rough</td>
<td>Renee</td>
<td>6</td>
<td>2</td>
</tr>
<tr>
<td>Describes life as “boring” but feels [he is] to learn to “see beyond one's vision”</td>
<td>Dan</td>
<td>4</td>
<td>1.3</td>
</tr>
<tr>
<td>very challenging</td>
<td>Arlene</td>
<td>2</td>
<td>0.7</td>
</tr>
<tr>
<td>TOTAL</td>
<td></td>
<td>88</td>
<td>29.3</td>
</tr>
</tbody>
</table>

The number of items kept and used by participants who expressed that living life with diabetes was challenging ranged from two items that were kept by Arlene who rated life as “very challenging” to 28 items that were kept by Kay who stated she found it difficult to give up sweets. Many of the items that Kay had in her home were given to her husband when he was
diagnosed with diabetes. She had not actively sought the items. Arlene also had not sought her items. She is a postal worker and said that she sees enough paper during her day. She throws away any paper item as quickly as possible. The items she kept were given to her by the diabetes center.

4.4.2.4 Emotion. The participants were not asked specifically about the time surrounding their diagnosis or the emotions that they may have experienced, but these stories frequently emerged and some participants specifically described strong emotions that they experienced. The number of information items discussed in the context of emotion (Table 24) is two-thirds of the sample (n = 200, 66%). While several spoke of calm acceptance, others expressed negative emotions, including disappointment, stress, and worry. June was the most adamant about her negative view of living life with diabetes. Specifically, she stated that she is unhappy and angry. While the number of items and the items kept (n = 28, 9.3%) reflect her frustration in figuring out how to modify recipes and what recipes work in managing life with diabetes, they did not directly indicate the anger and unhappiness she explicitly discussed. The contexts of worry and stress were described by participants who kept both minimal number of items (n each for Mona and Lisa = 6, 2.0%) and higher quantities (n for Renee = 94, 31.3% for worry; n for Jack = 21, 7.0% for stress). Further description of the emotional responses described during the interviews is provided herein.

Table 24. The theme of Emotion which emerged from the rich self-descriptions that were provided by the study participants.

<table>
<thead>
<tr>
<th>The notion of the Emotion of living with diabetes emerges as part of diabetes management</th>
<th>Participant</th>
<th>Emotion</th>
<th>F Items</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>“Lots of work right now to control it. A bit of a pain, but hope things smooth out. I want to kick diabetes in the butt.”</td>
<td>Louis</td>
<td>Acceptance</td>
<td>9</td>
<td>3</td>
</tr>
<tr>
<td>Describes life as “stressful”</td>
<td>Dan</td>
<td>Acceptance</td>
<td>9</td>
<td>3</td>
</tr>
<tr>
<td>Daughter and friends with diabetes</td>
<td>Mary</td>
<td>Acceptance</td>
<td>8</td>
<td>2.6</td>
</tr>
<tr>
<td>Asked friends who are doctors for advice</td>
<td>Alan</td>
<td>Acceptance</td>
<td>5</td>
<td>1.7</td>
</tr>
</tbody>
</table>
Table 24 - continued

<table>
<thead>
<tr>
<th>The notion of the Emotion of living with diabetes emerges as part of diabetes management</th>
<th>Participant</th>
<th>Emotion</th>
<th>F Items</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Implied though calm discussion</td>
<td>Kathy</td>
<td>Acceptance</td>
<td>3</td>
<td>1.0</td>
</tr>
<tr>
<td>Describes life as “unhappy, angry”</td>
<td>June</td>
<td>Anger</td>
<td>28</td>
<td>9.3</td>
</tr>
<tr>
<td>Wants to be here [in the future] for her daughter who is five-years old</td>
<td>Arlene</td>
<td>Disappointment</td>
<td>2</td>
<td>0.7</td>
</tr>
<tr>
<td>“Seems like you have to always watch &amp; think about what you eat. Hate to see high #'s on my meter.”</td>
<td>Renee</td>
<td>Worry</td>
<td>94</td>
<td>31.3</td>
</tr>
<tr>
<td>Describes life as “upside down, scary.”</td>
<td>Jack</td>
<td>Stress</td>
<td>21</td>
<td>7</td>
</tr>
<tr>
<td>Panic attack</td>
<td>Janice</td>
<td>Stress</td>
<td>9</td>
<td>3</td>
</tr>
<tr>
<td>Stressful</td>
<td>Mona</td>
<td>Stress</td>
<td>6</td>
<td>2</td>
</tr>
<tr>
<td>Rough</td>
<td>Lisa</td>
<td>Worry</td>
<td>6</td>
<td>2</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>200</strong></td>
<td><strong>66</strong></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**4.4.2.4.1 Disappointment.** Arlene was the sole participant who expressly stated that she was very disappointed with herself when she received her diagnosis of diabetes and hypertension. She started the interview describing the struggles she had faced as a single mother of two young girls, and then told of the pain she lived through recently when one daughter died at the age of two years. She was all too aware of the possibility that life can be short. But then, to add to her stress, she was diagnosed with diabetes. She misses her youngest, but she also lives for her living five-year old daughter. Arlene wants to stay healthy to ensure she will be here for her in the future.

**4.4.2.4.2 Worry.** Lisa’s mother was diagnosed with diabetes when Lisa was in high school, which is about the same age as Lisa’s daughter. Her mother took two insulin injections a day, but did not monitor or adjust her diet and ended up with double amputations. Lisa draws comparisons to her mother, but does NOT (emphasis hers) want to end up like her mother, so she worries if she is doing enough. Her worry is compounded by her concern for her daughter’s possibility of diagnosis and the need to manage the stress from her job. Renee, a near-retirement
age government services director who kept 94 items (31.3%), including 75 recipes (79.8% of the kept items), also displayed worry. She began the interview objectively talking about managing her life with diabetes. However, when she began to talk about her father’s experience with diabetes, tears began to flow. These tears clearly indicated loss, but given they continued as she described his end of life journey and the connection to diabetes, they were also perhaps tied to worry. Near the end of her father’s life, his “sugar readings” were in the range of 400 and he was wearing diabetic shoes. She tearfully concluded her story with: “he got congestive heart failure and died.”

4.4.2.4.3 Stress. Several participants also described feelings of extreme stress when they learned they were receiving a diagnosis of diabetes. When Jack learned that he had high triglycerides and high cholesterol, he was “upset.” This was said as he paced around the room. He elaborated on this basic description and added that the diabetes diagnosis nearly pushed him to tears. He explained that he was uninsured and quite upset about the life long implications of diabetes, especially as his two boys live with him and he does not consider his ex-wife to be supportive.

Janice, a single woman who had seen many people during her career working for the Federal Prison System who did not care for their diabetes and had ended up having amputations and blindness, was first angry when she received the diabetes diagnosis. Her anger quickly gave way to fear. She knew what complication of diabetes alone could mean, but she had been a heavy drinker, overweight, and sedentary. She worried about what damage had already been done. She said that she sees diabetes as a “silent killer.” She drew this conclusion, because her sugar was “off the chart” by the time she went to the doctor; her A1C was 15.9, while the optimal level is below 7.0. At the time of her diagnosis, she was given a glucometer and an insulin prescription. These items added to her fear. She described herself at that time as “so freaked out,” that she had a panic attack shortly after leaving the doctor’s office and ended up in the emergency room where she was given anti-anxiety medication.

Mona is a registered nurse and divorced mother of four older children; she works long hours, so has not been able to go to the gym regularly. She tested herself on a whim and when she realized that her values were at a critically high level, she went directly to the hospital. She described how she had watched diabetes ravage her dad and that he nearly needed double amputations. The University of Michigan hospital saved his limbs by using maggots to eat the
dead tissue, though. She says she has a hard time remembering to take her oral medications, and that she also finds it difficult to manage food. She is “rushed” in the morning and too tired at night to prepare dinner. She also finds it difficult to get to the gym. She knows what she needs to do, but she cannot seem to make the time to do it or to find a solution that will help her manage her life with diabetes.

4.4.2.4.4 Acceptance. Descriptions provided by several participants indicated that they reacted evenly to the diagnosis and were comfortable with the balance required to manage their life with diabetes. The participants described different contexts that may have promoted a rapid acceptance of the health diagnosis: spirituality; social networks; past health experiences. Dan exemplifies a spiritual context that may be connected to his calm acceptance. Dan is a business owner who created a business when he could not find work after a move from out of state. His description of this transition, a possible tumultuous time, was as calm as his description of his diabetes diagnosis and steps to manage it. This calm seemed to be explained when he ventured to discuss his spiritual views; he said views his diabetes as “the Universe's answer to [his] desire to be thinner.”

Personal connections seemed to help Mary and Alan accept a diabetes diagnosis from the outset. For Mary, her network of experience included that of both family and friends. Her granddaughter was diagnosed with Type 1 diabetes. Approximately eight years prior, when the granddaughter was about 13 years old, Mary retired from the Florida elementary school system where she had worked as a principal to begin helping caring for her. This assistance allowed Mary to become comfortable with various facets of managing diabetes. Mary also said that it seemed that almost all of her personal friends are diabetic and it is something that is discussed at times during frequent lunches and gatherings. Alan, an environmental engineer with a doctorate, has a lot of doctor friends whom he called immediately and discussed courses of action. He combined this medical advice with that of alternative management methods from friends with experience; he followed the suggestion of these lay people and increased his fiber intake. Overall, he was not perplexed by the diabetes diagnosis; he considered it a problem or challenge to address.

Past experiences, as Mary demonstrated, also seemed to help Emily and Louis accept the diabetes diagnosis. Emily, who had to wait 6-weeks for the diabetes education classes, did not worry at all, as she had had gestational diabetes “years ago.” She successfully managed it for the
last 6 weeks of her pregnancy. She was not unaware of possible complications of diabetes, as she knows someone who had two toes removed due to diabetes complications, but does not see herself in that position. This sense of “it won’t happen to me,” could possibly be connected to her focus on that her levels were "low for diagnosis.” Sandy had dealt with various health issues, i.e., fibromyalgia and gluten intolerance, before her diagnosis. Her mother and husband have Type 2 diabetes, so she “figured [she] would get it sometime.” This expectancy was also coupled with their examples of caring for themselves and complication-free experiences. Given this, although she has to be more creative in finding acceptable carbohydrates give her gluten intolerance, she does not worry about problems that may be associated with diabetes.

Louis is a very busy individual who is a programmer by career, carpenter by night – working to update a newly purchased house before they move in, and an involved family man with a son who has a development disorder that requires nutrition modification. The shelf of cookbooks and discussion of food and its effect on behavior demonstrated the family’s awareness of the importance and effect of food. Louis was not aware that he had been diagnosed with diabetes until he went to the diabetes center for his appointment and the educator told him that he had Type 2 diabetes. The doctor had only told him he had high blood sugar and high triglycerides. Louis had thought diabetes was a problem associated with insulin, so he did not make the connection between the doctor’s diagnosis of high blood sugar and an insulin problem, which Louis would then have equated to diabetes. Nonetheless, once the educator gave him the news, and he realized he was at the Diabetes Center for education, he was calm with the news and aware that he was getting help. Louis seemed by nature to be a calm person, so his response did not seem atypical. Part of his ability to take the news in stride may also have stemmed from his experience in parenting a child with special needs, who was present with Louis’ wife during the interview.

Kathy also portrayed seeming acceptance of her diabetes diagnosis, but the lack of concern may have had something to do with seeming memory issues. Kathy is a single woman who lives in an assisted living center. She had worked in the banking industry, retiring after 40 years. She had also worked in an elementary school cafeteria at some point during her life, which gave her some insight into and perspective of nutrition and food preparation. Prior to her diagnosis, she was aware that an uncle and great-aunt had lived with diabetes. Her great aunt had a foot amputated late in life as a result of diabetes complications. Kathy had been told for years
that she was pre-diabetic, but after surgery last fall she was told she needed to see a doctor to get her blood sugar checked again. The lab work done prior to the surgery showed extremely high A1C levels. She thought that this elevated level had previously occurred at least once. Prior to surgery and the recent blood work she had been receiving information about diabetes. She found the material provided by the diabetes educators to be useful, but she lives in an assisted living center where she meets with a dietitian/nurse once a month for guidance. Kathy discussed kept information items, but relied on her memory, which she described as “not good.” She has a hard time when things are moved, for example her shoes, as evidenced by her lack of shoes. She had greeted the researcher and promptly excused her shoeless feet, saying they were somewhere in the apartment. The center does have a dining hall, but she does not like the meals; “the meats have gravy and the vegetables are soft.” Although she had been working with the dietitian, she had not yet spoken to the cooks or identified better food choices when eating in the dining hall. Her apartment has a kitchen and she does cook, using a diabetes pamphlet to help her put meals together, but “the small kitchen kills her.” Her uncle and a great-aunt had diabetes. The aunt had to have a foot amputated, but not until she was much older. Kathy reported that she used only three health information items to help her manage life with diabetes, but had also sent away for a magazine, perhaps *Diabetes* magazine, using a card she had found in another magazine.

The individuals who managed life with diabetes within a context of acceptance kept similar number of items, ranging from five to nine. Arlene is the only participant who expressed disappointment, but she also kept the fewest items (n = 2, 0.7%). It could be thought that disappointment and low information keeping could be connected, but it is important to note that Arlene is a postal worker who does not like to keep paper in her home. She said that she has “enough of paper during my route.”

### 4.5 Use of Kept Personal Health Items (RQ3)

The third research question aimed to address, “What use was made of the personal health items that individuals keep with regard to living with diabetes?” Additionally, the study aimed to address the question of multiple uses attributed to kept health information items. In order to address these questions, participants were asked to describe how they had used the kept items. These uses were then categorized according to Song’s (2007) taxonomy and frequency totals were calculated. The results are depicted in Table 25.
The results show that participants kept and used a total of 300 items; some of these items were used for multiple instances. For example, the website DiabetesConnect was used to find recipes, but also to learn about medications. Therefore, the instances of use (n = 345) exceeds the number of items analyzed (n = 300). Analysis of item usage showed that the historical categories (Song, 2007) used to code use data, e.g., got understanding, able to plan, got skills, etc., (Table 26) fit the majority of data pertaining to item usage. In order to code all data, an additional category was needed to describe the uses of kept glucose and dietary logs. Therefore, the new usage category, “to monitor,” was developed.

Table 25. Uses of kept health information items.

<table>
<thead>
<tr>
<th>Use of Kept Item</th>
<th>F</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>got pictures, ideas, understandings</td>
<td>241</td>
<td>69.9</td>
</tr>
<tr>
<td>to monitor</td>
<td>32</td>
<td>9.3</td>
</tr>
<tr>
<td>able to plan</td>
<td>30</td>
<td>8.7</td>
</tr>
<tr>
<td>got started, got motivated</td>
<td>11</td>
<td>3.2</td>
</tr>
<tr>
<td>got skills</td>
<td>9</td>
<td>2.6</td>
</tr>
<tr>
<td>got control</td>
<td>7</td>
<td>2.0</td>
</tr>
<tr>
<td>kept going</td>
<td>6</td>
<td>1.7</td>
</tr>
<tr>
<td>got support, reassurance, confirmation</td>
<td>4</td>
<td>1.2</td>
</tr>
<tr>
<td>avoided a bad situation</td>
<td>2</td>
<td>0.6</td>
</tr>
<tr>
<td>reached a goal, accomplished things</td>
<td>1</td>
<td>0.3</td>
</tr>
<tr>
<td>went on to other things</td>
<td>1</td>
<td>0.3</td>
</tr>
<tr>
<td>got connected to other</td>
<td>1</td>
<td>0.3</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>345</strong></td>
<td><strong>100.1</strong></td>
</tr>
</tbody>
</table>

Examples of uses pertaining to this new category, “to monitor,” as well as others that accounted for at least 2.0% of the uses are described herein. The majority of uses attributed to the kept information items (n = 241, 69.9%) were categorized as allowing the participant to get “pictures, ideas, or understanding.” The categories “to monitor” (n = 32, 9.3%) and “able to plan” (n = 30, 8.7%) account for the next two highest number of uses. The remaining categories discussed herein each describe less than 5.0% of the uses: “got started, got motivated” (n = 11,
3.2%), “got skills” (n = 9, 2.6%), and “got control” (n = 7, 2.0%). Additionally, website items will be discussed with regard to the category “got connected to other.” There is only one item that was categorized using this label (n = 1, 0.3%), but this item was solely provided by the diabetes educator handouts. Whereas other categories included items from outside sources, this category demonstrates the use of information that is provided in preparation of an information need.

Note that Song’s (2007) taxonomy of information provided categories that were not used to categorize data collected during this study. These unused categories include: “got out of a bad situation,” “took mind off things,” “relaxed, rested,” and “got pleasure.”

4.5.1 Use: Got Pictures, Ideas, Understandings

The vast majority of kept health information items (n = 241, 70.1%) were used for the purpose of getting “pictures, ideas, understandings.” The types of items that helped participants develop an understanding of activities and needs associated with living with diabetes include class slides and handouts, books, website material, and magazines. The following examples are offered to show what reported uses of health information item were categorized as “to get pictures, ideas, understandings.”

Several participants reported the class handouts were instrumental in helping them understand what diabetes is and what is needed to manage life with diabetes. While all material covered in class was considered useful and important, the participants highlighted only a few items that they reported as used outside of class. Arlene, for example, identified the handout titled Short term Complications as useful. She said that this handout and “the instruction from the educators made her aware of what is a diabetic episode.” This handout was instrumental in giving her a foundation to help her “figure out how she feels when her blood sugar is low.” Kay said that the hand out of Fat Facts helped her understand which fats are better for her to eat. She explained that this means it is better to eat mono-saturated fats, while “trans-fats are bad.” She further explained that as a result of this information, she tries to eat salmon, tuna or halibut.

Several participants reported that books helped them gain an understanding about diabetes and management that is important. Sometimes this understanding came even when an item was used infrequently, as is the case described by Renee. Renee shared that she keeps the book, Eat This Not That: The No-Diet Weight Loss Solution, although she rarely uses it. The book is useful as it describes foods that make better choices. However, she keeps it because she
deems the message she gleaned as important: “stop and think about reading labels.” The book serves as a symbol and a reminder of this understanding.

Sue reported that the book, *Diabetes for Dummies*, was useful, because it provided information about diabetes using “simple” language. The book was especially helpful, because she wanted to learn all she could about diabetes as soon as she walked out of the doctor’s office. The doctor had told her that the diabetes center would call her to schedule an appointment for classes, but she did not know what that meant or how helpful they would be. She understood, but while she waited, she wanted a “life raft” and to learn about diabetes immediately. She wants an overall concept of the areas of concern, but she wanted something to help her in her immediate daily life. Therefore, she went to the local book store and bought this book with several others. She found that for someone not educated in diabetes, the simplified material made it a lot easier. She says this book in particular gave her the quickest way to get her “there” (to understanding).

Several participants had copies of the book, *The Calorie King*. The diabetes educators recommend this book early in the sessions and several participants who had not already purchased a copy said they planned to. The participants who had the book found it useful in helping them understand the content of food. For example, Dan said that he uses the book to help him make food choices; he will alter food selection based on the information in the books.

*Diabetes* specific magazines were not prevalent in participants’ homes, but participants who kept them reported uses that were categorized as providing understanding. For example, Lisa kept a special issue of *Woman's World*, entitled *Dr. Oz's Metabolism Makeover*. She had spotted the magazine in the grocery store before she was even diagnosed and picked it up on impulse. Interestingly, the magazine cover displays a Thanksgiving meal and pie. Post-hoc analysis found an article (O'Connor, 2011) that describes this magazine as conflicted, in that its cover regularly presents health story titles juxtaposed against pictures of desserts, such as pie or cupcakes heaped with icing. As for Lisa’s interest in the magazine, Lisa guesses that “in the back of her mind [she] knew something was not right and things needed to change.” It “caught her eye as [her] family history of diabetes was in the back of her mind, and [she] was interested in the diet and nutrition information.” Lisa said that she was diagnosed at about the same age as her mom when she was diagnosed. Lisa’s mom had not “taken care of herself” after she was diagnosed and it had been hard on Lisa, so Lisa was trying to take steps to get healthy. Lisa also kept an issue of *Diabetes Focus* that had caught her eye. The picture of the fruit parfait on the
front interested her, as she was trying to cut out sugar after her diabetes diagnosis. She used the various articles in the magazine pertaining to nutrition, exercise, and recipes.

The magazine *Diabetic Living* was also found to be a useful resource for participants. Alan said that the magazine had helped him realize that there is a range of food that he can eat. Renee also had an issue. She used to buy the magazine from WalMart, but she recently subscribed to the magazine. She uses it to learn diabetes related information, to find links to diabetes related websites, and to pick up more recipes. She is “always looking for more recipes.” Renee further expressed that she is open to information that helps her deal with her diabetes, as supported by the issue of *Health Magazine*. This magazine is not completely a diabetes-only magazine, but neither is it a popular press magazine. A friend who is very health conscious had given it to her, and Renee felt that it included useful information to help her manage life with diabetes.

Handouts were also used by participants to gain understanding. For example, Kay reported that the handout she had received from her husband’s doctor during his hospital stay, entitled *Diabetes: Exams and Tests* helped described tests that she needs to know about, such as yearly eye and dental exams. Looking over the handout, though, prompted her to ask if the doctor would tell her when she next needed to have her A1C tested. Kay then reassured herself saying that “the Doctor is pretty good, so I'll suspect he'll...” She then lost track of her statement as she had started looking at the next handout in her pile. Suzanne said she used the handout, *Diabetes Medications*, to learn about Atlantis insulin and when are better times to test her glucose levels.

Jack, one of the only uninsured participants in the study, described several information items that helped him gain an understanding about diabetes. He had been insured for a small period of time, allowing him to receive a diagnosis, but the insurance lapsed before he could attend diabetes education classes. He was quite concerned about managing his diabetes, so sought and read much before his family helped him pay for the education classes. Prior to attending class he found websites quite informative. Specifically, he used the websites for WebMD and the American Diabetes Association to find guidance and recipes. When he started education classes, food remained an important topic. He reported that the handout, *Daily Meal Planning Guide*, provided by the diabetes educators helped him get ideas for cooking efficiently. This handout includes a picture for determining portion sizes, food lists for meal planning, a
sample meal plan, and a personal meal plan log. Jack found a specific tip the most useful: rather than cook a single “diabetic meal” each day, cook more than one meal. This abundance then provides leftovers. He found this especially useful, as his kids like to eat his meals with fresh vegetables, rather than frozen foods. Cooking ahead allows him to cook with fresh vegetables. Jack also manages his diabetes using medication, so he found that a pharmacy provided prescription handout was very informative when he was concerned about a sunburn. He said that he normally does not burn, so he decided to check the prescription information to see “what was up.” He keeps the handouts for times like these, when he needs assurance and information.

4.5.2 To Monitor

Items that were coded using the new category “To Monitor” (n = 32, 9.3%) included dietary and glucose logs that were used by the participants, diabetes educators, and health care professionals to look at historical values in order to balance glucose readings within acceptable levels. These various logs that were used by participants – paper logs using the template provided by the diabetes educators; digital logs that are stored in the glucose meters, the booklets that are provided by glucose meter companies, electronically using a Microsoft Excel spreadsheet, or scraps of paper - are used for similar purposes, to track glucose readings and food intake. The process of keeping the logs, and the information that was entered, varied across participants, though, as described herein.

Arlene, a postal worker, was slow to start using the paper log that was supplied during class to record glucose readings. She explained that this was partly due to trouble learning to use her glucose meter, but also because she often did not test during work. She said that the “machine was inconvenient to use in the mail truck.” [The truck environment] is dirty, and often hot.

Mary uses her paper log mostly to track her meter reading, but she sometimes includes what she eats. She may make a note of her food intake and meal times alongside her meter readings, or she may use a separate log. She refers to the information to see if she can determine if eating certain foods or at certain times leads to higher glucose readings. For example, she looked back to an entry of elevated glucose after she had eaten fried chicken, peas, and rice. She also notes that her glucose “scores” are frequently higher in the morning than during the day. She
thinks this is information that she will need to discuss with her physician, as there can be an issue of glucose levels spiking in the morning.

John discussed that he uses his glucose meter to track readings. He stores the readings in the machine’s memory for the diabetes educators to download and review, but he personally does not “go back and look.” The meter tells him the information he needs to know at the moment and he then turns it off until it is time to test again. He writes the glucose reading information down in a vendor provided “daily diabetes management book,” alongside health encompassing information that he tracks: weight, caloric intake, exercise activities, medication dosage times, and food intake times.

Participants also reported that they used additional food intake logs. Some recorded this information alongside glucose readings and medication dosage times, while others used paper scraps or online applications. Trying to keep food logs as simple as possible, Jack kept his notes about carbohydrate intake on scraps of paper that he would occasionally refer to. Carla used a slightly advanced paper mode and keeps notes throughout the day about her food intake on a paper in her pocketbook. She later transfers the information to her personal log. She does not record frequent blood sugar readings, but she uses this log to check to see if she went over the mealy/daily allotment. For example, one day after she had a slice of pizza and chicken legs, her sugar was sky high when she tested, so she felt that the combination of fried chicken and pizza were to blame and plans not to eat both items during the same day again.

Dan chooses to keep his log using an online version of *The Calorie King*. Dan is enthusiastic about this tool and raved that it is “an amazing diary.” He explained his enthusiasm in that, “all the companies that you can think of are pre-loaded, for example, Kraft macaroni and cheese. [You select the product from the application’s drop-down list and] the software then does all the calculations of sodium, carbs, etc… It gives you great level of detail.” Although, the software is currently helping him monitor his food intake, he thinks that in six-months his need to keep this log to the current level of detail will decrease, because he “will know what is in the food.”

Suzanne reported that, although, she had previously used a spreadsheet that she created in Microsoft Excel as a log in which she recorded “everything,” meaning glucose readings, food, and medication, she is now using the paper log provided by the diabetes center. She switched to the paper log, because her physician preferred the format of the standard log and Suzanne
indicated that he asked her to switch her recording habits, or record information in duplicate so she could provide what he preferred. Suzanne chose to switch completely. She misses the detail she previously recorded, as she used to it determine when she was "doing good." She had been having a very hard time getting her blood sugars under control so "she wants to know how to keep that going." Therefore, she is willing to give the doctor what he wants. She is also hoping that making-up a missed diabetes education session on medications, will help her get her glucose readings stabilized.

4.5.3 To Plan

The use category, “To Plan,” was applied to item uses (n = 30, 8.7%) that included shopping; meal planning, preparation, serving; and eating out. Several participants described that these instances of item usage made it easier for them to make better food choices, because they were able to plan ahead. For example, Kay found the information in the handouts, Diabetes: Food Pyramid, Diabetes: Shopping For and Preparing Meals, Healthy Meals for Diabetes, and Diabetes: Learning about Serving and Portion Sizes, helped her plan meals, purchase food that would help, and eat appropriate serving sizes. She would select protein that is rich in fiber, limit unhealthy fats and sugars, and limit the amount of food on her plate. Louis found that the handout provided by the diabetes educators, Daily Meal Planning Guide, helped him plan his meals. Specifically, he uses the “carb count chart” in the guide which “breaks carbs down into chunks and tells you what the food groups are,” He knows how much he could or should eat and refers to the chart to help him pick foods. He says he finds this easier than comparing food labels. Louis uses individual recipes in much the same way as the Planning Guide chart. When he finds one that looks appetizing, he will alter the recipe or make adjustments to meal plans to accommodate his goal carbohydrate count. Kay said that the handout, Eating Out When You Have Diabetes, helped her plan her meal selections when she goes to a restaurant on Sundays. She had underlined broiled, steamed, baked, or grilled in the handout to help her remember.

4.5.4 Got Started, Got Motivated

Several participants described using kept items in ways (n = 11, 3.2%) that suggested that the item had served as an impetus for action, i.e., had served as motivation. For example, Emily used the book, The Cheat to Lose Diet, for recipes to help her change her diet. The book offers ideas for three different ways of eating, but she focused on and continues to use the low
carbohydrate recipe options. Emily said that she likes the recipes, as this means she does not “have to think much” about what she needs to make changes. The book has been instrumental in helping Emily make diet changes, but she would like to get a book specifically for “dieting with diabetes.” She thinks this would make it easier for her to change her diet. She thinks there are probably books out there that fit this description, but for now the book is just a thought; she said that she may look for it later, though.

While a book of recipes helped Emily make diet changes, because it gave her ideas about specific recipes to fix, other participants reported that information in handouts and lab results motivated them. For example, Kay said that the information in the handout, *Long Term Complications of Diabetes*, motivated her to watch her diet. Kay said that the handouts motivated her, because she found the information in the handout to be quite alarming. She had no idea what could happen as a result of diabetes. Jack reported that his blood work laboratory results motivated him to watch his diet. While the initial lab results scared him and helped him decide to make changes, such as in his eating and smoking habits, he was further motivated to keep working toward change when his doctor wrote the original A1C, triglyceride, and cholesterol numbers on the improved follow-up results. The original numbers continued to motivate him by the memory of the effect his bad behaviors had on is health, but the better numbers motivated him to stick to his changed behaviors and to keep making changes. While the quarterly lab results served as motivation for Jack, Louis said that the log he keeps of food and sugar reading is motivational in that it reminds him about what food does to his sugar readings. It reminds him that making food choices outside that which is recommended has an effect.

### 4.5.5 Gain Skill

Participants reported that several items (*n* = 9, 2.6%) provided by the diabetes educators were used to develop skills for balancing nutritional needs that promote stability in living with diabetes. While some participants reported that various handouts simply provided useful information, other participants talked about applying the skills that were discussed and demonstrated. For most, the new skills allowed participants to plan better with regard to what they eat and to comply with their doctor’s orders for their diabetes-related medication. Specific handouts and their use are further presented herein.
Kay reported that several handouts had been given to her husband when he was diagnosed a year prior to her diagnosis. He was diagnosed during a hospital visit for an unrelated event, and the doctor asked her attending resident to provide educational materials. The resident used the hospital’s patient education material database and gathered an extensive pile. Kay said that some of the items, after her diagnosis, helped her develop necessary meal planning skills, as well as helped guide her in performing maintenance skills necessary to prevent complications. Specifically, the Kay said that the handout, Caring for Your Body, is all about feet. She used the handout’s information to help guide her to do feet scans. As for making dietary adjustments that help her balance her nutritional needs, Kay said that the handout, Diabetes: Understanding Carbohydrates, was very helpful. She learned to correctly identify food items that are considered as carbohydrates and to identify specific servings that are 15 grams, e.g., a cup of milk, a slice of apple, etc. The handout Hyperglycemia, a term applied to high blood sugar, helped her to “prevent the high sugar.”

Janice said that the books, The Gold’s Gym Encyclopedia of Bodybuilding and The Complete Idiot's Guide to Weight Training, helped her try different techniques that encouraged weight training to develop muscle, rather than lifting to “tone.” While toning is often important for health, she preferred to gain muscle strength to help her prepare to lift heavy containers for her volunteer work with the Red Cross. Both books contain specific information about diabetes and discuss balancing glucose, lactates, carbs, and fatty acids. This information, as well as that about nutrition, aerobics, and stretching, helps her stay motivated. If she begins to tire of any routine, she will get ideas from a different section, which motivate her to go to the gym another day.

4.5.6 Got Control

Participants reports that various types of items - calendar, log book, personal notes, and prescription information material - were used in ways (n = 7, 2%) that helped them “Get Control” with regard to living with diabetes. Most of the items pertained to medication, although Sue reported that her use of her log book gave her a sense of control. She noted that although, she often is keeping track of glucose reading and food intake so “someone can tell me what I am doing wrong or what could be happening,” she thinks that as she continues to learn about foods, and learn to get control of it, [keeping the log] will give me control.” She is learning to sense
“the symptoms” of when “my sugar probably got low” so she can test. She then makes “notes in the log and follow the rules” to stabilize her glucose levels.

Several participants described a sense of control that was gained using different information items that are related to medication as treatment for their diabetes. Jack reported that he uses a calendar, elaborately annotated to track usage for his diabetes-related medications. He lists the medications, the condition treated by the medication, and dosage instructions. He also uses the calendar to keep track his dosage.

Renee uses personal notes that she made during the diabetes education classes on the handout, *Medications*, to remind her when she needs to take her diabetes-related medication. These notes, and her compliance with medication dosage, give her the sense that she is successfully in control of managing her diabetes. She hopes that she can begin to use the notes less in the future, once she memorizes the schedule.

Carla uses the prescription information handouts to ensure she has a record of her medications’ shape and color. She found from experience that this information gave her a sense of control when the pharmaceutical company changed what her medication looked like. She worried when she opened a new container of a continuing prescription and found that the pills looked different. She called the pharmacist for help, but she also pulled out her prescription forms to double-check the information the pharmacist provided. She felt comfortable taking the pills after this verification. She also uses the information to review the side effects of medications, such as metformin. The ability to reference this information gives her a sense of control in that she can use them to see if problems that arise may be related to her medications.

4.5.7 Example of Get Connected: Use of Handout Available to All, But “Used” Once

The diabetes educators provide to each class participant many handouts (n = 11) and slides (n = 5) during the class period that were selected as a means to meet diabetes standards of education and care. Some of these, e.g., *Medications* and *Daily Meal Planning Guide*, are discussed in results wherein multiple items, some from other sources are identified within a category. The category “Get Connected” was only attributed to the use of one item, a handout, *Community and Resource List*, which was provided by the diabetes educators. This handout provides reference to national, local, and online resources, including diabetes support groups. Every participant was asked about this handout, as it is part of the packet that is provided to them.
and so was an item that was known to be in the home. The participants realized that it was available, but Mary was the only participant who said that she had used the item. She plans to take stress reduction and relaxation classes that are listed. The class had made her aware of the need, but this item connected her to class options that could help her learn the skills.

4.6 Information Needs Associated with Kept Personal Health Items (RQ4)

The fourth research question aimed to address, “What information needs are associated with kept personal health items?” Additionally, the participants were asked about multiple needs associated with an item. In order to address these questions, participants were asked to describe the general problem or need that was related to the kept item. These information needs were then categorized according to the literature and frequencies were calculated for comparison. The results are depicted in Table 26.

The primary information need identified by participants pertained to “Nutrition” (n = 184, 57.5%) accounted for more than half of the identified information needs. Information needs associated with “Living and Managing” (n = 87, 27.2%) account for more than one-quarter of the information need results. Another three categories, “Overview and Facts” (n = 14, 4.4%), “Healthy behaviors” (n = 12, 3.8%), and “Treatment Options and Care” (n = 10, 3.1%) account for much of the remaining 15% of identified information needs. Examples of these categories are discussed herein.

Table 26. Information needs associated with kept health information items.

<table>
<thead>
<tr>
<th>Categories of information needs</th>
<th>F</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nutrition (includes 75 recipes from one participant)</td>
<td>176</td>
<td>53.5</td>
</tr>
<tr>
<td>Living &amp; Managing</td>
<td>88</td>
<td>26.7</td>
</tr>
<tr>
<td>Healthy behaviors</td>
<td>28</td>
<td>8.5</td>
</tr>
<tr>
<td>Overview &amp; Facts</td>
<td>14</td>
<td>4.3</td>
</tr>
<tr>
<td>Treatment options &amp; Care</td>
<td>10</td>
<td>3.0</td>
</tr>
<tr>
<td>Access to resource/services</td>
<td>3</td>
<td>0.9</td>
</tr>
<tr>
<td>Complications</td>
<td>3</td>
<td>0.9</td>
</tr>
<tr>
<td>Diagnosis</td>
<td>2</td>
<td>0.6</td>
</tr>
</tbody>
</table>
Table 26 - continued

<table>
<thead>
<tr>
<th>Categories of information needs</th>
<th>F</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cause of problem</td>
<td>2</td>
<td>0.6</td>
</tr>
<tr>
<td>Impacts on life/family</td>
<td>1</td>
<td>0.3</td>
</tr>
<tr>
<td>Products</td>
<td>1</td>
<td>0.3</td>
</tr>
<tr>
<td>Support Groups &amp; Resources</td>
<td>1</td>
<td>0.3</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td>329</td>
<td><strong>100.0</strong></td>
</tr>
</tbody>
</table>

4.6.1 Nutrition

The results show that the majority of kept health information items (n = 176, 53.5%) served to address an information need pertaining to nutrition. This category included items that refer to food or supplement information pertaining specifically to diabetes. In application of this category, information needs that pertained to recipe ingredients or identifying nutrition counts, e.g., carbohydrate or fat counts, were categorized as “nutrition” information needs. Items that were categorized as pertaining to information needs included recipes, cookbooks, handouts, and self-selected website print-outs. The defining boundary of this category is that the item contains content (information) that may later be applied to assist in making a health behavior decision. The items coded within this category that contained information about healthy behaviors, e.g., shopping, as well as nutritional information, were coded to represent these dual information needs. Details of the “Healthy Behavior” category are provided later. Note that the results include the large number of recipes that Renee kept (n = 75). If an adjustment is made to exclude Renee’s data, the information needs (adjusted n = 245) attributed to nutrition would drop to less than 50% (n = 109, 44.5%). Renee’s data demonstrates a different type of information keeping behavior, however, and is included in subsequent analysis. Examples that pertain to the different types of items, as well as nutrition information needs that cover various topics are described herein.

Several participants identified different handouts that helped learn what to eat. For example, Sandy who is gluten intolerant and tries to manage fibromyalgia symptoms with diet, reported that handouts supplied by her doctor’s office, *Diabetes: Sample Menus & Portions* gave her an “idea of how many carbs to have per meal depending on calorie diet,” while *Healthy*
Snacks gave her some ideas about different food choices during the month she had to “fend for [herself] to learn about what to eat.” Alan, an engineer whose wife is very involved in the household food preparation, said the handout, *Mix and Match Meals in Minutes*, provided by the diabetes educators gave him ideas of what he could eat. Kay kept many handouts (n = 28, 51.9% of the total handouts kept) that had been given to her husband when he was diagnosed with diabetes during a hospital visit. Several of these handouts, including *Understanding Carbohydrates, Diabetes: Food Pyramid, Eating Out When You Have Diabetes, Healthy Meals for Diabetes*, and *Diabetes: Learning About Serving and Portion Sizes*, helped her to understand how to deal with carbohydrates and calories, to “figure out what to eat … [to] limit unhealthy fats and sugars,” and to learn “how much food to put on your plate.”

Renee also kept items that contained information that is similar to that in handouts provided by health professionals. However, Renee obtained her material by printing handouts that are available from the dLife website, e.g., from the handout, *The 25 Lowest Carb Vegetables*, she “figure[d] out different things to eat.” Renee even “made different purchases at a grocery story based on recommendations.” For example, she “now buy[s] more kale, which was more work than [she] wanted it to be.” After reading *25 Lowest Carb Fruits*, she decided that she wanted to try casaba melon. From reading *Best & Worst Carbs*, Renee realized that she needs to pay attention to food labels, because “sugars can be increased when fats are reduced.”

The results of information needs associated with nutrition also show that participants kept books and restaurant provided pamphlets to learn about the nutritional values in specific food items. The most frequently kept single item pertaining to nutritional content is *The Calorie King*. This book includes nutritional information of food items from several fast food chains and restaurants, as well as that of food that may be produced by either major- or off-brand companies. According to Janice, the book “also has information about fat in the back.” The breadth of the book makes it applicable for eating out or grocery shopping, as demonstrated by Janice who said that it “helps to make the shopping list, especially when it comes to different carbs.” Dan said that he “refers to it frequently to find things like, how many carbs in rice.” He “will alter [his] food selection based on the information” found in this or another pamphlet containing nutritional information, *Nutrition in the Fast Lane*. Carla uses restaurant supplied pamphlets from Olive Garden, Tropical smoothie, and Chik-Fil-A. She specifically used the items from Chik-Fil-A and Olive Garden to determine the carbohydrate and salt content. She
decided that the salad dressing at Olive Garden “has a lot of carbs and salt,” so it is “best to take your own.” It is in using the items like this that she feels that they are “very helpful.” They allow her to “choose what she has,” before placing an order, “rather than looking something up” after she has eaten. Frequently, the nutritional information books and handouts are used to help assess food content of prepared items. However, Louis said that he uses his book, *Diabetes Carbohydrate & Calorie Counter*, to look up natural food like oranges and broccoli. Louis takes a simplistic view that to live successfully with diabetes, he basically needs to “eat a lot of vegetables and avoid carbs.” He uses the nutritional values to help him choose foods with “better carbohydrate” values.

While some participants wanted to know nutritional content of food items that were already prepared, other participants wanted ideas for food and daily meal plans items that they could be make and stay within suggested guideline. Emily found that the book, *Secrets of Good-carb Low-carb Living*, helped her find menu plans. This book “explained the good vs. bad carbs and had meal plans and a lot of recipes with types of food [she] might eat and ways to lose weight by watching bad carbs.” The book is not diabetes specific, but helpful. It offers plans that are limited to “30 carbs, but the diabetes educators allow for 45. [She is] thrilled [she has] an extra 15 carbs to work with.” Suzanne, who has struggled with finding a routine that helps keep her glucose readings stables, said that the book, *Mastering the Zone*, provides a useful “carb breakdown in the back” and that she uses the recipes for basic guidelines. She likes “to know things, like how many carbs are in a cup of broccoli.” The book is not diabetes specific and gives information in units called “blocks,” thus adding some complexity to its use. But Suzanne believed she has successfully translated “what a block means for its counting ability” and is able to determine nutritional content provided recipes.

This category further includes handouts, recipes, cookbooks, magazines, and websites that provide recipes and meal ideas. These items may include nutrition information. Those recipes that do not include specific nutrition information make it possible to determine this information using the ingredient lists and available nutrition books. June used two handouts that she had received in a previous diabetes course taken nearly 20 years prior. First is a Nova Max poster, *Diabetes Nutrition Placemat*, presents the notion of meal planning and what size portions of meats, starches, and vegetables should be consumed at meals. She also kept and has been referring to the *CCS Medical 14 Day Diabetes Menu*. This item provides suggested food items
and serving sizes to consume for each meal during a two week period. The cookbooks spanned various content specializations, including: diabetic specific topics, e.g., *Diabetic Microwave Cookbook* and *Diabetic Meals in 30 Minutes or Less*; nutritionally oriented, e.g., *The Diabetes Carbohydrate and Calorie Counter, Play Your Carbs Right*, and *The Complete and Up to Date Fat Book*; desserts, e.g., *Sweet and Sugarfree: All Natural Fruit-Sweetened Dessert Cookbook, Sweet Ideas from Equal*, and *Sweet Inspirations: A Sugar Free Dessert Cookbook*; and complete meal ideas, e.g., *Diabetic Meals in 30 Minutes or Less* and *Carb Counting and Meal Planning*.

Many (n = 21) of the cookbooks were reported by June, who said that she sometimes uses these books to help plans her meals. She first decides what meat to fix and thaws it. Then she decides what side items to add. The cookbooks help giver her ideas about combinations. She specifically uses them to determine “counts of various food, [because she] want[s] to get high fiber food with good amount of carbs.” Magazines used for recipes include *Eating Well* and *Diabetes Focus Magazine*, while the websites included Diabetic Connect, dLife, Kraftdiabetes, and Splenda.

### 4.6.2 Living and Managing

The items identified as addressing information needs pertaining to “Living and Managing” life with diabetes (n = 88, 26.7%) include items that cover a range of topics, including stress, strategies for taking glucose readings, developing a lifestyle that promotes diabetes management, dealing with possible medication reactions, as well as other life activities and behaviors, or life management strategies related to living with diabetes. The items described in this category include various types of material, including handouts, daily planners, glucose logs, books, magazines, and web sites.

The diabetes educators discuss and provide a handout, *Stress*, which pertains to the effects of stress on glucose levels. Sandy, a state employee who is gluten intolerant and has fibromyalgia, described that her mother and husband have Type 2 diabetes, but they care for themselves and have not had problems. She “figured [she] would get this sometime.” She was surprised to learn about the effect of stress, but has not acted directly on the information. She has been living with fibromyalgia for years, and participates in hobbies that project a calm demeanor or lifestyle: sewing, piano, crafts, reading, and networking on computer. Given Sandy’s background, it seems unlikely that the information pertaining to the effects of stress is something that she needs to act on directly. However, she stated that the information was useful; based on a
pause in the conversation, it seemed that Sandy mentally referred back to the material. Earlier discussions had revealed that Sandy had contended with the loss of her teenaged son to a car wreck the previous year. The raw emotion was evident, but quickly controlled, and the interview resumed focus. Given a holistic view of the exchange, it seems that the information in the Stress handout resonated with Sandy and that it is applied in some fashion toward managing life with diabetes.

Lisa is a working mother with a teenaged daughter. She works in a stressful position as a project manager for the state legislature. To add to her stress, she experienced strong emotions when she received her diabetes diagnosis. Her mother had been diagnosed with diabetes when Lisa was in high school, about the same age currently as Lisa’s daughter. Her mother had taken insulin to manage her diabetes, but did not monitor food intake. As a result of diabetes-related complications, Lisa’s mother endured double amputations. The emotion and stress of this memory was evident as Lisa teared up and said that she does “NOT want to end up like [her] mother, but worr[jes] if [she] is doing enough.” The handout, Stress, provided by the diabetes educators strengthened her understanding that she needs to manage her stress, so she does things like go to the beach for the weekend. She is also in the middle of a home remodeling project, with plans to knock out a wall. When asked specifically about the stress of living with the dust and disarray caused by remodeling, Lisa said that she finds the project relaxing. She is participating in the demolition and enjoys it. Lisa also uses the website Foot Care Express to help her with foot care, after the diabetes educators emphasized its importance and provided a handout, Good Foot Care. Lisa has used the site for information such as, “figur[ing] out what to do about cracking heels.” After realizing how important foot care is, she is no longer embarrassed about pampering her feet and “now moisturizes them daily and uses a foot soaker.”

Sandy also described how she uses instructions she wrote down from a website, possibly that of the Mayo Clinic, “all the time” to guide her through checking her “blood sugar.” She learned that it is important to “check sugar” before meals, two hours after each meal, and at bedtime. This routine discipline, and her medical treatment, may contribute to her sense that “since being diagnosed … [she] feel[s] so much better.”

Calendars were mentioned as useful tools in managing life, but in different capacities. John said that he finds a daily planner is imperative for him in trying to successfully manage life with diabetes. While it is handy for the typical life tracking events, such as doctor’s
appointments, it is especially useful for planning events like a recent trip to New York. He keeps track of medication refill dates, so he can “make sure to have meds lined up.” Jack used a calendar to manage his daily medication needs. Jack lists all his medications on the calendar, tracks what they are for, notes when each medicine is to be taken, and marks the calendar when medication is taken.

Several participants described usage of their glucose logs or glucose meter history information in terms that indicate that these items are used to help them manage life with diabetes. Louis created and keeps a log based on the form provided by the diabetes center, on which he records both “food and sugar reading.” He said that “the form is useful in that it is motivational and it reminds [him] about what food does to [his] sugar readings. It reminds [him] of what it means to go outside the edges of what he recommends.” Suzanne said that she keeps the logs mostly “so the educators can help [her] to figure out what is going on … [she] want[s] the formula as to how much insulin to take for the amount of carbs [she] eats. Emily uses the glucose log provided by the diabetes educators and regularly reviews the readings. It has helped her decide if she has “improved, stayed the same, getting better the same. The problem is taking the measurements. [She has] to do it two hours after she eats and [has] a hard time remembering to do it. When [she] think[s] about it, it hasn't been two hours... and then [she] forget[s] or [she has] eaten or drank something.”

Mona has found that magazine articles in *Diabetes Forecast* and *Diabetic Living* provided tips that are useful for living with and managing diabetes. Specifically, she has found help with “cooking for one;” she realizes she needs to “sleep more than seven hours to help A1C;” she has learned how to “eat less, feel full, weigh less;” and she has also picked up on “travel tips” and eating for “on the go.”

The number of items categorized as “Living and Managing” may account for only approximately one-quarter of information needs, but the importance of the items and this information need is best expressed by John. In talking about his daily diabetes management log book in which he writes his glucose reading, weight, and caloric intake, he says that:

It gives me a lot of information and helps me keep track of things. It lets me know if I am controlling my eating habits like I should. Knowing helps me get back on track. Just because you have a bad week doesn't mean you don't get back to what you were doing. You have to manage life or you're going to die. (John)
4.6.3 Healthy Behaviors

The category “Healthy Behaviors” was used for items that pertain to positive behaviors that help a person to maintain a healthy lifestyle, such as eating or exercise habits. This category is complementary to the “Nutrition” category, but they are distinct. While items coded within the “Nutrition” category pertain to factual information about the content of food, items coded within this category contain guiding information about healthy behaviors that may include food information. The results show that the less than one-tenth of the kept and used items pertain to the information need, “Healthy Behaviors” (n = 28, 8.5%). These items pertain to content related to eating and exercise.

With regard to eating, there were many behaviors that participants identified as information needs. Louis used the class slides of Putting it All Together to review material presented during class. The slides present material about eating out, portion sizes, calories, fats versus carbohydrates. The slides contain much information, and he thinks the material is important, but he does not have time to read the material thoroughly. So, he periodically reviews the slides to refresh his memory, focusing on “the highlighted bullets.” He has found from scanning the material that “it is easier for [him] to estimate [portions and counts], rather than do exact calculations [of nutrition content].”

The handout, Daily Meal Planning Guide, supplied by the diabetes educators was noted as serving information needs for several participants. This handout includes picture for determining portion sizes, food lists for meal planning, a sample meal plan, and a personal meal plan log. John, who was diagnosed with diabetes approximately 10 years ago, enrolled in the diabetes classes to learn better tools for managing his diabetes, because he had some complications. He said that he is starting to use the Daily Meal Planning Guide, primarily when selecting food, e.g., to discern starchy vs. non-starchy foods. He is “starting to figure out” that non-starchy foods, e.g., “green beans or pea pods,” are better than starchy items, e.g., “peas, baked beans, black beans.” Louis also uses the Daily Meal Planning Guide to help him plan his meals. To ensure he knows how much he could/should eat, he refers to the carb count chart. “The chart breaks carbs down into chunks and [therefore] makes it very easy” for him to pick foods. It is easier than “comparing [ing] to food labels.” The Meal Planning Guide is also used by Alan and his wife. Alan is an environmental engineer who described living with diabetes as stressful, yet also seemed to take the diagnosis in stride. He refers to the handout to determine food choices.
and nutritional information. His wife said she also uses it to help develop menus for the week, as she carries a larger role in food preparation.

Exercise is also stressed by the diabetes educators as an important part in managing diabetes. Results of kept items also show that participants recognize an information need pertaining to exercise. The slides, *Exercise for Diabetes*, remind Louis, a computer programmer by profession and a semi-active individual who is busy renovating a newly purchased home, of the lesson learned during a diabetes education class. He had found that after exercising for 15 minutes, his sugar had dropped 10 points. He tries to use that lesson as motivation to go exercise more.

In addition to the information items that provided nutritional content or meal plan ideas, participants also kept items that helped them keep track of the food they ate for the day, week, or month. Jack described that he used a food intake log “to know what I was eating for breakfast, but I now have a standard breakfast so don't write it down.”

### 4.6.4 Overview and Facts

The items categorized as pertaining to “Overview and Facts” (n = 14, 4.3%) were deemed to provide descriptions of diabetes and facts/statistics about diagnosis, care, complications, population size, etc. The diabetes educators provided many handouts and slides that covered topics pertaining to living and managing diabetes. These items were found in every participant’s home, but many participants reported that while the material was very informative, the items were often not used outside of class. The course materials, as well as other outside-class materials, that were reported as used are discussed herein. The section begins, though, with a description of the impact of the course materials that were not considered used outside of class. While various comments could be used, Sue provided a thorough description of her interaction with the material.

Sue was familiar with diabetes, as both her father and sister have diabetes, yet she was slow to recognize her own symptoms and to get diagnosed, even though she had been diagnosed with high cholesterol several years ago. After her diagnosis, she left the doctor's office not knowing what to eat and was “afraid to eat,” thinking that her next meal could kill her. However, she was confounded by the realizations that “you have to eat, but that is what causes the problem.” She had to wait two weeks to see the diabetes center, so she independently searched
for information, including trips to the local book store to immediately load up on books. Her thought is that “You shouldn’t leave the doctor's office on day one, not knowing what you can eat.” Going into her diabetes classes, she had already read much. Upon completion of the classes, she said that she has not referred to the informational sheets, which included “information you need about daily living,” because the “information is still fresh.” However, she said that “the class packet as a whole is a 10.” After using it and attending classes she “understands stress and fats… The food thing - making 40 g carbs - is the hard part.” While “meal planning is probably [her] biggest thing. [She] know[s] how to read the labels.” While she found much of the information useful, she did not “see learning about medicines [she is] not on.” She said that she wants the information to “narrow it down to her.” However, she also thought, that while the packet is “good,” “the packet needs to be a book, [wherein] the information was condensed, and understandable…The material could be understood without the instructor.” These comments led the researcher to consider that perhaps the course material had been more informative than the books she had purchased, and that she wished the material could be more readily available to apply at the beginning of diagnosis to immediately help take the first steps in managing and living with diabetes.

One of the items that Sue found prior to attending the diabetes education class, and continues to use, is the book, *Diabetes for Dummies.* She thinks it was useful, because it was simplified reading. She further explained, that “for someone not educated in this, that makes it a lot easier. It covered everything in a simplified manner. [She] was looking for the quickest way to get her there (to understanding).” She described that she was looking for information that provided an overview of all areas of concern, but she also wanted something to help her in her daily life now. She knew she would hear from the diabetes center for help, but she “did not know what that meant or how helpful they would be. That was fine, but [she] was looking for the life raft.”

While Sue’s material that provided a general knowledge of diabetes came by way of course materials and materials that she sought prior to attending the class, other participants continued to seek and refer to information throughout and after diabetes classes. The remaining participants, like Sue, noted that the general diabetes material presented by the diabetes educators was useful for class. They referred to other material outside class, though. Kay, for example, found that the handouts provided by her husband’s doctor during a hospital visit and
diabetes diagnosis, *Understanding Type 2 Diabetes* and *What is Type 2 diabetes?*, provided informational general information that was “helpful to know.” She learned that diabetes is a “chronic life-long condition. [The handouts] tell you what it is and how to control it.”

A quest for factual information was also shown to waylay a participant into considering ways to make diet changes. Lisa stated during her interview that she wants to “learn everything about diabetes.” This desire is grounded by the memory of her mother’s experience with diabetes and the resulting amputations. With this in mind, after her diagnosis, she would regularly browse magazine covers at the grocery store and pharmacy, always on watch for advice or tips. She was specifically looking for what she called “general information.” However, a dessert pictured on the cover of a Diabetes Focus magazine “caught [her] eye.” It was a parfait. This caught her attention, because after she received her diabetes diagnosis, she “cut out sugar altogether… [She] misses ice cream,” so the idea of a non-sugar dessert piqued her interest. She has not made the parfait recipe, but she has read the magazine and picked up tips on food, exercise, and recipes.

Sandy was familiar with diabetes prior to her diagnosis, because her mother and husband have Type 2 diabetes. However, she found that the handout, *Diabetes Mellitus: Type 2*, obtained from her doctor's office, provided a useful overview of Type 2 diabetes and information about medication. She has “referred back to it many times to try to understand [what Type 2 diabetes is]. [She has] learned about the medication; some of the symptoms, which [she] did not know about…[such as] unexpected weight gain and frequent yeast infections.”

Although many items, such as those described above, were paper-based, participants also used digital items for general reference. Lisa found two websites when she was looking for online reference information about diabetes. *Diabetic Connect* and *American Diabetes Association*. These two websites are included in the resource list provided by the diabetes educators, but Lisa found them herself by entering the search term “diabetes” into Google. After successfully finding general information that was useful, she now regularly uses *Diabetic Connect* for recipes or if she has questions about her “sugar readings, like what to do if it goes too low.” She said that she will go to *American Diabetes Association* website first, if she has a question about diabetes. Jack described that he also uses *American Diabetes Association*, but in addition to WebMD and Infodiabetes. He regularly checks these sites “for new guidance,” as well as recipes.
4.6.5 Treatment Options and Care

The results show that kept items categorized as pertaining to the information need of “Treatment Options and Care” (n = 10, 3.0%) encompassed medication, as well as factors that affect glycemic control, e.g., diet and exercise. Examples of a handout, book, and pamphlet that were used are described herein.

The results show that medication was used by several participants to manage life with diabetes. The use of medication is discussed during the diabetes education classes and the educators provide the handout, *Diabetes Medications*, which several participants stated they used. The handout provides a list of various medications that are used to treat Type 2 diabetes and describes how the medications work, when to take them and how to test to ensure their effectiveness. Sandy discussed that the handout gave her insight about the possibility of weight gain or loss with specific medication, and that she needed to take her medication 15 minutes before eating. She also described that she is now using the handout’s content “to think about whether not taking the med is as good as not taking it at the right time.” Suzanne said the medication handout helped her understand how Atlantis insulin works, and realize that she needs to “test based on when the form says the glucose peaks” so she can comply with the treatment plan. Renee uses notes she took during class when the diabetes educators were discussing the medication related slides and handout. Renee focused on the specific time she is to take her medications; she used her notes every day until she memorized the schedule, but does refer back to them for reinforcement.

John, who has lived with diabetes for 10+ years, keeps an annually updated copy of *Davis’s Drug Guide for Nurses* to stay informed about medications he takes. These medications are not necessarily diabetes specific, but various medications can affect managing his diabetes. When he was in the hospital several years ago, he noticed that had a nurse had one in the front pocket of her uniform. He soon noticed that many nurses were carrying one, so he bought one as soon as he got out of the hospital and has found the book to be “very handy.” He looks up any medication he is prescribed to acquaint himself with the side effects. He takes this pro-active measure, often repeated as problems arise, because he believes that “when you take medications to help with an issue, and then you start having other issues… When you take 6-8 medications, and if you feel nausea, you look up the side effects and see many cause nausea… you [then] know what is causing the problem.” John would then make a judgment, based on the knowledge
provided by the book, whether to contact his doctor or to manage his life around the current
treatment and any side effects.

While John contended with medication as part of his diabetes treatment regimen, Sarah
manages her diabetes with diet and exercise. She views this as her course of treatment, but found
that her “biggest challenge since [her] recent diagnosis has been knowing what [she] can eat…It
is encouraging that nowadays, the patient makes their own choices.” However, Sarah struggled
with deciding what foods she could eat. As such, in addition to information she learned in the
diabetes education classes, she picked up a pamphlet, Prevention: Outsmart Diabetes Naturally.
The document provided information about the glycemic index and she learned to apply the
principles to food choices, e.g., she realizes “sweet potatoes are better than baked and that brown
rice is better than white.” She also felt that “learning to use the information on nutritional labels
is literally a life saver.”

4.7 Relevance of Kept Health Information Items to Living with Diabetes (RQ5)

The fifth research question aimed to address, “What is the relevance of kept health
information items to living with diabetes?” This overarching question was addressed through
four sub-questions: 1) how do the information needs and uses associated with kept items relate to
the national diabetes education standards; 2) what situational relevance encompasses the kept
health information items; 3) what relevance decisions are attributed to kept health information
items, but that do not seemingly relate to either the information need or items use; and 4) do the
information items portray information needs of participants living with diabetes that are different
than what is expected, e.g., a phone book reflects a need for contact information, but also
possibly a need for increased height when sitting on a chair.

4.7.1 Information Needs Relative to Current Diabetes Education Categories

Official diabetes education courses that seek insurance driven reimbursement need to
conform to specific diabetes education guidelines and topics that pertain to nine categories
defined within the National Standards for Diabetes Self-Management Education (Funnell et al.,
2009). These categories of self-management behaviors that are recognized as critical for diabetes
self-management include: physical activity, healthy eating, medication taking, monitoring blood
glucose, diabetes self-care related problem-solving, reducing risks of acute and chronic
complications, and psychosocial aspects of living with diabetes.
In order to address this question, the information needs and the usage of the kept and used information items were categorized according to the Diabetes Self-Management Education categories. Note that some items had multiple information needs and/or uses associated with them. All needs and uses were considered as attributions of relevance and were therefore coded separately. For example, websites offer content that pertains to many topics, including nutrition, exercise and medication. An individual may have information needs pertaining to life management strategies and use the information to get ideas relative to these three topics. Given multiple relevance decisions can be attributed to each item, the number of relevance attributions (n = 381) analyzed is higher than the number of individual items described by the participants (n = 300). During coding, the need for additional categories was considered, but no further categories were needed.

The frequency of relevance decisions across the diabetes education categories are presented in Table 27. The majority of relevance attributions (n = 247, 64.8%) pertain to “Incorporating nutritional management strategies.” This category included needs and uses associated with cookbooks, recipes, handout pertaining to food selection and shopping behaviors, as well as the items to provide information about food nutrition counts, e.g., carbohydrates and fats. This overall result averaged across all participants equates to approximately 10 relevance decisions attributed to nutrition per participant (mean = 11.7). If the relevance decisions are standardized against the number of information items kept by the participants (n = 300, mean = 14.3), the number of relevance decisions attributed to nutrition (n = 247) is equivalent to 194 items. This standardized value illustrates the cohesive relevance of the various types of items that were kept and used, including: recipes (n = 89, 29.7%), handouts (n = 54, 18%), books (n = 34, 11.3%), cookbooks (n = 19, 6.3%), websites (n = 16, 5.3%), and diabetes specific magazines (n = 14, 4.7%). In considering these results, note that the average of relevance decisions includes the results of participants who tended to keep more information items, e.g., Renee who had many recipes (n = 75), June who had many cookbooks (n = 17), or Kay who had many handouts from an outside source (n = 27) that were specific to nutrition (n = 8). As discussed previously, while these participants may be greater information users than others, their data illustrates the range of information keeping and use behaviors. Further analysis without their data would eliminate critical data points.
The category that encompassed the second most number of relevance attributions is “Monitoring blood glucose and other parameters” (n = 47, 12.3%). This category includes the glucose logs (n = 19, 6.3%), glucose meters (n = 9, 3.0%) that contain memories that are used for reference, and dietary logs (n = 3, 1.0%). The number of relevance decisions in this category is approximately one-fifth (19.0%) of the relevance decisions attributed to nutritional management (n = 247) and averages to approximately two relevance decisions (n = 2.2) attributed to “Monitoring” per participant. While the results show that participants may have kept many items pertaining to the various aspects of food and eating, the results also show that participants kept and used limited numbers of logs. Note that some of the item uses were coded as “monitoring” using the base action of recording a reading into a log. If this category were tightened for “monitoring” to mean that participants reviewed or acted upon the data, the results would change. However, this category included both glucose logs and meters. A paper log typically contains a history that can be used for review. The glucose meters typically also have historical functionality. However, when asked about their meters, some participants did not know if their meters had the functionality, others stated they did not use it, although it was available, and some participants did review the history. Sue described that she used her paper glucose log and regularly reviewed it to learn about the influence of food on their sugar readings. John identified his glucose meter as a kept and used information item, but he saw its need simply as to provide data to be recorded elsewhere.

The remaining seven categories of diabetes-related situational relevance defined by the National Standards for Diabetes Self-Management Education (Funnell et al., 2009) each account for less than 5% of relevance decisions. The category “Developing personal strategies to promote health and behavior change” is the only category to include more than 3% (n = 16, 4.2%) of the relevance decisions. The uses and needs that were coded as relevance decisions pertaining to developing personal strategies include different items. For example, Jack picked up a specific magazine, Diabetes Self-management Magazine, for general knowledge of management ideas. Jack’s bookmark for Publix Pharmacy Diabetes Management was also coded as developing personal strategies, because he described that he actively decided to go to the website after he found the URL in a book that he had brought home. This bookmarked URL symbolized, in the context of Jack, a personal strategy to drill down through resources to find sources that will provide regular guidance for diabetes management. John described a personal management
strategy that drew upon his previous of his daily planner as a foundation. He described that “we (meaning he and his wife) don't make a move without the daily planner and [my] use of the planner increased with diabetes… A daily planner is almost essential.”

Table 27. Situational relevance, as described using the National Diabetes Education categories, attributed to the kept item with regard to living with diabetes.

<table>
<thead>
<tr>
<th>Situational Relevance Category</th>
<th>F</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Incorporating nutritional management into lifestyle</td>
<td>247</td>
<td>64.8</td>
</tr>
<tr>
<td>Monitoring blood glucose and other parameters and interpreting and using the results for self-management decision making</td>
<td>47</td>
<td>12.3</td>
</tr>
<tr>
<td>Developing personal strategies to promote health and behavior change</td>
<td>16</td>
<td>4.2</td>
</tr>
<tr>
<td>Using medication(s) safely and for maximum therapeutic effectiveness</td>
<td>14</td>
<td>3.7</td>
</tr>
<tr>
<td>Describing the diabetes disease process and treatment options</td>
<td>13</td>
<td>3.4</td>
</tr>
<tr>
<td>Incorporating physical activity into lifestyle</td>
<td>13</td>
<td>3.4</td>
</tr>
<tr>
<td>Preventing detecting, and treating chronic complications</td>
<td>11</td>
<td>2.9</td>
</tr>
<tr>
<td>Developing personal strategies to address psychosocial issues and concerns</td>
<td>11</td>
<td>2.9</td>
</tr>
<tr>
<td>Preventing, detecting, and treating acute complications</td>
<td>9</td>
<td>2.4</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>381</strong></td>
<td><strong>100.0</strong></td>
</tr>
</tbody>
</table>

4.7.2 Kept Health Information Items and Situational Relevance

The kept health information items and their use were considered within the framework of situational relevance. That is, participants’ descriptions of their use of kept health information items and their associated information needs were considered in context of beliefs and knowledge that participants described during the interviews. These personal descriptions serve to illuminate the specific life context, thereby providing rich situational context that offers insight into attributions of relevance. While the context of each participant was unique, the cases of Arlene, Renee, June, Janice, and Alan are presented herein, as they exemplify unique information keeping behaviors that portray different information needs. Arlene is further described herein, as she portrays an individual who greatly engages with information to manage life with diabetes, but yet keeps and uses few items in her home. Renee also represents high levels of information engagement, but she maintains a large number of items and portrays a need
for information to help manage an intangible need for control. June is another participant who kept and used numerous information items, but when her keeping and use behaviors are considered in light of her personal context, the information need to balance culture and managing diabetes is illuminate. Janice is described herein, as her context of a practicing Buddhist provides insight into limited information keeping behaviors, although she portrays a participant who had a great need to balance strong emotional responses to her diabetes diagnosis. Alan represents participants who primarily keep and use information items acquired from others, specifically a spouse.

4.7.2.1 The case of Arlene: Few kept items and high information seeking. Arlene is a 38-year old, postal worker and single-mother with a young daughter who was quite disappointed with herself when she received her diabetes diagnosis. She described that she wants to take care of herself in order to “be around” for her daughter. She was learning much in the diabetes education class, but the results show that she did not keep any items other than the items provided by the diabetes educators, and of those items, she reported that she used very few (n = 2). This information keeping and use pattern seems to indicate that Arlene either had few information needs that required ready available resources, or could be someone who is little interested in information about managing life with diabetes, i.e., an information “blunter.” The presence of only items that had been given to her seemed to reinforce the possibility that she could be considered an information “blunter,” or possibly a passive information gatherer. However, throughout the interview and discussions about her job, Arlene described a life of highly engaged information seeking that is indicative of an active journey of learning to manage life with diabetes. Her descriptions of specific information seeking behaviors, e.g., finding recipes, indicate that Arlene is a highly engaged information seeker and could be considered a probable example of an information “monitor.” These engaged seeking behaviors are further described herein.

Arlene revealed that she hates to have paper around the house. She disposes of any paper as quickly as possible, because she sees enough paper on her job as a mail carrier. She did have the entire packet of materials from the diabetes class, but she will likely dispose of it shortly after the class ends. While her job turns her off to the presence of paper, it also gives her ready access to various materials, including diabetes-related items that she delivers along her route. She is quite comfortable reading any materials she finds during her mail delivery, so plans to continue
to learn more about diabetes using any magazines and articles that interest her. Arlene also described she does not have a computer, but she has access to one at her mother’s, who lives nearby. Arlene uses it periodically to look up information or recipes. She feels she recalls encountered information well, so is comfortable seeking and using information in this disposable manner, and is therefore probably unlikely to keep any material. She does not envision that she would refer back to any material.

Thus, while the study aimed to identify potential information needs that kept and used information items may indicate, the results show that the lack of items in a home indicated, in the case of Arlene, a need for useful information readily available, because she does not like to keep paper items in her home and does not have a private computer. Also, the lack of information items present in a home did not indicate that Arlene was an information blunter, or a low information seeker. Based on her life description, Arlene is a heavy information user, but the items are elsewhere, primarily along her mail route.

4.7.2.2 The case of Renee, recipe keeper extraordinaire: Continuously seeking recipes to achieve successful diabetes management. Renee is a state government worker who was diagnosed with diabetes over ten years ago. When first diagnosed, she went to a dietitian who told her “about the exchange stuff, but [she] couldn't work it given her schedule and travel.” Given the difficulty, she slid into a routine of not overly concerning herself with diabetes management for several years. Her recent participation in the diabetes education classes occurred because her doctor found heart problems during a pre-surgical screening. As a result of the classes, she learned about “the big picture” and now realizes the implications that the stress of her job brings. Plus, the passage of time has provided her reflection and she now connects her diagnosis with her dad who also had diabetes. “Near the end he didn't care about his sugar - and they got into the 400. He was wearing diabetic shoes,” Renee began to tear up, but continued: “He got congestive heart failure and died.”

The data showed that Renee kept and used approximately four-times more items than the participants with the second highest number of items. This can be partly explained by the fact that the majority of items Renee kept are clipped recipes (n = 75), as opposed to entire cookbooks reported by other participants. It is possible that Renee’s keeping behavior may also be a symbol reflective of her life description: “I have a goal [of being healthy], but struggle to get there.” Renee works long hours, travels for work, and is active with her family, but yet she
takes the time to read daily emails from Prevention a weekly newsletter from D-life, a diabetes resource website. She has been collecting recipes for years, but began finding more recipes from the websites after she realized she needs to better manage her diabetes.

Therefore, the high number of items, specifically recipes, may indicate a struggle for balance, or it may indicate the need to find a way to manage life with diabetes and is focusing on food for now. Informed by the additional insight of the fairly high level of stress that Renee contends with at her job, her struggle to reach her goal of being healthy, and her vision of a possible future, as demonstrated by her father, it is also possible to consider that the keeping of recipes is a tangible symbol of control. Each time a tangible item, such as a recipe is kept, it may indicate Renee’s desire to deal with the intangible concerns of managing and living with diabetes. This notion is further supported in that these kept items are generally used infrequently, for specific times, or as guides for developing a personalized meal. Her diabetes management may be as fluid.

4.7.2.3 The case of June: Many cookbooks show struggle to connect identity as Jewish and diabetic. Early on in the interview with June, she explained that she had moved to the region in the Southeast from New Jersey and had found the adjustment difficult for the “stereotypical, cultural reasons.” This was initially understood as a difference between stereotypical notions of culture between “northerners” and “southerners.” As the interview progressed and rapport developed, June further explained that her adjustment, with regard to the area, was made more difficult in that she was Jewish. Other than during this period of rapport building, June did not mention her Judaism. At no time did it play a specific part in the interview regarding information items that were kept and used. However, during analysis, June’s comments about her heritage and the timing of these comments were considered as possibly relevant to the discussion of her large collection of cookbooks and her struggle to make “traditional” foods using ingredients she could eat, but produce a product her family enjoyed.

June was diagnosed with diabetes in the 1980s. She described that she loves to cook, and the number of cookbooks in the home that were identified as used relative to managing life with diabetes (n = 17) backed this up. (Note that June had many more cookbooks in the home other than these 17.) Many of the cookbooks discussed with regard to the study pertained to desserts and the use of sugar-substitutes, a frequent dietary change previously encouraged for individuals living with diabetes. June tried to make these alternative recipes, but said that she had found that
her family preferred not to eat these foods, as they tasted different. According to June, these modified foods were not considered "traditional." June repeatedly used the word “tradition,” perhaps belying the importance she placed on sharing these traditional foods with family. She expressed that since sharing the “traditional” items is so important, now that she has learned that portion control can be used to control intake of carbohydrates, she is going back to the traditional recipes. Unfortunately, June did not identify the specific recipes as she did not directly equate them to managing her life with diabetes, so only possible inferences can be made. However, given June’s comments were made during discussions of her diabetic related cookbook pertaining to desserts, her comments of her Jewish background, and large family meals, which seemed to imply something larger than daily fare, it seems that a possible interpretation of the cookbooks is that, although they reflect an information need that was imposed on them, June’s true need was possibly how to manage meals for diabetes within the context of her Jewish traditions.

Judaism is a culture, as much as religion, and includes traditions that may demand focus on food. Food considerations arise throughout many parts of Jewish life: 1) as part of daily dietary laws, e.g., no pork or shellfish and no mixing of milk and meat; 2) during holidays for symbolism, e.g., the Passover / Seder meal. The foods served during the meal carry specific symbolism, e.g., Matzah is unleavened bread the symbolizes the rushed departure, the bitter herbs serve as reminders of the bitter and frightening journey, and Karpas is a bitter combination of vegetable, often celery or potatoes, and salted water or vinegar that symbolizes the brutal life of the Jewish slaves. Also during Seder, Ashkenazic Jews - the Jews of Central and Eastern Europe and their descendants – avoid rice, corn, peanuts and beans during this holiday. 3) Food also reinforces identity as part of Jewish culture, e.g., Ashkenazic Jews tend to eat food considered “Jewish-style deli food.” This includes blintzes (buttery dough filled with sugary cheese or sugary fruit filling), latkes (fried potatoes, come on people), and Pastrami. Given June’s frequent discussion of dessert, it is possible that her comments were made in regard to the “traditional” foods consistent with the standard fare of Ashkenazic Jews.

4.7.2.4 The case of Janice: Keep life simple and use limited resources to manage life with diabetes. Janice is an African-American, former federal prison guard, and practicing Buddhist who had watched colleagues who had not adequately cared for their diabetes suffer various complications, including amputations and blindness. Her life had been quite stressful,
because of her job, and prior to her diagnosis she had been overweight, sedentary, and a “heavy drinker.” When she received her diabetes diagnosis, the doctor “read her the riot act.” As a result of the diagnosis and dire warning, she was first angry. This quickly transformed into fear, though, and likely contributed to the panic that sent her to the emergency room the night after her diagnosis. Upon calming a bit, she decided that she needs to do things like diet and exercise daily if she wants to live. She is on fixed income, though, so had to be strategic. She moved to a central location into an extended-stay unit that includes kitchenettes and a fitness room that she uses daily. She also takes advantage of her central location, though, and walks to the local library for computer access, as another way to stay mobile. The information items that she kept include books that she had around pertaining to weightlifting and bodybuilding, a free issue of *Heart Health and You* that she picked up from Walgreen’s Pharmacy, and her glucose logs. June said that because of her limited income, she had not made food changes prior to the diabetes education classes. However, as a result of the course, the recipes featured in the magazine, and the magazine’s information about food alternatives, she is making slight changes. Specifically, she now frequently makes the tilapia, and she also makes the spinach dish from front cover. Janice also frequently refers to her bodybuilding books in order to find fresh ideas to keep her routine interesting and to make sure to work all muscles, especially heavy upper body work to “have muscles to lift heavy containers for [her] volunteer work with the Red Cross.” She also likes the information about nutrition, aerobics, and stretching, because this as it “helps [her] build her endurance.”

While the limited number of items could indicate that Janice had few information needs or was not interested in diabetes-related information, her description of her use of the weight training books indicates that she wants and needs to engage with information regularly to work toward her goals of being strong and staying alive. Her fixed income and choice of a simplistic life compel her to make use of readily available resources. Interestingly, although Janice regularly walks to the library she did not discuss ever using it to obtain information pertaining to diabetes. It seemed that the library was simply a conduit to the Internet.

4.7.2.5 The case of Alan: Kept health information items chosen by others, but depict his information need for “credible” general information. Alan is a married, 59-year old, African-American male with an advanced degree in environmental engineering. He had only been recently diagnosed with diabetes. He left the doctor’s office without any information, other
than the referral to the diabetes center, who met with him within a month. During this time between diagnosis and diabetes education, he “had discussions” with his “doctor friends” to figure out what he “should do.” They told him the basics of diabetes and gave him ideas about “alternative methods,” such as the importance of eating fiber.

Alan’s wife was present during the interview, which was conducted at the kitchen table, but seemed to try to give Alan privacy in that she excused herself to work in the kitchen, starting to prepare dinner. Alan did the majority of talking throughout the interview, describing himself and the time surrounding his diabetes diagnosis. However, he deferred to his wife for answers of health quality, his activities, and other questions about his lifestyle. His wife also frequently interjected when discussions of cooking and shopping arose.

Alan identified limited number of items (n = 5) as kept and used, none of which he personally acquired. Two items were obtained from the diabetes educators, the Daily Meal Planning Guide and a handout titled Mix and Match Meals in Minutes. Alan said he thought the item was very useful, scoring it a 9 out of 10, and that he refers the former item to help him determine food choices and to get nutritional information. The wife interjected, though, saying that she does more of the food preparation and that she thought the item scored a 10 out of 10. Alan also keeps and regularly refers to the lab work that was used to assist in the diabetes diagnosis. He reviews it periodically to “remind [himself] of what [his] scores were; what [his] baseline was.” Alan scored the item’s usefulness as a “10,” because it gives him the historical information, although he does not consider one lab test alone as useful on its own. Alan’s wife added that she considers the report of the A1C results to be useful in that it provides “encouragement.” The other two items pertained to the general topic of diabetes. Alan’s wife picked up the book, The Diabetic Body, shortly after Alan was diagnosed. Alan’s wife purchased the book, before they attended the diabetes education classes, because she wanted “to learn about what diabetes is.” Alan also read “portions” and said that “it does a good job of letting you know things that are important to diabetics.” He liked it, because “it is simple reading” and helped him “figure out [topics such as] the complications and how the organs are affected. [He] was looking for cause and effect; things that will help me.” The final item that Alan used was the magazine, Diabetic Living, that Alan’s wife’s friend had picked up from Publix for them after learning about his diagnosis. Alan reported that he had leafed through the magazine and skimmed the articles. He noted that the main thing that caught his eye was the advertisements, “and that was a
turn off.” He added that on a positive note, he did notice, that there is “a range of food that [he] can eat.” These two items that were provided by non-healthcare provider sources were regarded as less useful, with scores of 7 and 5 respectively.

The interview and discussion of items, uses, and information needs seemed to depict a low level of concern. This was further portrayed by some discussion that Alan was “barely” diabetic. He had identified himself as diagnosed with Type 2 diabetes, but at times he considered himself “pre-diabetic.” However, this seemingly low level of concern was met with an active search for information about diabetes in general. While Alan sought answers from friends with healthcare backgrounds, his wife actively purchased a book and spoke with friends who also provided resources. Alan used these items, although he considered information from healthcare professionals as more useful.

4.7.3 Information Needs and Item Uses Considered within Framework of National Diabetes Education Standards

The kept and used health information items were considered in terms of the needs associated with them, how they were used, and the relevance that conforms to diabetes education standards (Table 28). The needs and uses are presented in rows across the columns that correspond to the diabetes education standards. This holistic view comprised of needs, uses, and relevance provides insight into the congruency of information needs, item use, and expected necessary educational demands. As described herein, this analysis illustrates that general information needs pertain to various topics and are addressed through different uses of information items. Furthermore, this analysis provides insight into whether kept items are not congruous in these areas and will be considered in the subsequent section.

For example, an item that pertains to “Nutritional Management” was used by a participant to “get connected to [an]other,” thereby addressing the need of “Access to resources / services.” Further analysis of the data across need, use, and relevance (Table 28) also shows that of the numerous relevance decisions of “Nutrition management” (n = 247), a large number of items (n = 130) pertain to “Nutrition” and were primarily used in ways that allowed the participants be “able to plan” (n = 95) or to get “pictures, ideas, understandings” (n = 92). This view of the data provides a holistic overview of the interaction of an information need – item use – diabetes education category for kept items, and illustrates that kept items were mostly
associated with information needs of “Nutrition” (n = 143) or “Living and Managing” (n = 104) and were often used to get “pictures, ideas, understandings” within these categories (n = 97, 67.8% and 56, 53.8% respectively).

Table 28. Situational relevance attributed to the kept item with regard to living with diabetes.

<table>
<thead>
<tr>
<th>RELEVANCE</th>
<th>Nutrition management</th>
<th>Monitoring blood glucose and others</th>
<th>Personal strategies to promote health and behavior change</th>
<th>Medication</th>
<th>Diabetes disease process and treatment</th>
<th>Physical activity</th>
<th>Chronic complications</th>
<th>Personal strategies to address psychosocial issues</th>
<th>Acute complications</th>
<th>Grand Total</th>
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</thead>
<tbody>
<tr>
<td><strong>Nutrition</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>got pictures, ideas, understandings</td>
<td>130</td>
<td>5</td>
<td>1</td>
<td>2</td>
<td>2</td>
<td>3</td>
<td>143</td>
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<td>able to plan</td>
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<td>96</td>
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<tr>
<td>got started, got motivated</td>
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<td></td>
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<td></td>
<td></td>
<td>3</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>kept going</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>2</td>
<td></td>
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<tr>
<td>got control</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>2</td>
<td></td>
<td></td>
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<tr>
<td>things got calmer, easier</td>
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<td></td>
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<td></td>
<td></td>
<td>1</td>
<td></td>
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<td></td>
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<tr>
<td>reached a goal, accomplished things</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>avoided a bad situation</td>
<td>1</td>
<td></td>
<td></td>
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165
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| Grand Total | 247 | 47 | 16 | 14 | 13 | 13 | 11 | 11 | 9 | 381 |

### 4.7.4 Information Needs Portrayed by the Kept Items

A primary aim of this study, as signified by its title, was to examine what kept personal health information items may portray as expressions of need. Research questions addressed earlier examined direct statements of item uses and information needs, as well as descriptions of personal context to provide single-faceted views of the need-use-context triangle that is associated with each kept item. This question aims to holistically consider this triangle and address what need the item may also express.

Earlier findings show that kept items are primarily associated with expected uses and information needs and uses, e.g., cookbooks are associated with an information need for nutrition...
information and instruction. However, the rich narratives provide insight into deeper contexts that surround information needs and item uses and demonstrate that items, such as cookbooks that June kept, reflect much deeper needs.

4.7.4.1 Cookbooks for nutrition, as well as psychosocial information needs. June was diagnosed with diabetes in the mid-1990’s. She received diabetes education at that time, but described it as “much different” than what she received during her current session. Her original instruction promoted sugar-free baking, or later, using sugar replacements, such as Splenda. During the interview in which several cookbooks were described, June talked about her love for baking, and that she valued making and sharing “traditional” foods with her family. She had tried various sugar substitutions in her favorite recipes, but while she enjoyed the product, her family tasted the difference and often did not eat it. June struggled with this tension of making the traditional items so her family would enjoy it, or making it so she could. It is this tension that is expressed by the presence and use of the numerous cookbooks in June’s home. June was delighted to learn that the current diabetes education classes approached diabetes management using portion control, more than sugar avoidance. She was looking forward to going back to her recipes, and while still possibly trying to modify them a bit for cholesterol, was looking forward to again baking the “traditional” recipes that everyone, including herself, could enjoy.

4.7.4.2 Recipes for nutrition, as well as psychosocial information needs. Renee is director of a state government department. She was diagnosed with diabetes 10+ years ago and learned about the program of “exchange stuff” to manage diabetes, but said that it required too much effort and that she “couldn’t work it given her schedule and travel.” Instead she clipped recipes through the years and tried to buy items in bulk to make them and freeze. When she had to undergo surgery recently, the precursor lab tests showed problems that led her physician to send her to the current diabetes classes, helped her “learn about the big picture and realize the implications of stress.” Renee is a successful director who manages to excel at her job, yet when it comes to managing life with diabetes, she has “a goal [in reference to being healthy], but struggle[s] to get there.” While the kept and used recipes, as well as the daily emails from Prevention and the weekly newsletter from dLife, offer primarily nutrition related content, these items in the context of Renee’s struggle also represent an information need of psychosocial and personal strategy guidance. She has much information, but needs a plan to put it in effect relative to her life.
4.7.4.3 Nutrition management books for nutrition, as well as personal strategy information needs. Several participants kept various items that included content pertaining to fat, sugar, and cholesterol content, e.g., *The Calorie King*, *The Complete Book of Food Counts*, and *Total Food Counter for Healthy Living*. These items provide nutrition information and as such, serve an information need of nutrition knowledge. However, participants describe uses of these items that express an information need to develop personal health management strategies. For example, Dan described how he would “grab either *The Calorie King*” or the pamphlet, *Nutrition in the Fast Lane*, when he needs to make a food choice. He first looks up what he wants to eat, but will make an adjustment depending on nutrition information given in the items. Janice uses the book, *The Calorie King*, mainly to create a shopping list, especially when it comes to choosing different “carbs.” The book also has “information about fat in the back,” so “it really helps to make the shopping list.”

4.8 Conclusions

This chapter provided the results of the questions posed by this study which aimed to determine information items that are kept by adults living with Type 2 diabetes to help them manage their life. Specifically, the results presented herein served to explore the influence of personal context on keeping, the information needs and item uses associated with these kept items and the situational relevance attributed to these items. The specific findings include:

1. Types of information items that are kept and used include e-books and websites.
2. The participants’ health information keeping and use behaviors were conducted in three contexts: adjustment; challenge in living with diabetes, and emotion.
3. Some kept health information items were associated with multiple uses and information needs.
4. The majority of kept health information items were used for the purpose of getting ideas and understanding.
5. New categories (5) for item type were created: logs, meters, handouts, recipes, and prescription information.
6. A new category for item use was created: To Monitor.
7. All items mapped to categories of information need found in literature, or those of the National Standards for Diabetes Self-Management Education. Over half of
information needs associated with the kept and used items pertained to Nutrition, and another quarter pertained to Living and Managing life with diabetes.

8. When kept and used health information items were considered using a holistic lens of stated information need, item use, and personal context, some items were found to express information needs other than what was expected.

The next chapter, Chapter 5: Discussion, aims to put the results presented in this chapter in context. Specifically, the results are discussed relative to the literature and insights are provided regarding potential implications of these results. The study limitations are also presented.
CHAPTER 5
DISCUSSION

This study explored the information needs and associated behaviors that were identified by examining health information items that adults with Type 2 diabetes keep in their homes to help manage life with diabetes. The specific concepts of interest include health information items, item use, usefulness, specific relevance, and corresponding information need. A framework of situational relevance served to investigate these information behaviors as the specifically to participants personal context. The methods employed and the results of this study were presented in earlier chapters. The research questions in this study focused on exploring the items that are kept; taxonomies of item types, uses, and information needs; cohesion across item types, information needs, and item uses; as well as the relevance of the item with regard to diabetes management (situational relevance). The baseline taxonomies used to code the data were pulled from the literature, but the need for additional categories was identified. This chapter presents a review of the research questions and the analysis procedures; offers a review of key findings; discusses the implication of findings with regard to current literature and to theory; highlights the limitations of the study; provides recommendations for future research; and offers implications for professional practice.

5.1 Review of the Research Questions and Analysis

This study sought to address the overarching question: What do the health information items kept in homes of adults living with Type 2 diabetes, and used to help manage life with diabetes, say about the information needs of the individuals? This question and the sub-questions presented below were addressed by through semi-structured interviews (n = 21) conducted using a naturalistic approach. Interviews conducted in participants’ homes encouraged discussion that was focused on health information items kept in the home. The specific research questions posed and the subsequent analysis procedures are described herein.

The first research question, RQ1, pertained to personal health items kept relative to living with diabetes and aimed to investigate the specific types of items that the participants kept and to assess the prevalence of kept items. The analysis procedures used to address these questions included coding item types using categories derived from relevant literature. Analysis also
addressed the potential need for additional categories in order to describe all items. Results were presented as a list of used categories and a table of frequency.

This second research question, RQ2, sought to explore and present factors of personal context, e.g., demographics and family history, associated with the information keeping behaviors of participants, i.e., individuals living with Type 2 diabetes who kept and used personal health information items. Results were presented as cross-tabulations.

The third research question, RQ3, sought to address the uses of kept information items and the fourth research question, RQ4, sought to address the information needs that were associated with kept health information items. The uses described by participants and the participants’ descriptions of information needs that were associated with the used items were coded according to historical or study developed categories. Results were presented as frequencies.

The fifth and primary question, RQ5, sought to address the relevance of kept health information items to living with diabetes. Specifically, the sub-questions examined situational relevance; the relevance of the kept health information items relative to the national standards for education curriculum categories; the congruency of information needs, item use, and relevance decisions; and any information needs associated with the kept health information items that are implied. These questions were examined using rich descriptions provided by the participants and by examining the coded information needs and item uses within the framework of the diabetes education national standards. The results are presented as cross-tabulations and qualitative rich descriptions.

5.2 The Participants: As a Reflection of the Population with Type 2 Diabetes

The participants interviewed for this study (n = 21) were diverse in context of demographics, living situations, diabetes management, and diabetes history. Specifically, this study gives voice to: men and women; African-Americans and Caucasians; retired and working participants; home owners and renters; those with children in the home and those who were childless; those managing diabetes with medication and those who do not; those who are new to diabetes and those who have lived with diabetes for several years; those with incomes spanning from low to above-average; those with high school educations to those with graduate degrees; and those who are insured and non-insured. This diversity of participants, however, does not
specifically reflect the national diversity of diabetes as reported by the American Diabetes Association (ADA).

According to the ADA (2013) the “face” of diabetes affects men and women of various ages, races and ethnicities. While more men aged 20 years or older are diagnosed with diabetes (13.0 million, 11.8%), the diagnosis prevalence for women aged 20 years or older is not far behind (12.6 million, 10.8%). While there is insufficient data to accurately estimate the prevalence of diabetes for many race groups, diabetes is estimated to be more prevalent among individuals considered non-Hispanic black (4.9 million, 18.7% of the non-Hispanic black population) than non-Hispanic whites (15.7 million, 10.2% of the non-Hispanic white population). Diabetes is diagnosed in individuals of all ages, but is more prevalent among adults aged 65 years or older (10.9 million, 26.9% of people in this age group). Using data from 2005–2008, the estimated percentage of adults aged 20–44 years with diabetes was 3.7%, and 13.7% among those aged 45–64 years (National Center for Chronic Disease Prevention and Health Promotion, 2011). According to the Centers for Disease Control and Prevention (2012), the age prevalence of diabetes by 2010 in Florida, where this study took place, follows national trends in that more older adults were diagnosed with diabetes: ages 18-44 (3.7%); ages 45-64 (11.6%); ages 65-74 (20.2%); and ages 75+ (18.4%).

The sample used for this study is different than the national “face” of diabetes, as it was comprised of more women (n = 15, 71.4%), was predominantly non-Hispanic white (n = 17, 81.0%), and drew more from middle-aged adults (ages 18-44, n = 1, 4.8%; ages 45-64, n = 14, 66.7%; ages 65-74, n = 4, 19.0%; and ages 75+, n = 2, 9.5%). The results provide voice to both men and women, as well as individuals of both non-Hispanic black and non-Hispanic white races. The study also included at least one Jewish participant and gives voice to individuals who have a family history of diabetes (n = 12, 57.1%). While national data do not report the percentage of individuals with diabetes who have a family history, the Centers for Disease Control and Prevention (2011) reports that individuals who have “parents, siblings, or children with diabetes are 2 to 6 times more likely to have the disease than are people with no affected relatives” (para. 8).

As for diabetes management means, e.g., oral medication, insulin, diet, or exercise, according to the ADA (2013), among adults with diagnosed diabetes, 16% do not take either insulin or oral medication. Over one-third of study participants (n = 8, 38.1%) reported that they
managed their diabetes using means other than medication. Thus, the study’s sample represents more individuals, relative to national averages, who are managing life with diabetes without medication.

National data pertaining to the background of individuals with diabetes is void of mention regarding greater personal context, such as occupation, hobbies, and overall life story. Therefore, while the differences in the study’s sample relative to the national “face” of diabetes are noteworthy, this study provides insight into items maintained and used by individuals. It is the context of each of these participants that contributes to the overall landscape of life with diabetes. The results of this study are limited due to sampling and are not generalizable, but the results are robust in that they were obtained using a diverse sample across aspects beyond age, race, and gender. Participants varied across richer dimensions that include familial history of diabetes, emotional response to the diagnosis, life experiences, goals, and adjustment strategies. The study’s participants are representative exemplars and are well suited to inform information professionals, diabetes educators, and health information management tool developers of the information needs and item uses that may be associated with health information items that are kept by adults living with Type 2 diabetes.

5.3 Key Findings

The results of this study included the following key findings. These findings are discussed herein, alongside relevant literature and, as relevant, theoretical implications.

1. Types of information items that are kept and used include e-books and websites. Two types of information technology not previously found in literature to keep and access health information items were identified in the current study: e-book readers and smartphones.

2. Participants’ health information keeping and use behaviors were often discussed with regard to four contexts: activity; adjustment; challenge in living with diabetes; and emotion.

3. Historical categories for Item Type were not sufficient to describe all data, so new categories were created for: logs, glucose meters, handouts, recipes, and prescription information.
4. Historical categories for Item Use were not sufficient to describe all data, so a new category for item use was created: To Monitor.

5. When kept and used health information items were considered using a holistic lens of stated information need, item use, and personal context, some items were found to implicitly express information needs other than what was explicitly described.

5.3.1 The Items within the context of Personal Information Collections

This study first sought to determine what health information items are kept in homes of adults with Type 2 diabetes. Based on the work of Moen and Brennan (2005), anticipated findings included an array of items, such as stacks of receipts; journal clippings; lab results; special cards holding vital information, e.g., medication, blood type, medication information; folders and notebooks with personal health information or insurance information; medical record information; calendars; phonebooks; folders that include medical history or separate sheets of paper with information of procedures, medication side effects; and, less commonly, personal digital assistants or personal computers. Based on the findings of the current research, participants with Type 2 diabetes keep and use an array of items, but the diversity of items is not as vast as that found by Longo (2010) or Moen and Brennan. This study’s results likely differ from those of Moen and Brennan in that they investigated items and their use to manage the overall health for a family, as opposed to this study’s focus on keeping and using items specifically to Type 2 diabetes. Longo examined a similar population as this study, but the majority had lived with Type 2 diabetes 5+ years, as opposed to this study’s participants who were primarily newly diagnosed. This difference with experience may account for the additional types of items that Longo found, including audiotapes, story clippings, product information (e.g., Glucerna or information in insulin kit). While it is likely that this study’s participants kept some of the items previously found (Moen & Brennan) - e.g., birth certificates, immunization records, x-rays, and health insurance cards - the participants were not prompted for this type of material. Based on the findings that these items were not revealed as kept and used, participants who are managing life with Type 2 diabetes do not readily consider these items as related to managing life with diabetes. The only exception is the health insurance card, kept by 88% of participants who mentioned it to Moen and Brennan. John identified that he “kept” a health insurance card
and that he uses with regard to health management. However, he did not consider it as
specifically used to manage life with diabetes, and the health insurance card was not included in
the study’s analysis and results.

Although only John recognized a health insurance card as possibly related to managing
life with diabetes, the symbolism of a health insurance card as access to health care merits
discussion. While all participants had access to healthcare, in that they were recruited from a
diabetes education center associated with a teaching hospital, a majority of participants (n = 19,
90.5%) had health insurance. The exceptions are Dan, a sixty-year old business owner, and Jack,
a forty-nine year old male who had worked for companies that did not provide health insurance
or had been without work for “quite some time,” so was without insurance. Jack accidently
received insurance coverage when a company put him on their group policy for three months. He
quickly took advantage of the opportunity and went to doctor, because he had not been “feeling
right.” Prior to that recent visit, he had not seen a doctor for ten years. The doctor ordered many
lab tests, but unfortunately, Jack’s insurance coverage ended before he had the blood work done.
Once he received coverage through Medicaid and had his lab work completed, he finally learned
that he had diabetes. He also then learned that Medicaid in Florida does not cover diabetes
education. He had access to the classes, but without insurance, Jack had to pay out of pocket
$240 for each of the three, three-hour sessions. Fortunately, his family provided a loan after they
realized how important the classes were to him and he “learned more in a one hour session with
the educator at the diabetes center” than he learned in all his reading and the time with the nurse.
Given this, although the participants did not readily identify the importance of a health insurance
card to managing diabetes, Jack’s story sheds insight that a health insurance card may be
perceived more importantly by individuals who do not have coverage.

The results of Moen and Brennan (2005) also identified that over half of the participants
(59%) identified that “medical schedules” were used to manage general health. These schedules
include calendars, and their use seemed to symbolize pre-planning of health management
appointments. Based on the results of this study, in that only John and Jack (9.5% of the sample)
identified a calendar or planner as relevant to managing life with diabetes, individuals with Type
2 diabetes tend not to consider planning beyond a day’s or week’s limit as needed for living and
managing life with diabetes. Given the possible complications associated with diabetes,
individuals with diabetes need regular foot and eye exams. Depending on insurance, these exams
may be covered annually, so it is possible that a calendar could be used to monitor these exam dates. In lieu of planning activities that could be associated with calendars, the results of this study show that individuals with Type 2 diabetes may use calendars for tracking or pre-planning activities. Specifically, Jack used his calendar to simulate some functions of a medication box; he kept track of and monitored adherence to medication dosage times. This method seemed to promote compliance, and thus fostered effective diabetes management. The results of this study also show that individuals with Type 2 diabetes may use calendars to pre-plan, but not specifically for appointments. John described how he used his planner along the lines of pre-planning of life activities, like a recent trip to New York. He used the calendar to monitor pending travel dates and medication refill dates, so he could ensure that he had his “meds lined up.” While the results of the participants’ actions and description indicate the importance they place on managing his diabetes, the importance and relevance of a planner was best summarized by John: “It's not about what you want to do, it's about what you have to do. If you don't keep track of it [meaning glucose readings, food intake, and medication dosages], it [meaning diabetes] can kill you.”

Based on the results of this study, of further importance to individuals living with Type 2 diabetes, more so than to individuals merely focused on managing general health, are reference material and lab results. While Moen and Brennan (2005) found that their participants kept these items, over half of their participants who were focused on general health kept more of different items, specifically: prescription information, health care provider information, medical schedules, medical history, and personal observations. Less than half of their participants kept lab results and reference material, e.g., instructions on self-care. Based on these findings, it is likely that participants with Type 2 diabetes have specific information needs with regard to living with and managing diabetes, and therefore keep and use items that encourage learning about the disease and its management.

The findings of this study also show that individuals with Type 2 diabetes are slow to use new information technologies, specifically PDA-like devices and e-book readers, or current home computer technology to manage life with diabetes. Specifically, individuals with Type 2 diabetes are moving away from the use of personal digital assistants (PDAs) that Moen and Brennan (2005) found among individuals who managed their general health, to today’s smartphones. The findings show that while access to smartphones may be common across
patients with Type 2 diabetes, use of diabetes related apps is limited. Access to e-book readers is limited in comparison to smartphones, but based on the study’s findings access to an e-book reader does not equate to keeping and use activities of diabetes-related e-books. Additionally, the results of this study show that while individuals with Type 2 diabetes may have home computers and Internet access, few individuals regularly bookmarked diabetes-related websites and few create or store digital documents. The low saturation and use of e-book readers among adults managing life with Type 2 diabetes stands in contrast to the recent findings of Zickuhr, Rainie, Purcell, Madden, and Brenner (2012) who report that following the 2011 holiday season nearly one-fifth of American adults reported reading an e-book in the past year. Given the high adoption rates and general use of many personal electronics such as smart phones and e-book readers, the minimal of use of electronic items, such as smartphone applications (i.e., apps) and e-books, the low use of digital resources may indicate that these information technologies are not perceived as useful for managing life with diabetes.

**5.3.1.1 Online health information items.** Based on the findings of this study, personal information collections (PICs) continue to grow “in diversity and complexity” (Bruce, Wenning, Jones, Vinson, & Jones, 2011) and the collections of adults living with Type 2 diabetes include website bookmarks and e-books. Few participants kept electronic health information items or bookmarked diabetes related websites to manage life with diabetes, although the majority of participants had computers in the home with Internet access. The limited amount of digitally stored health information may be a reflection of 1) the continued preference for paper books, although literature that states digital books are gaining in popularity (Rainie & Duggan, 2012), and 2) the predominantly paper world of healthcare, which may include paper copies of lab results, paper educational handouts given by healthcare providers, and paper prescription resource sheets provided by pharmacies. At the time of the study, hospitals and healthcare providers were increasingly moving to electronic health records and were not required to provide digital material as part of meaningful use. The preponderance of paper items may change when the requirement of providing digital patient education materials and copies of patient records begins October 2014. As adoption of smartphones and other digital patient monitoring devices increases, the frequent use of paper logs may also drop. Based on the results of this study, some individuals prefer to track diabetes-related data using electronic items, such as a spreadsheet in Microsoft Excel, although providers prefer and request to see paper-based logs. As providers
adjust to using electronic systems, their preferences may adjust and patients may increasingly be encouraged to use non-paper means.

Individuals with Type 2 diabetes may bookmark sites that are useful to managing life with diabetes, but based on this study’s findings these individuals are also comfortable using a search engine, e.g., Google, and may prefer to search using keywords that reflect their question, rather than going directly to a specific site. The search engine first approach can help direct Type 2 diabetics to useful sites, i.e., DiabeticConnect, dLife, or Mayo Clinic, or to specific information items, e.g., “Foods You Can Eat with Diabetes.” This comfort of searching for health information online is well documented. These findings are similar to those found in a recent study by the Pew Internet and American Life Project (2013). While more than half of all Americans search for health information online, nearly 75% of individuals who have access to the Internet do and over three-quarters of these individuals begin at a search engine, such as Google, Bing, or Yahoo. Another one in ten begin a search “at a site that specializes in health information, like WebMD,” while fewer online health information seekers use general sites, like Wikipedia, or social network sites, like Facebook. This study is silent regarding the use of general and social network sites that were found by Pew (2013) because of the research design and focus on kept and used information items. While it is possible that the individuals with Type 2 diabetes use social networking sites, given that nearly three-quarters of adults age 18 – 29 and one-third of those age 65+ years (Brenner, 2013) use these sites. However, the findings from this study show that individuals with Type 2 diabetes who keep and use information items to manage life with diabetes do not bookmark general and social networking sites. They may, however, use the sites to help manage life with diabetes be gaining access to the sites using search engines or by specifically typing the URL. The current findings expand upon past literature pertaining to sites used by online health information seekers to show that those with specific conditions, such as Type 2 diabetes, bookmark and use condition-related sites, such as DiabeticConnect or dLife.

5.3.1.2 Source of information items. Findings from this study show that nearly six in ten items that adults living with Type 2 diabetes keep and use are personally acquired, while one in three are provided by doctors and healthcare professionals, including pharmacist. Only one in twenty items that are kept and used are provided by friends and family. Self-acquired items tend to primarily include recipes or recipe booklets and magazines that are picked up on impulse when running errands, such as picking up medication. Some self-acquired items are purchased as
a result of a trip to the book store for the specific purpose of purchasing diabetes related material. These findings of high levels of self-acquisition indicate that the importance of information items chosen for oneself may be overlooked. Findings from a Pew (2013) study of online health information seeking showed that when individuals last had “a serious health issue or experienced any significant change in … physical health,” they sought information – online and offline – primarily from doctors or other health care professionals (62%, 1% online) and friends or family (40%, 1% online). By focusing on the kept item, as opposed to asking about the process taken when an information need arose, this study showed that adults living with Type 2 diabetes primarily kept and used items they found themselves, even when they had been given many items during diabetes education classes. The materials provided by diabetes educators and healthcare providers tend to focus on instructional information, whereas the self-acquired items tend to be about mechanics of eating.

5.3.1.3 Nature of information items: Active or passive. Based on the findings of this study, although management of Type 2 diabetes can include activities of monitoring various measures, such as glucose readings or carbohydrate intake, the majority of items kept and used by adults living with Type 2 diabetes are primarily to be read, assimilated, and personally applied, i.e., passive in that the items serve to inform the reader via words and pictures. Health information items that pertain to instructions for behavior change, such as a stress management handout, could be considered more active. However, many adults simply read and store the knowledge; some actively apply the lessons and take active steps to respond to the information, e.g., going to the beach on the weekends or taking relaxation classes. Items actively used by adults with diabetes include glucose, nutrition, and food logs. The study’s findings show that while many adults engage with the various logs to some degree, only some engage with this created material to generate knowledge and action. For some, the action of keeping the log is meant to inform a healthcare provider and will thus use a log format this is specified by the outside party.

5.3.2 Importance of Personal Context and Item Use

Similar to previous studies of health information seeking (Pew, 2013; Weaver et al., 2010), findings from this study show that gender appears to be associated with information keeping and use behavior, in that women were found to use more health information items than
men to manage life with diabetes. Beyond gender, however, based on the findings of this study, demographics plays little role in information keeping and use. Findings showed though, that larger contexts, as defined by specific personal situations bound information keeping and use behaviors. These personal situations, which may include length of diagnosis, family history, presence of children in the home, hobbies, interests, and goals, as well as specific knowledge and beliefs, provide a holistic picture of the situational relevance (Wilson, 1973) in which an item was kept and used. Although, all adults living with Type 2 diabetes operate from within this global frame, results show that information keeping and use activities occurred in four, more specific contexts: activity, adjustment, challenge in living with diabetes, and emotion. Examining keeping and use of information items within these contexts provides insight into specific situational relevance of kept items. These contexts are discussed herein.

5.3.2.1 Activity. Based on the findings of this study, adults with Type 2 diabetes who participate in diabetes education classes are aware that activity is important and helpful in managing glucose levels. A memorable activity led by diabetes instructors that demonstrates the effect of exercise on glucose readings ensures that students grasp the importance of activity. Findings show that while many recognize the importance of activity, and that they strive to stay active or increase activity, individuals who actively employ activity to help manage life keep and use fewer items. Thus, it appears that those individuals who keep and use more information items choose to manage diabetes using means other than activity.

5.3.2.2 Adjustment. The findings show that adults living with Type 2 diabetes may experience adjustment as indicated by statements of “wanting to learn,” “struggling to meet a goal,” and “making changes.” Often the adjustments described were in reference to diet or exercise, but for some it also referred to changes in overall approaches to life. Findings show that a strong sense of needing to make adjustment does not necessarily translate into retention or use of information items, though. Adults living with diabetes may keep numerous items that seem to mark attempts to find some balance, while others depend on regular searches or opportunistic acquisitions of information that is used and then discarded. Information items that lend themselves well for a journey of adjustment include newsletters, magazines, and websites. These items provide different content at regular intervals. Frequent clipping of recipes or regular purchases of new cookbooks are other avenues through which adults living with diabetes strive to adjust to managing life with diabetes.
5.3.2.3 Challenge. The study’s results show that adults diagnosed with Type 2 diabetes tend to keep and use information items in a context of living and managing the disease that they describe as challenging. For some the challenge is associated with food and may be in learning what to eat and in what portions; how to cook, especially in earlier years when the guidance was to modify recipes; or “giving up” beloved sweets, or at best cutting down on the amount. Others find challenge in figuring out when to take medications, while others simply see the challenge in dealing with life that seems changed. Presence and use of kept information items within this context seem to express the notion that adults with Type 2 diabetes work to find some control, in ways such as learning to read nutrition labels or to figure out what diabetes is.

5.3.2.4 Emotion. Based on the findings of this study, some adults living with Type 2 diabetes experience various emotions in the context of living and managing life with diabetes. Strong emotions, e.g., fear, anger, or disappointment, often arise at time of diagnosis, but may also occur prior to health information items acquisition or use. Based on this study’s findings, adults who have a family history of diabetes or children living at home may demonstrate stronger emotional responses, e.g., fear or anxiety. In order to deal with fear that may arise when a diabetes diagnosis is received, adults may seek information, i.e., monitor. Sometimes healthcare providers may immediately provide educational material, but sometimes patients are simply told that diabetes educators will call them to schedule time to meet with them. The knowledge that they will be given instructions in the near future is enough for some patients, while others may go home and panic, and others may actively seek information. For some the act of seeking and readily finding diabetes-related information items is enough to produce calm. Others however, may need to read much of the material they find before they begin to feel some control.

5.3.3 Item Types

The results of this study show that the historical taxonomies for types of items that adults with Type 2 diabetes keep and use (Longo et al., 2010; Moen & Brennan, 2005) are not sufficient to describe all items that are found in homes. Therefore, based on the study’s findings, five new categories for Item Type were created: logs, glucose meters, handouts, recipes, and prescription information. The need to add these categories demonstrates the insights provided through the information keeping lens that guided this study, as opposed to the information seeking focused study of Longo et al. (2010). Adults with Type 2 diabetes do seek information,
but they also keep information items that healthcare providers, pharmacists, and diabetes educators give them, e.g., glucose and dietary logs, glucose meters, or prescription information sheets. These items are not actively sought. The current work is similar to that of Moen and Brennan (2005) who also investigated information keeping behaviors, but their focus was on health information items kept to manage the overall health for a family. Based on the findings of the current study, individuals with Type 2 diabetes keep information items that fall under additional categories in order to specifically manage life with diabetes.

5.3.4 Item Usages

Based on the findings of this study, Song’s (2007) list of Item Use categories, developed from the results of various health information seeking situations, include many categories that do not apply to adults with Type 2 diabetes and their use of kept health information items. Specifically, based on this study’s findings, adults managing life with Type 2 diabetes do not use kept information items in ways that could be categorized as: “got out of a bad situation,” “took mind off things,” “relaxed, rested,” or “got pleasure.” However, based on the study’s findings the categories for Item Use need to expand to include “To Monitor,” adults with Type 2 diabetes keep and use various information items, e.g., glucose meters, and glucose and dietary logs, to record, and to potentially monitor, various health and nutrition parameters.

The study’s findings also show that adults with Type 2 diabetes use the vast majority of kept health information items for the purpose of getting “pictures, ideas, understandings.” Kept health information items frequently promote understanding about diabetes and offer suggestions for successful diabetic management, such as learning to recognize how their body feels when sugar levels are low and to then test or do something like drink orange juice. For Arlene, the information of "what is a diabetic episode" was an important lesson. By using the kept health information item, she now understands that when she is sweating and feels anxious that it may be due to low blood sugar. Prior to the diabetes education classes, she often attributed those feelings solely to the heat in her mail truck. Other kept and used items contain information about nutrition and gaining skills to balance nutritional needs of living with diabetes. These skills allow participants to plan better with regard to what they eat and taking their medication. Further based on the findings, some items that are kept, such as a bookmark for the DiabeticConnect website,
are used for support where peer responses and "blog bits" can reduce feelings of loneliness as one adjusts to managing life with diabetes.

5.3.5 Information Needs: Explicitly Stated or Expressed through Narratives

Based on the findings of this study, adults with Type 2 diabetes primarily use kept information items for information needs that are readily attributed to them, e.g., reference type diabetes books are associated with information needs to learn about diabetes; recipes and nutrition content books are associated with information needs of preparing or purchasing meals that meet suggested carbohydrate balances; and dietary and glucose logs are associated with information needs of recording measures helpful for managing diabetes. As such, these kept items are readily considered as “topic-appropriate” for individuals managing life with diabetes and are logically relevant (Cooper, 1971) to the seven key behaviors or lifestyle habits identified by the National Standards for Diabetes Self-Management Education (Funnell et al., 2009):

- Describing the diabetes disease process and treatment options
- Incorporating nutritional management into lifestyle
- Incorporating physical activity into lifestyle
- Using medication(s) safely and for maximum therapeutic effectiveness
- Monitoring blood glucose and other parameters and interpreting and using the results for self-management decision making
- Preventing, detecting, and treating acute complications
- Preventing detecting, and treating chronic complications
- Developing personal strategies to address psychosocial issues and concerns
- Developing personal strategies to promote health and behavior change

Additionally, based on the study’s findings, persons with Type 2 diabetes do use items not readily associated with diabetes for the purpose of managing life with diabetes. For example, some general cookbooks and recipes may double as useful resources for cooking to manage life with diabetes. However, this use of the items was coupled with knowledge of portion control or ingredient substitution in order to successfully make the crossover from general use to diabetes-related use. Thus, while common household items such as thick phonebooks or catalogs can readily double for other items, such as booster seats for children or window supports to keep an
older window open, the use of kept general information items for diabetes-related information needs requires some knowledge.

5.3.5.1 Information needs expressed by narrative. Based on the findings of this study, some health information items that are kept and used by adults living with Type 2 diabetes portray information needs that vary from the needs that are explicitly described. These implicit information needs are found to emerge through the situational relevance described during narratives detailing item acquisition and item use. According to Raber (2003) information needs are non-observable, cognitive notions that must be inferred from observing the search process or evaluating the result of search. However, this study evaluated information needs after a search or item acquisition process, i.e., an item was received had occurred. By focusing on a kept and used health information item, descriptions of what was occurring during the time that an item was acquired or of what use was attributed to a kept information item provided explicit statements of information need. Additionally, personal narratives that emerged throughout the interviews offered insights into specific situational context that encompassed item acquisition and use descriptions. These narratives, thus, provided insight into information needs that were not readily described or attributed to the items. Specifically, based on the findings of this study, health information items that are kept and used by adults with Type 2 diabetes are associated with explicit information needs pertaining to managing life with diabetes, but some items also represent implicit information needs. For example, items such as cookbooks and recipes are readily identified as meeting information needs pertaining to nutrition; however, these items may also portray needs associated with psychosocial needs. This study found that these types of items may portray a personal struggle to find successful management strategies in order to achieve a goal for positive health, or a struggle to find ways to adjust diet to meet family meal and food norms. For example, adults with Type 2 diabetes may find it difficult to modify “traditional,” family-cherished foods in ways that make the item more suitable for their needs, but that leave it “the same” as family members remember. While diabetes management strategies now promote portion control more than sugar substitutes, cookbook and recipe keeping behaviors may signify needs for information with regard to the psychosocial difficulties.

Findings from this study also show that kept and used nutrition management books were mainly associated with information needs pertaining to nutrition. However, personal narratives revealed that these books also express an associated information need to learn about and develop
personal strategies that promote positive food selection and purchase. Kept and used nutrition information items, e.g., *The Calorie King*, *The Complete Book of Food Counts*, and *Total Food Counter for Healthy Living*, provide content about nutrition that adults living with diabetes need to know about food in order to make choices that meet various nutrition bounds, e.g., no more than forty-five carbohydrates per meal. However, these items represent other strategies that are useful for optimal management. For example, with knowledge of nutritional content of various foods, as well as personal meal and daily limits, adults with diabetes can use the content in the books to help them make food choices, create a shopping list, or identify different carbohydrates.

The results of this study also revealed that the near absence of health information items in the home of adults with diabetes can demonstrate the importance of making diabetes relevant material available at different places where it may be identified and used on location. While it is not possible to determine specific information needs that individuals who do not keep health information items may experience, absence of items does not necessarily indicate that information is not sought or used. In fact, information may be as actively sought and used in this case as it is for individuals who keep many items in their home to help manage life with diabetes. This insight was provided by Arlene, who purposely chose not to keep a computer or paper items in her home. She has access to resources through her work or through family, so she opts to depend on her memory and keep her home free of papers. A possible implication of this type of information seeking behavior is that searches may need to be repeatedly conducted for similar information needs, or perhaps happenstance access to diabetes related information may drive item use. Further study of this type of information behavior is warranted.

### 5.3.5.2 Possible explanations for prevalence of nutrition-related items.

In addition to examining whether kept and used health information items represented information needs other than their intrinsic purpose, the prevalence of nutrition-related items could represent more than nutrition- or psychosocial-related needs discussed above. The tendency for participants to keep more nutrition-related items than items associated with any other category from the diabetes self-management education (DSME) framework could indicate a focus on nutrition during diabetes education classes. This is a possibility as one class session and parts of the other two classes covered nutrition-related topics, e.g., portion control, nutritional content, daily meal planning, and eating out. The classes included time for topics within each DSME category, e.g., an exercise activity to demonstrate the effect of exercise on blood sugars, discussions of foot exams,
and time to draft an action plan, but it is possible that the prevalence of nutrition-related kept and used health information items indicates a focus on nutrition content in the diabetes education classes. The prevalence of nutrition-related items could also indicate that participants perceive that Type 2 diabetes is basically a food-related disease. Another possible reason for the prevalence of nutrition-related health information items is that many participants were recently diagnosed. Some participants who had lived with diabetes the longest had numerous recipes and cookbooks, while those who were recently diagnosed had more nutrition-counting books and pamphlets or meal planning guides. If participants do perceive Type 2 diabetes as a food-related disease, then the possible evolution from nutrition-counting books to recipes may indicate that as individuals with Type 2 diabetes learn about managing nutrition, they need to continually find fresh ideas to sustain management.

5.4 Implications for Theory

Unlike traditional studies of information behavior, this study investigated information needs and use, from the perspective of a kept health information item that had already been sought or acquired. This approach used to study the information behaviors of adults living with Type 2 diabetes is similar to that taken by Moen & Brennan (2005) in their investigation of kept items used to manage general health. While Moen and Brennan took this approach for the purpose of identifying personal information management strategies, this study aimed to identify information needs. The approach of focusing on a kept item views the information seeking process as a tangential concept. As a result, insights of the information seeking process associated with the item are available, but they are limited. This approach of using the item to lead discussion of information behaviors, while limiting insight into the information seeking process, provided findings that have implications for theories of information needs and use. Specifically, the study’s results inform: imposed query (Gross, 1999); information encountering (Erdelez, 1997); and monitoring-blunting (Miller, 1987).

5.4.1 Imposed Query

The framework of the imposed query (Gross, 1999) has provided a lens to examine the information behavior transactions of questions that are considered to be “self-generated,” in that they arose “from the context of an individual’s life and are pursued by the person who thought them up” (Gross, 2005, p. 159), or imposed, in that the question is asked for the benefit of
another. For those questions that are imposed, the answer does not benefit the individual specifically, and the importance and personal investment placed on the question and answer can vary.

The findings of this study potentially serve to inform the theory of imposed query, in that a medical diagnosis, by its nature, is a frame that is imposed upon a patient. While any symptoms that may have been present may have served to prompt “uncertainty” (Kuhlthau, 1993) or an “anomalous state of knowledge” (Belkin, 1978) that an individual may choose to act upon, the act of receiving a diagnosis potentially represents a reality that was not desired or created. It is a reality that an individual can ignore, or it can be addressed. A medical diagnosis is similar to notions of other imposed concepts, such as term projects which students are assigned. Students often have flexibility to determine topics, but certain criteria are fixed by the teacher or professor. Likewise, patients may have some flexibility in selecting treatment options, but the notion of living with a diagnosis and managing life toward a goal for positive health is bounded by external forces, e.g., available medications, finances, access to treatments, time constraints for optimal care, etc.

The findings of this study showed that although a medical diagnosis had been imposed, and education classes provided health information item in accordance with imposed notions of information needs, i.e., the National Standards for Diabetes Self-Management Education (Funnell et al., 2009), participants personally seek and acquire the majority of information items that are kept in order to address specific self-generated information needs. This knowledge extends the notion of an imposed query. While a medical diagnosis of Type 2 diabetes is an imposed reality, and material that is provided by diabetes educators is further imposed in accordance with imposed categories, adults living with Type 2 diabetes generate personal questions. While some of the imposed material addresses these self-generated questions, more questions are addressed using items that are personally acquired. It is unknown if adults living with Type 2 diabetes would readily develop self-generated questions that address the imposed categories that diabetes educators deem important to understand in order to manage diabetes.

Additionally, this study found that adults living with diabetes may be asked by providers to maintain glucose and dietary logs to inform future treatment. This study’s findings show that while keeping logs is an imposed activity, and the questions that are asked of the data are imposed, adults living with diabetes strive to use the information to address self-generated
questions, such as: what is my glucose reading after I ate fried chicken and white rice for dinner. Thus, the act of imposing an activity may lead to self-generated questions that may result in information seeking activities or use of kept information items that were imposed or self-acquired. The flow of this process warrants consideration in order to examine the interaction of imposed items and self-generated questions, or the development of imposed queries to those that are self-generated. Further study of this process of responding to imposed activities and developing self-generated questions, conducted in terms of the acceptance process of a medical diagnosis may shed light on changes in information behaviors that occur during stages of acceptance, health engagement, and health empowerment.

5.4.2 Information Encountering

Erdelez (1997) originally conceived information encountering as an accidental, or serendipitous, find of personally relevant information, pertaining to a pre-existing information need, that could occur at any time (Raber, 2003). However, the phenomenon of opportunistic acquisition of information, given its happenstance occurrence, is difficult to investigate in controlled studies. The application of information encountering in digital systems requires that bounds of information encountering (Erdelez, 2004) adapt to be more in line with the notion of serendipity, in that information discovery within these frameworks occurs during an active search for other information (Allen & Ford, 2003). By focusing on kept items that were used, the study’s findings illuminated narratives of opportunistic acquisition of information that occurred during times when a participant was engaged in an activity outside of active information seeking. Based on the findings though, adults with Type 2 diabetes tend to experience few instances of information encountering when interacting with digital systems. They tend to experience the event more in physical locations, e.g., the pharmacy.

Specifically, findings show that pharmacies provide ideal locations for these opportunistic behaviors. Primarily, individuals visit a pharmacy for the purpose of submitting a prescription script or of purchasing a filled prescription. Frequently during these visits, wait times are involved, and pharmacies contain products and racks of information items that consumers may browse while they are waiting. These racks and shelves are also positioned such that, as a consumer walks to the pharmacy desk, they can observe products and items. Given economics is involved with these products and items, marketers have taken steps, e.g., packaging
colors, branding images, and product placement, meant to encourage attention and promote impulse purchases. This study’s findings show adults with Type 2 diabetes do purchase diabetes related content that they encounter during their walk to the pharmacy to pick up a prescription. The consumer may have been primed to look for diabetes related material in that they were purchasing diabetes related prescriptions. However, although they had a general information need for recipes and information about diabetes, they were not specifically entering a pharmacy to look for information. These results, therefore, offer insights into alternative methods that may be used to investigate information encountering or opportunistic acquisition of information. By focusing on items that individuals have acquired and further examining instances in which the item was encountered, insights into conditions that influence and promote encountering will be gained.

5.4.3 Information Monitoring and Blunting

The information seeking literature contains a vein of research that examines the characteristics of individuals who seek information, i.e., monitor, and those who avoid it, i.e., blunter (Miller, 1987) during times of anxiety stress. Baker and Pettigrew (1999) posed that this theory offers a useful framework for examining consumer health information seeking behavior, as periods of medical information needs often occur in tandem with the stress of a medical diagnosis. Thus, the context of this study, adults with Type 2 diabetes, who were mostly newly diagnosed or had recently experienced difficulties in managing their diabetes, lends itself to the monitoring-blunting framework. However, while this study examined a time period of potentially high stress and anxiety, it focused on items that were kept, as opposed to examining the information seeking process. All participants had been given information items, so it was possible for participants to have items in their home, but to not have actively sought anything. This shift in focus provides opportunity to examine this theory from a rotated view. Specifically, the study’s findings are considered in light of the theory of monitoring-blunting to examine whether presence of information items could thus potentially serve to indicate that an individual was an information monitor, while the presence of only items that had been given to them could indicate characteristics of an information monitor.

The study’s findings showed that while the monitoring-blunting (Miller, 1987) framework offers a useful framework for examining consumer health information seeking
behavior (Baker & Pettigrew, 1999), it comes with limitations and that caution has to be used in extending the theory to determine if use of kept items indicates seeking or avoiding strategies. Based on the findings of this study, presence of kept items, or the presence of only items that had been given to them does not necessarily indicate whether an individual is a monitor or blunter. There were several cases in which information keeping behaviors and information acquisition did not necessitate information seeking, but also, lack of evidence of information seeking does not necessarily indicate information blunting. One participant, specifically, kept and used only two items, thus presumably presenting as someone who avoided information. However, she was actually a ravenous monitor. She used her access to information items at work and a family member’s computer to frequently seek information. In contrast, adults living with diabetes who keep and use many items could also be considered information bluters in cases when they did not actively seek any information items, but that kept and used items are provided by healthcare providers and diabetes educators. Additionally, the presence of a spouse can blur whether an individual seeks or avoids information. For some adults living with Type 2 diabetes, who attend diabetes education classes and have spouses who actively seek and bring home information, there may be no need to seek additional information. Based on the definition, individuals who do not seek kept and used information, are presumably bluters. However, this characterization is undermined in that they are willing to consume provided information, they simply do not personally seek it.

5.5 Limitations of Study

This study was bounded by several limitations, as discussed in Chapter 3: Methods. However, there are some key limitations within the categories of sample, method, and topic foci that bear noting again. With regard to sample, this study is first limited in that the majority of participants were diagnosed no more than three months prior to the interview. The findings of this study, therefore, are biased toward those who are newly diagnosed, although they do include insight of individuals have managed life with diabetes for 5+ years. Additionally, the study’s sample limits the findings in that recruitment through a diabetes education center provided a sample that had been given information items that could have been kept. This exposure to education classes possibly served to address information needs through the provided information or to provide participants with imposed concerns and information needs that they may not
otherwise had. Furthermore, with regards to the limitations imposed by the recruitment methods, participation in the diabetes education classes was not consistent. Many participants were recruited during the second class session, and some of these individuals had completed the third session prior to the interview. However, some participants had missed sessions and others had yet to complete the third and final class session. These differences in scheduling and class participation across participants means that participants had learned different amounts of material and had covered different diabetes class handouts. Specific data pertaining to the diabetes classes that the participants had attended were not collected. It is possible that differences in class participation, as well as differences in time from diagnosis and referral to class to actual class participation, may have influenced information seeking and keeping behaviors. For instance, Suzanne had missed the second class session in which medications were diagnosed. She shared during the interview that she was struggling with stabilizing her glucose readings. In attempt to successfully manage her glucose, she kept a very detailed glucose and nutrition log. This is an example where a gap in class attendance, or the expectation for instruction, appeared to influence information keeping and use behaviors.

The procedures followed for data collection and analysis methods may also serve to limit findings. Data pertaining to information item acquisition, information needs, and item use were collected by asking participants to focus on a kept item and to use the item to “telescope,” i.e., to attempt to focus the participant’s attention to a specific time. Depending on the item and its context, some participants were able to focus more on certain items, as some memories were stronger than others. Other participants displayed memory limitations or depended upon a spouse to provide responses. Therefore, the amount of detail provided across participants and items is inconsistent. The information needs and item uses, therefore, may be skewed toward items that are associated with memorable or critical incidents, toward items that reflect needs and uses more from the view of a spouse, or toward items that were kept by participants with stronger recall abilities. Furthermore, findings may be biased in that coding activities were not validated using a second researcher. Examples are provided throughout the Results to support the study’s findings in an effort to demonstrate credibility.

The findings are further limited in that some interviews were conducted with the participant’s spouse present. In most cases where spouses were present the individual with Type 2 diabetes addressed the posed research questions. However, at times spouses would also add
their comments, and sometimes they would attempt to speak for the participant. The researcher took notes as to whether a spouse was present and if details were provided by the participant or spouse. In all cases of when a spouse was present, the participant was male. The study does include views of male participants who did not have spouses present at the interview. The presence of a spouse did seem to influence the rhythm of the interview. The researcher attempted to establish rapport with the spouse and to redirect questions to the participant as needed in order to get their view, but the detail that a participant would provide in the presence of a spouse varied. Therefore, while some male participants were talkative when a spouse was present, the findings of the study are biased in that the voices of some males with spouses were subdued.

This study employed a naturalistic frame in order to investigate kept and used information items in the context in which they are used. As such, interviews were conducted in participants’ homes. This data collection process limits findings in that it specifically focused on information items kept within the confines of participants’ homes. However, individuals with diabetes must manage their diabetes in multiple settings, e.g., work, church, or restaurants. The study’s findings show that some items, such as nutrition content pamphlets and books, are purposely intended to help adults with Type 2 diabetes make food selections when they purchase food at restaurants. Some items are specifically geared to inform food selections from a grocery store. The study’s design promoted discussion of these items, but unlike discussions of items that were used in the home, discussions of items used outside the home were without benefit of occurring in precise location of item use. This difference potentially weakened the recall of specific uses that occurred outside the home and gave more weight to items used in the home.

Lastly, this study’s findings are limited in that the data reflect a snapshot in time. Although participants had been diagnosed for different amounts of time and kept and used health information items had occurred at different times, this study’s findings do not provide insight into changes in a personal information collection that may occur over time. Specifically, the findings do not include health information items that had been previously used but discontinued.
CHAPTER 6

CONCLUSION

This study was exploratory work of information needs associated with health information items that are kept in homes of adults living with Type 2 diabetes. Background for this study was provided in Chapter 2. Data were collected using semi-structured interviews (n = 21) and analysis required coding of information items, information needs, item uses, and situational relevance. Details of the study design and analysis methods were provided in Chapter 3. The specific results, which include rich narratives, as well as descriptions of the sample and the interviews, are provided in Chapter 4, while Chapter 5 presents key findings and their relationship to literature and theory; and limitations of the study. This final chapter offers implications for professional practice and recommendations for future research.

6.1 Implications and Recommendations

The results of this study with regard to the types of information items that are kept by adults living with Type 2 diabetes have various implications for library information professionals, diabetes educators, and developers of health information management tools. These implications are discussed herein. Additionally, recommendations are offered based on the study’s findings. While consideration was given to various facets of these recommendations, they are not considered a complete review of the topics and options.

6.1.1 For Library and Information Professionals

This study potentially serves to inform library and information professionals with regard to collection development for public libraries and to metadata that may be assigned to diabetes related, health information items or considered in development of information systems that direct adults with Type 2 diabetes to information that this study indicates is useful. This current research may seem far removed from libraries and information professionals, but it is actually in the crosshairs for the reasons of: the changing healthcare landscape, the push for individuals to assume increasing responsibility for their health, and the role that Elsevier and the National Library of Medicine are already undertaking with regard to integrating patient education materials and health information technology. These recommendations recognize that public
libraries and librarians are not in the business of providing diabetes education or specific health information and that there may be reasons for not acting upon these recommendations.

6.1.1.1 Findings inform collection development for public libraries. The inequality in access to healthcare in the United States is well documented (Braveman, Cubbin, Egerter, Williams, & Pamuk, 2010), and the library and information literature acknowledges an increasing discussion for public libraries to address the need of health information for those with limited access to health care in a system that is widely considered fragmented (Linnan, Wildemuth, Gollop, Hull, Silbajoris, & Monnig, 2004). The current research suggests that adults with Type 2 diabetes are frequently on the lookout for information about what foods they can eat - as an individual living with diabetes - and ideas for appropriate recipes. While some of the resources were sought directly by going to a book store, other items were serendipitously obtained, sometimes during errands to pharmacies. Therefore, while libraries may already have diabetes related material in their collections, it may be beneficial to include items like the book, *The Calorie King*, which is recommended by diabetes educators. Other titles of books, magazines, diabetes related cookbooks, and guides to nutrition that were provided during interview are listed in Appendix H. Note that the list only includes one ebook. Given the adoption rate of e-readers, though, the importance of ebooks for diabetes related material should not be discounted.

6.1.1.2 Serendipity and diabetes related material. The findings showed that adults living with Type 2 diabetes will impulsively pick up magazines and recipe booklets when pictures on the front covers catch their attention. Given the possibility that some patrons visiting a library may have pre-existing information needs for diabetes related information that they are not immediately acting upon, libraries may consider presenting diabetes specific materials in ways that encourage spontaneous selection, e.g., through the use of “end caps.”

6.1.1.3 Metadata: New categories for item types. Adults living with Type 2 diabetes keep and use health information items that fall under categories that are not found in the literature (Longo et al., 2010; Moen & Brennan, 2005) and include: logs, glucose meters, handouts, recipes, and prescription information. Of this list, the categories of handouts and recipes are applicable for public libraries, in that these items indicate that adults living with Type 2 diabetes have information needs pertaining to topics, such as self-care and complications, as well as recipes. The category title “Handouts” may need further development to provide clarity
of content in library paper collections, but may suffice for a digital configuration. The importance of the five categories is for library and information professionals who may participate in the development of health information systems that could be used to direct patients to diabetes education materials. It may not be appropriate for libraries to provide some of the kept and used items, e.g., glucose and dietary log templates, but these are items that users of information systems will need and want.

6.1.2 For Diabetes Educators

Throughout the interviews, many participants commented that they were very pleased with the diabetes education classes they attended through the diabetes center and that the information they learned in the education classes was extremely useful. Many also said that they would go back to topics, such as stress or complications, later when it seemed relevant. While many discussed what they had learned and what had helped, however, one participant noted a suggestion for improved visual aesthetics in the course handouts, as they thought it would help them engage more in the material. Specifically, a suggestion was made for a color version of the handout showing the A1C relationship to glucose readings.

Other than the one suggestion made specifically by a study participant, the researcher offers the following recommendations that emerged from discussions and participants’ comments about the items that had been provided or that they personally acquired. These recommendations are offered in the context of positive feedback.

1. Several participants had purchased the book *The Calorie King* based on the suggestion by the diabetes educators. One participant had thought about purchasing the item, but was not sure it would be useful. They trusted that it was probably useful, but needed more information about its content. Having the book on hand at the diabetes center or at the associated hospital for students, family members, or friends to peruse or to purchase might help patients feel confident about acquiring and using the item sooner.

2. Some participants had looked at the list of resources provided as a handout during class. Many participants reported that they were seeking information before they had attended the classes, though, so this list might be a useful sheet to mail with the Introduction letter that is mailed by the diabetes center.
3. Some participants left their physician's office with much information and others left with nothing except notice that they would hear from the diabetes center. Stage 2 requirements for meaningful use will encourage the provision of education material pertinent to a diagnosis. Perhaps the diabetes center can suggest material to include.

4. Several participants picked up various diabetes related magazines and cookbooks in the pharmacy or grocery store. Sample recipes, cookbooks, or cooking tips might be a welcome literature in the waiting room.

5. Along the lines of sharing cooking tips, the educators could consider setting aside a specific time during class for sharing tips. Some participants reported that they had learned about testing strip or meter acquisition from classmates, where another learned that Publix would steam shrimp and fish, making changing eating habits a bit easier.

6. The diabetes educators include various websites in their list of community resources. However, few participants had looked through the list. Given that several participants had purchased the book, *The Calorie King*, after the diabetes educators had discussed the book during the class, the diabetes educators may want to either present select websites or include an activity where class participants visit and report on a website of choice.

7. More people have and use smartphones and more applications that are relevant to diabetes, e.g., Diabetes Pal or GoMeals (Neithercott, 2013), are available. The diabetes educators may want to include suggested diabetes related apps in the resource list.

8. Participants keep many information items pertaining to nutrition and management. The recipes and cookbooks help them address the question of what they can eat, but they seem to struggle more with developing management strategies. They try resources that are encouraged, such as the book *The Calorie King*, and work to develop a strategy for keeping glucose and nutrition logs. Some record information on sticky notes, while others jot things down at the end of the day. Although successful management strategies will occur after trial and error, class participants may be able to help themselves and others if they discuss what they have tried and what has worked. Others may have ideas that are useful, and sharing information about the process may help participants to keep trying different strategies until they find something that works. Adjustments will likely be needed throughout their journey, so perhaps an idea planted in class may provide a spark for a change later.
6.1.3 For Developers of Personal Health Record Technology

The American healthcare system is undergoing a transition wherein healthcare providers are increasingly encouraged to purchase and use electronic health records. Use of electronic information systems in healthcare, primarily for business operations, can be traced back to the 1960’s. However, the current changes and increased use of electronic clinical information systems are reflective of former President Bush’s 2004 Executive Order that called for development of a national health information network by 2014 and H.R. 1, The American Recovery and Reinvestment Act of 2009 (ARRA) that President Obama signed into law on February 17, 2009. Foundational to these bills are the six aims that the Institutes of Medicine (2001) determined were critical for improvements in healthcare: safety, effectiveness, patient-centered, timeliness, efficiency, and equity.

In order to reach the goal of a fully-integrated and interoperable healthcare system by 2014, the federal government created the Medicare and Medicaid EHR Incentive Program in which financial incentives are offered to healthcare providers and physicians who purchase and use electronic health records (EHRs) in ways that are considered as “meaningful use” (Centers for Medicare & Medicaid Services, 2012a). The program consists of three stages that require increasing demonstration of functionality, which is set up as active demonstration of “meaningful use.” The criteria set up for Stage 1 required eligible professionals, eligible hospitals, and critical access hospitals to collect and transmit to the Centers for Medicare and Medicaid Services (CMS) specific measures that are considered clinical quality measures (CQMs), e.g., percentage of prescriptions generated and transmitted electronically; percentage of patients for which specific demographic data – i.e., preferred language, gender, race, ethnicity, and date of birth - are entered; percentage of patients for which vital signs are recorded; and percentage of patients for which smoking status is noted. The need to meet requirements of Stage 2 is beginning for some providers and hospitals beginning October 2014, and they will then need to face Stage 3 requirements in 2016. The differences in requirements between Stage 1 and Stage 2 include the need to submit clinical quality measure (CQM) data for an increased number of patients, and the need to “provide patients the ability to view online, download and transmit their health information within four business days of the information being available” to the healthcare provider, and relevant to this study, use the EHR to identify patient-specific education resources (CMS, 2012b). This study recognizes the importance of patient education resources,
but offers insight, based on current health information item keeping and use behaviors of adults living with diabetes, into considerations what other information to provide.

6.1.3.1 Resources beyond traditional patient education materials. In order to address the pending requirements of Stage 2 meaningful use measures, vendors have been identifying different solutions from where they can source patient education resources. There are different methods and sources that may be used to source patient education material, including traditional patient education material providers, such as Kramer or KODI. The increasing need, though, has created opportunities for new players, including traditional library and information sources, i.e., EBSCO Publishing, Elsevier, and the National Library of Medicine. The National Library of Medicine developed MedlinePlus Connect as a means to provide patient education materials for any EHR vendor who chooses to establish a connection (U.S. Department of Health & Human Services, 2011). EBSCO Publishing, however, chose to develop a resource specifically for one EHR vendor. Epic, who is credited with the largest market share of EHRs, provides functionality for clients to integrate directly with content provided by EBSCO’s Patient Education Reference Center (PRWeb, 2012). Elsevier recently expanded its healthcare specific clinical decision support content and tools with its acquisition of ExitCare, a provider of patient education and discharge instructions (Capot, 2012). These materials are unique in that they are written at a 4th grade reading level and are fully editable, meaning healthcare providers can tailor the content for specific needs, e.g. using patient friendly terms, such as “pee,” rather than “urine” (Elsevier ExitCare, n.d.).

While the corporate community of EHR vendors is readily striving to meet the requirements that the Federal government is putting in place to direct healthcare providers to send patient education materials following an office visit, this study’s findings show that patients already acquire, keep, and use various types of health information items. They keep and use patient education materials, but they also keep and use the following items: e-books, prescription information forms, lab results, and contact information for diabetes related organizations and resources. Therefore, if developers of patient-specific health information technology aim to develop technology that is truly relevant to the needs and demands of patients, they need to provide: electronic resources; links to prescription medication sites; health related links; means to determine local support resources; and means to display lab results and diabetes related medical information.
6.1.3.2 Benefit of developing personal health technology using participatory design and patients as informants. As the healthcare industry moves forward with the process of meaningful use and the automatic provision of healthcare information via healthcare information systems, the results of this study show that it would be beneficial to include patients, the recipients of patient education material, in the process of determining what items to provide and at what times in the disease journey. The participants in the study all received a set packet of health information items from the diabetes education classes they attended. These items were selected and provided based on diabetes self-management education standards and the experience of the healthcare providers. Many items served educational purposes, but others, e.g., glucose and nutrition logs, are tools that are useful in managing and monitoring diabetes. The study results also show that participants kept and used many self-acquired items. More self-acquired items, than items that had been given to participants, were used. Given the importance of empowering individuals to take an active role in managing personal health, developers of personal healthcare technology would benefit from partnering with patients in order to develop systems that meet their specific needs. This participatory design (Muller & Druin, 2011) and patient-partnering strategy, such as what is encouraged by the grant funding organization, Patient-Centered Outcomes Research Institute (PCORI), serves to provide “patients and the public…the information they need to make decisions that reflect their desired health outcomes” (PCORI, 2013).

6.1.4 For Developers of Diabetes Education Curriculums and Technology other than Personal Health Records

This study emerged from observations that some PHRs, such as that of WebMD, offered consumer health education functionality in which the technology automatically pushed emails and newsletters that contained content that was relevant to the user based on entered information, e.g., diagnoses, medications, and age. PHRs are not the sole technology that is concerned with linking appropriate education materials with consumers, however. Health care technology, such as patient portals that are linked to the electronic health records of providers, are adding this functionality, and a fit between information provision and patient is also a goal of diabetes education, be it in face-to-face settings or offered electronically. As such, this study offers insights that are relevant to technology and curriculum development. The results show how items
that are provided are used and also provide insights into what additional items adults with Type 2 diabetes independently acquire. Individuals may acquire items, such as books pertaining to the basics of diabetes or nutrition monitoring, purposely, or they may impulsively purchase recipe booklets. While participants evaluated provided items as useful, they used more items that they self-acquired. Given the importance of self-acquisition, technology and curriculum should consider implementing means for users and participants to experience opportunities of self-discovery.

6.1.5 For Future Researchers

This study included a pilot study in order to identify weaknesses in the study’s methods. As a result of this pilot study, modifications were made to the data collection process. Specifically, the pilot evaluated the benefits of using paper data collection sheets or survey software to capture participant responses. As a result of the pilot, it was determined that both paper data collection sheets and the use of survey software that mirrored the data collection instrument were difficult to use. The data collection instrument assumed a linear progress of the interviews. It started with information about an information item, what was going on (i.e., the information need) that prompted use or acquisition, details about item acquisition, and description of information use. The researcher expected to fully discuss one item before proceeding to the next item. The pilot study showed that the interviews were likely to proceed in a non-linear fashion. Participants sometimes discussed details of memories sparked by an item, including stories of family members who had died of complications from diabetes, before they shared the full details of the information item. Sometimes participants would discuss multiple items at one time. These various interview flows made data collection difficult using survey software or a paper data collection instrument. As a result of the pilot, the researcher adjusted data collection methods and entered notes directly into a spreadsheet with cells that corresponded to the data collection sheet items. This data collection process allowed the researcher to record data as it was provided during the interview, rather than forcing the interview to follow a flow dictated by a survey’s structure.

This adjustment in data collection methods was beneficial and provided the means to address the research questions posed by this study. However, additional consideration of wider
recruitment methods and the use of audio-recording may have been beneficial. These recommendations are provided herein for the benefit of future researchers.

6.1.5.1 Recruitment. The focus of this study was on adults with Type 2 diabetes. Rather than using general recruitment means, such as news postings or flyers, participants were recruited from a diabetes education center. This recruitment process ensured that participants had a diabetes diagnosis and also provided a venue for potential participants to see, hear, and ask questions of the researcher. This initial interaction possibly provided a baseline of comfort and security between research and participant. Despite this personal recruitment, recruitment was slow. During the four months participants (pilot n = 3, study n = 21) were recruited, May – September 2011, less than one in five (18.5%) of the class participants chose to participate in the study. Recruitment methods directed to the general public may have resulted in a shorter recruitment time period. Recruitment from a diabetes center also had the effect that participation tended to mainly include insured individuals who were newly diagnosed or had recently encountered a health issue that warranted diabetes education classes. Recruitment outside of the diabetes education center may have attracted participants who are at different stages of living with Type 2 diabetes, thus allowing for insights of information keeping and use behaviors of individuals at different stages of Type 2 diabetes. Recruitment from a diabetes education center also meant that study participants were given specific diabetes-related information items. Individuals recruited from outside a diabetes education center may not be given the amount and kind of material that is provided by a diabetes education center. Recruitment that included participants from both the general public and a diabetes education center would provide insight into the effect of providing information items on the information keeping and use behaviors for adults with Type 2 diabetes living with diabetes.

6.1.5.2 Audio- or video-recording. This study opted not to use either audio- or video-recording. This decision was primarily based on the idea that individuals would be more likely to participate if they were not recorded. With this approach it took four months (May - September 2011) to recruit 24 pilot and study participants from a possible pool of 130 (18.5% recruitment rate). St. Jean (2012), however, included audio-recordings during her study of adults with diabetes, and recruited 34 participants over a period of four months. The majority of the participants (n = 32) participated in the follow-up interview which was also recorded. It should be noted that St. Jean recruited using wider means, e.g., flyers in a University hospital and
several associated clinics, and diabetes-related support groups, including weigh loss groups. While it is possible that possible participants were not discouraged by audio-recording of interviews, a wider recruitment means or longer recruitment period may be needed.

While it is possible that audio-recording may slow recruitment, the benefits of audio-recording need to be considered. This study is limited in that audio- or video-recordings were not available to provide a means for inter-rater validity checks. The researcher took copious notes, but these are not full substitutes. Note, though, the audio-recordings are not full substitutes for a co-investigator. The researcher made notes of glances, tone, and emotion. While tone can be detected in audio-recordings, body language and signs of emotion, e.g., frowns or tears, are best detected visually. The use of video-recording would provide means to capture and validate these behaviors, but potential implications of their use should be assessed in a pilot study. Use could affect recruitment, and participants could be guarded. If these behaviors are important to identify, the data collection instrument should include specific areas and instructions to note any behaviors, e.g., that a participant walked away from the interview location.

6.2 Contributions

This study was exploratory, but its qualitative approach and focus on kept items to drive discussions of information item keeping and use behaviors provided rich insights from a diverse sample that contribute to the health information management literature. Specifically the results of this study make the following contributions:

6.2.1 Kept Items Primarily Paper-Based

Consumers are generally increasing use of information technology, e.g., smartphones, e-readers, Internet, etc., and the American healthcare system is also moving toward digital records, electronic connectivity, and digital patient education materials. However, the majority of items that were kept and used were paper-based items, e.g., books, cookbooks, recipes. Even some items that had digital components, e.g., the nutrition content book, *The Calorie King*, that is also available from the Internet or as an Iphone application. Adults living with Type 2 diabetes often discussed comfort in conducting Internet searches, but they still printed off handouts that they would find. As healthcare slowly transitions to providing more digital patient education material, this may lead to a larger transition. At this stage though, adults currently being diagnosed with Type 2 diabetes tend to want paper health information items.
6.2.2 Expanded Taxonomies for Health Information Item Type and Item Use

The results of this study also contribute to knowledge of categories used to describe of information item type and information item use. Specifically, the taxonomy for Item Type needs expanded to include five new categories: logs, glucose meters, handouts, recipes, and prescription information. The category for Item Use needs expanded to draw attention to the use of items to “Monitor” health. The study’s findings also contribute to the knowledge as to what Use is not associated with health information items with regard to managing life with diabetes. These items are not associated with the notions: “got out of a bad situation,” “took mind off things,” “relaxed, rested,” and “got pleasure.”

6.2.3 Situational Relevance Provides Insight into Kept Items Expressions of Information Needs

This study’s approach to focus on kept information items in order to investigate information needs provided insights of information needs that individuals may not readily recognize. Generally, studies of information needs begin with this concept, investigate the information seeking process, and evaluate the acquired information item. Adults living with Type 2 diabetes may be given information items, though, and they may also be given a prescribed plan for treatment or behavior change. This process serves to influence perceived information needs and may also curtail the information-seeking process. The results of this study contribute knowledge of information needs that adults with Type 2 diabetes experience, but do not readily realize. These information needs are recognized by diabetes educators, in that content pertaining to these needs are included in the National Standards for Diabetes Self-Management Education, but adults living with Type 2 diabetes may not realize they are experiencing these needs and therefore use items that offer tangential support. By looking at the items that are kept in relation to an individual’s specific context, it may be possible to provide recommendations for health information items that may be of more benefit.

6.4 Future Research Directions

The current study investigated information needs that were explicitly and implicitly expressed through descriptions of information keeping and use activities associated with health information items that were kept by adults with Type 2 diabetes, who were recruited from a
diabetes education center. Future research directions are suggested with regard to the studied population.

6.4.1 Purposive Sample to include Individuals with Various Diagnosis Durations

One future research study would focus expand on the current findings, but specifically include participants who had been living with Type 2 diabetes for different lengths of time. The current study included participants who had been diagnosed as recently as 1 month or as late as 10+ years prior to the study, but the majority were newly diagnosed. Future studies that specifically recruited a pool of participants with disparate diagnosis durations would offer further insights into personal information collections and information needs of individuals who have lived with and managed life with diabetes for specific durations. This study could include a longitudinal component that would allow for comparison of data captured at discrete times to data of information behaviors that emerge across time for an individual. The participants would be asked to keep a diary and to participate in annual interviews to determine the evolution of the collections and needs.

6.4.2 Purposive Sample to include Individuals without Diabetes Class Experience

A second future study would draw upon the methods used in the current study, but recruit participants who had not taken part in diabetes education classes. These individuals would not have acquired information items that were purposely chosen according to critical topics identified within the National Standards for Diabetes Self-Management Education. This study would, thus focus on, and provide insight into information items and information needs that individuals with Type 2 diabetes may personally identify. These data could be compared and contrasted to the information needs and item uses of individuals who do participate in diabetes education classes.

Note that either of these future studies should include measures that would connect personal information collections, diabetes education, and information behaviors with health outcomes. While information and education is important for knowledge and skill building, knowledge of information and education that promotes and supports diabetes management toward the goal of improved health outcomes is needed.
6.4.3 Large Scale Survey

Another possible future research direction that would extend the results of this study of health information items that are kept and used to manage life with diabetes is to administer the data collection instrument using a large scale survey. A large scale survey could be administered to different groups of people, e.g., diagnosis duration, socio-economics, types of insurance, thus providing insights that would ensure further data saturation. Ideally, the large scale survey would draw upon a random sample in order to provide results that are generalizable. Although it is not possible to ascertain a regional or national sample frame of individuals with Type 2 diabetes, collaboration with hospitals, health care centers, or diabetes medical supplies may provide sample lists. Additionally, the results of a large scale, potentially random, survey could be supplemented with interviews. The selection of survey respondents should draw upon both random and purposeful selection. Random selection of survey respondents for further interviews may provide insight in potential implicit meaning associated with kept items, such as the psychological needs associated with cookbooks, or reveal that context, such as employment, affects information and keeping behaviors, as the work as a postal worker influenced Arlene’s behavior. Purposeful selection of survey respondents could be used to examine special cases or outliers that are identified in the survey data. These special cases could be selected based on different characteristics, such as number (high or low) of items kept, diagnosis duration, or family history. Please note that the administration of a large scale survey should be preceded by a process of retrospective interviews in order to assess potential difficulties or reasons that could prevent participants from completing the survey (Dillman, 2007).

6.4.4 Health Literacy

In addition to aiming to produce generalizable results, future research should look at reasons, e.g. health literacy, certain information items were kept and used. This study examined what health information items are kept and used, and the information needs that were associated with the items. An underlying assumption of the study was that participants’ selection of items and subsequent use was associated with information needs. Implicit to this assumption is a fit between the reading level at which kept and used information items were written and the participants’ health literacy levels. Given the importance of the ability of adults with Type 2 diabetes to use health information items to manage life with diabetes, future research should
examine the interaction of health literacy and the readability of kept and used health information items. Health information items are increasingly written at 5th–8th grade reading levels, but the ability of patients to understand the items, i.e., health literacy, also needs to be assessed to determine the fit between content and abilities. Tools available to assess health literacy that could be incorporated include the Rapid Estimate of Adult Literacy in Medicine assessment (REALM) (Arozullah et al., 2007) and the Newest Vital Statistic (NVS) (Weiss et al., 2005).

6.4.5 Co-occurring Morbidities

Individuals living with diabetes may also experience co-occurring morbidities, e.g., depression, hypertension, arthritis, mental disorders, and immune disorders, at some point during their life with diabetes. Any medical condition can provide various challenges, but when coupled with diabetes, individuals may experience greater challenges in managing diabetes and, thus, increased impact on health status (Piette & Kerr, 2006). In instances when individuals are treated for multiple conditions, priorities may vary and information keeping and use behaviors may adjust. Future research of kept and used health information items should include insight into the behaviors of individuals managing life with Type 2 diabetes, as well as co-occurring morbidities.

6.4.6 Effect of Information Item Advocacy during Diabetes Education Classes

Another possible path for future research could build upon the use of items recommended in class. Some participants reported that they were interested in or began using the book, The Calorie King, to help them monitor food content, because the diabetes educators discussed it in class. Future research should examine if this type of advocacy for specific items encourages use of nutrition tracking and monitoring tools, or why some individuals who learn about these tools through diabetes education classes do not seem to use them. It is possible that individuals may respond to suggestions for tools with a backlash, similar to the marketing notion of consumer reactance (Zemack-Rugar, Fitzsimons, & Lehmann, 2007). While this backlash often occurs in conditions when consumers perceive that “core free behaviors are threatened” (Goldsmith, Clark, & Lafferty, 2005, p. 592) or constrained, reactance and backlash may also occur when individuals receive any recommendation, even from loved ones (Fitzsimons & Lehmann, 2004). However, this potential for psychological reactance may be tempered by an individual’s tendency to conform (Goldsmith, Clark, & Lafferty, 2005). Given the importance for individuals to apply the lessons provided in diabetes education classes, future research should examine
possible backlash effects with regard to diabetes education in order to offer insights for indirect versus direct “persuasion” or recommendations. For example, rather than directly recommending the nutrition content book, *The Calorie King*, more course emphasis could be placed on discussion of exercise, but copies of the book could be placed around the room.

### 6.5 Conclusions

This study served to step back from functionality of personal health information systems that aim to automatically push information items to users and to examine personal health information management and health information need and use behavior that could inform means to provide health information items to adults living with Type 2 diabetes. This population was chosen for investigation because the prevalence of Type 2 diabetes continues to increase, and continued effort is needed to encourage successful management in order to minimize future complications, thus reducing the overall cost-burden of diabetes. Technology, healthcare providers, and diabetes educators do not know what items the recipients already have or what information they want, though. Therefore, the specific purpose of this research was to investigate the overarching question: What do kept personal health information items say about the needs of adults with Type 2 diabetes? In order to fully address the primary question, the study also investigated:

- Within an individual’s context of living with diabetes, what items are kept?
- How are the items used in relation to a precipitating information need?
- What does the use of these items say about the needs of the individuals?

These questions served to address the study’s goals of examining information needs, item types, and item within the framework of existing taxonomies, and exploring what kept health information items, within the lens of situational relevance, may express about information needs that adults living with Type 2 diabetes may experience. This study was naturalistic, exploratory, and used kept health information items as evidence, i.e., expressions, of information needs. Semi-structured interviews, conducted in participants’ homes, were used so that participants could describe significance of the kept item to their specific situation, as well as provide insights as to how a kept item was acquired and used. Participants were recruited solely from one diabetes education center. The results of this study are, therefore, limited to the participants. However, while the results are not be generalizable, the results may apply to other adults with
Type 2 diabetes who participate in education classes at the center and who keep and use health information items to manage life with diabetes.

The findings of this study suggest that in the face of the growing digital landscape of healthcare and general technology, adults with Type 2 diabetes are given and seek primarily paper based items. This includes a large number of cookbooks and books, but also items that are meant to be used in locations other than the home, e.g. nutrition content books and pamphlets. The results of this study show that some individuals with Type 2 diabetes keep choice restaurant specific nutrition pamphlets in their car in order to support making informed meal selections when eating at the restaurants. Others realize that they can check a restaurant’s menu online and make a choice before even going to the restaurant. However, others feel that the coverage of different foods and restaurants offered by a general nutrition book is preferable. Paper-based items are discussed in the diabetes education classes, so digital counterparts may simply be a recommendation away. Other health information items that are kept and used include items that are more medical in nature, e.g., glucose meters and dietary logs, and are used to help adults with Type 2 diabetes monitor various factors, e.g., dietary intake, nutrition, and glucose readings. The use of these and all kept health information items identified during the study occur in four primary contexts: activity, adjustment, challenge in living with diabetes, and emotion. By focusing on the items and their uses within these contexts using a lens of situational relevance, expressions of information need that were portrayed by some items differed from the information needs that were explicitly described. For some individuals, these expressions of information need, e.g. psychosocial support for balancing nutrition needs in the context of social settings, was an on-going, pressing struggle, but was being addressed tangentially as a stated need for nutrition information. Information items that offer specific support for these subtle expressions of need are available, but the needs must be identified so they can be addressed.

Diabetes is a serious issue in the United States, and rates are rapidly increasing, possibly preparing to affect nearly 10% of the population. It is a manageable disease, but without education and treatment, complications can include blindness, amputations, heart disease, and death. When adults are diagnosed with Type 2 diabetes, some can optimistically view their future life with diabetes as “a bit of a pain,” but others tend to view it as “very challenging,” “completely changed,” “stressful,” “upside down,” or “scary.” Information and education is helpful, though, as demonstrated by this study’s findings, and may allow those diagnosed with
diabetes to begin to think that they can “hope that things smooth out” and want to “kick diabetes in the butt.” In order to help people get to this point, though, it is important to identify and to provide health information items that meet their needs. Sarah’s comment regarding part of her journey to learn to manage her diabetes offers insight into benefits that adults with diabetes experience as a result of acquiring and using health information items that meet their needs:

My biggest challenge since my recent diagnosis has been knowing what I can eat. It is encouraging that nowadays, the patient makes their own choices. Learning to use the information on nutritional labels is literally a life saver. (Sarah)

In conclusion, this study offers another step forward in identifying information needs of adults with Type 2 diabetes. The results of this study showed that individuals with Type 2 diabetes who attend diabetes education classes are given information items, and that sometimes they seek additional health information. They keep and use health information items that were given to them and that they obtained independently. More health information items that are self-acquired, as opposed to those that are given are used, though. A majority of used health information items pertain to nutrition information, but individuals with Type 2 diabetes also keep and use items that are more oriented toward medical monitoring, e.g., glucose logs and lab results. The study’s lens of situational relevance provided insight into unspoken psychosocial information needs of this limited sample. The diabetes self-management education standards identify that individuals with Type 2 diabetes should be offered education that would meet psychosocial needs and information items that fall within this category are available and provided at various times during diabetes education classes. However, as demonstrated by this limited sample individuals with Type 2 diabetes keep and use few items that seem explicitly related to psychosocial needs. Instead, they use disparate items, such as cook books, to meet psychosocial needs, such as determining how to prepare a “traditional” dessert that is diabetic friendly, but tastes like it was made using the family recipe so the family will also eat it. Learning to identify when a cook book is a cook book, or when it is a symbol that assistance is needed, will help connect individuals with Type 2 diabetes to health information items when they have information needs they cannot readily self-identify. These connections will help make sure people are truly living with Type 2 diabetes, and not just managing.
APPENDIX A

RECRUITMENT FLYER & SIGN-UP SHEET

Diabetes and Your Life... What Information Do You Use to Help You Manage?

I want to hear about what helps you live with diabetes.

What informational items do you keep in your home and use to help you manage your life with diabetes? Are they books, pamphlets, Internet blogs? What?

Please tell me.

I want to hear about how these items and how they help you.

Eligibility: Age 18 or older and diagnosed with Type 2 diabetes. Only 1 member per household, please.

Project Description

As a participant in this study you will be asked to:

1. Meet with the researcher in your home.
2. Talk about any information items that you use to manage your life with diabetes.

The meeting will last about 1-2 hours, depending on the number of items you have from the past year to talk about. You will be compensated for your time.

Researchers: Melanie Whittington
(850) 264-3362  mw06j@fsu.edu
Florida State University
School of Library & Information Studies

CALL NOW to sign-up to share your story

888 244-3312  888 244-3312  888 244-3312  888 244-3312  888 244-3312  888 244-3312
Sign-up Sheet

Please indicate you interest in participating in the study of information items that you keep in your home that help you manage your life living with Type 2 diabetes.

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APPENDIX B

LETTER OF INTRODUCTION

Melinda Whetstone
School of Library & Information Studies
Florida State University
PO Box 3062100
Tallahassee, FL 32306-2100

RE: participation in a study about information items you keep in your home

Dear Participant,

Thank you for your interest in participating in my study. Let me tell you a bit more about me and the study.

I am doctoral candidate at Florida State University, and this study is required for me to complete my doctoral degree. The purpose of this study is to learn about the informational items that you keep in your home and that you use to help manage your life with diabetes. I am specifically interested in items that you brought into your home in the past year or so. I want to hear about how these items help you.

It is up to you to decide what items you think of when you think about managing your life with diabetes. However, some examples may include calendars, books, news clippings, magazine articles, printouts from an Internet site, glucose meters, notebooks of sugar levels, or files that are you store on a computer in the house, such as spreadsheets, bookmarked URLs, etc. Please know that I do not want you to show me the contents of the information items, such as lab results, though.

If you choose to participate in the study, I ask that you do the following:

1. Schedule a meeting time with me. Please be prepared to meet with me for 2 hours, but the length of the meeting will depend on the number of items you have to talk about.
2. Before our meeting, think about the informational items that you want to talk about.
3. Meet with me in your home to discuss the informational items that you keep and use to help manage your life with diabetes.

You will be compensated for your time and effort to participate in this research project.

Thank you for thinking about helping with this project. I look forward to meeting with you.

Sincerely,

Melinda R. Whetstone
APPENDIX C

BEHAVIORAL INFORMED CONSENT FORM
APPROVED BY FSU AND TALLAHASSEE MEMORIAL HOSPITAL

INFORMED CONSENT FORM

Title of Project: The Situational Relevance of Kept Personal Health Artifacts: An Exploratory Study of Kept Articles as Expressions of Need By Adults Living With Type 2 Diabetes

Researcher: Melinda Whetstone, doctoral candidate with the School of Library & Information Studies at Florida State University

IRB PROTOCOL: 2010-32 for Tallahassee Memorial HealthCare; HSC # 2010.4408 for FSU

This is a research study. Research studies include only people who want to take part. Before you agree to participate in this research study, it is important that you read the following explanation of this study. This form gives you information about this research, which will be discussed with you. This form may contain words or procedures that you do not understand. Please ask questions about anything that is unclear to you.

Purpose of this Research:
The purpose of this study is to learn about paper or computer information items that you keep in your home and that you think of when you think about living with diabetes. During the study of these items, you will be asked questions about why you needed the item and how you use it. The focus of this study is the type of item that you keep in your home and your use of it. This study is not concerned with the specific information that is in the artifact, such as sugar levels.

Approximately 25 people will participate in this study.

Explanation of procedures:
If you agree to be in this study, I will ask you to do the following:

1. Talk to me about any paper or computer information items that you keep in your home and that help you live with diabetes. You will be asked to describe:
   - how you use the item,
   - what question or problem the item helped with,
   - and how the item may help you live with diabetes.

During the meeting, I may take occasional notes using an audio recorder. I will only use the recorder if you give permission. The only purpose of the recording is to help me with written notes taken during our meeting. The recording will not include any information that can be used to identify you.

Discomforts Risks of being in the study:
You will not be exposed to any physical harm or risk at any time during your participation in this study. There is one minimal non-physical risk anticipated from your participation in the study. It is possible that you may feel that you are expected to talk about your health and medical information. I do not expect you to talk about your health or medical information. You also do not need to show me any kept health items that you do not wish to share.

Please be aware, though, I must report any evidence of witnessed abuse, neglect, or exploitation of any vulnerable person, such as a child or elderly person, while in your home.

FSU Human Subjects Committee Approved 2/21/11. Void after 2/20/12 HSC#2010.4408
Benefits of being in the study:

This study offers three primary benefits. First, this meeting is an opportunity for you to discuss your experiences of living with diabetes. Your insight and experience are invaluable.

The second benefit to participating affects you indirectly. The results of this study will be shared with the community of diabetes educators. The knowledge gained from this study will help them make decisions about the types of information they could provide.

The third benefit to participating also affects you indirectly. Findings from this study may help developers of technology, such as personal health records. In order for tools to improve and provide services that users want, the habits and needs of the users must first be understood. This study serves to provide information about these habits.

Time Duration of the Procedures and Study

The specific length of the interview depends upon the number of information items that you want to discuss. I expect that the meeting will last between 1 and 2 hours. If the meeting will last longer you will be given the opportunity to conduct the rest of the interview at a later date and time, although completion during one session is encouraged. You will also be able to rest at any time during the interview if you need.

Confidentiality:

The records of this study, including your name, address, telephone number, unique identifying code/number, responses you give during the interview and all data that I record, will be kept private and confidential, to the extent allowed by law. Specifically, data will be kept on the researcher’s computer which is password protected and encrypted. Data will be backed up to flash drives; password protection and data encryption will be used for these drives. Any paper datasheets will be kept in locked cabinets. No one except the principal investigator, Melinda Whetstone, will have access to it, unless the research oversight organizations described below request access.

Representatives of the following people/groups within Florida State University and Tallahassee Memorial HealthCare may share your health information (e.g., address, birth date, email address, website URL, or unique identifier) with other specific groups listed below during the course of a research audit for the purpose of research oversight.

- The principal investigator, Melinda Whetstone
- The Florida State University Human Subjects Committee
- The Institutional Review Board at Tallahassee Memorial HealthCare
- The U.S. Department of Health and Human Services

The results of the research will be published in a dissertation and may be published in a professional journal or presented at professional meetings. The results from the study will be written or presented in such a way that it will not be possible to identify you as a subject.

There will not be any identifying names, telephone numbers, or addresses on any tapes, and participant’s personal information will not be available to anyone. As for audio recordings, only the researcher will have access to the audio recordings for the sole purpose of double-checking

FSU Human Subjects Committee Approved 2/21/11. Void after 2/20/12 HSC#2010.4408
notes. A unique identifier will label study documents. The recordings will be erased no later than one year from the date of the interview. The data sheets and files will be erased 5 years after the completion of the study.

All reasonable efforts will be used to protect the confidentiality of your protected health information. There is the potential for individually identifiable information and the associated health information obtained with this authorization to be re-disclosed by the recipient(s). After such a disclosure, the information may no longer be protected by the terms of this authorization against further re-disclosure

The use of private health information:
Information about you that is stored in medical records will not be collected if you choose to be part of this research study. However, it is expected that you may accidentally share health information during this study, such as lab reports. Your information will only be used or shared as explained and authorized in this consent form or when required by law.

Voluntary nature of the study:
Whether or not you take part in this study is your choice. There will be no penalty if you decide not to be in the study. If you decide not to participate or if you decide to stop taking part in the research at a later date, there will be no penalty or loss of benefits to which you are entitled.

You are free to withdraw from this research study at any time. Your choice to leave the study will not affect your treatment with physicians at Tallahassee Memorial HealthCare or your relationship with this FSU or Tallahassee Memorial HealthCare. To end participation you must state this in writing. Write to Ms. Melinda Whetstone and let her know that you are withdrawing from the research study. Her mailing address is FSU School of Library & Information Studies, PO Box 3062100, Tallahassee, FL 32306-2100.

If you withdraw your permission:
- We will no longer use information about you.
- We may continue using the information obtained prior to your withdrawal if it is necessary for the soundness of the overall research.

Cost and/or Payment to Subject for Participation in Research
There will be no cost for participation in the research. You will receive $30 for your time to participate in this research project.

Research Funding:
The institution and investigators are currently not receiving any funds to support this research study. The study may receive funding at some point from Florida State University.

Contacts and questions:
The researcher conducting this study is Melinda Whetstone. If you have any questions about this study, please feel free to ask now or during the study. If you have any questions later, please contact Melinda at Florida State University, email: mrw06j@fsu.edu, or her advisor: Dr. Melissa Gross, Ph.D., email: melissa.gross@cci.fsu.edu, phone: 644-8119.

FSU Human Subjects Committee Approved 2/21/11. Void after 2/20/12 HSC#2010.4408
If you have questions regarding your rights as a research participant or you have concerns or general questions about the research or about your privacy and the use of your personal health information, contact the research protection advocate Julie Haltiwanger, FSU Human subjects committee, 850-644-7906 and Cynthia Blair, Administrative Liaison/IRB, Tallahassee Memorial HealthCare, 850-431-5676. You may also call this number if you cannot reach the research team or wish to talk to someone else.

Additionally, you may contact the FSU Human Subject’s Committee at 2010 Levy Street, Research Building B, Suite 276, Tallahassee, FL 32306-2742, or 850-644-8633, or by email at jjecoper@fsu.edu.

Agreement:
You will not lose any legal rights by signing this form.

Before making the decision regarding enrollment in this research you should have:
- Discussed this study with an investigator,
- Reviewed the information in this form, and
- Had the opportunity to ask any questions you may have.

Your signature below means that you have received this information, have asked the questions you currently have about the research and those questions have been answered. You will receive a copy of the signed and dated form to keep for future reference.

The authorization indicated by your signature will expire and your protected health information collected for the purposes of this study will be destroyed 5 years after the completion of the study. This date is approximately December 31, 2016.

Participant: By signing this consent form, you indicate that you are voluntarily choosing to take part in this research.

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<th>Signature of Participant</th>
<th>Date</th>
<th>Time</th>
<th>Printed Name</th>
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Participant’s Legally Authorized Representative: By signing below, you indicate that you give permission for the participant to take part in this research.

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<th>Signature of Participant’s Legally Authorized Representative</th>
<th>Date</th>
<th>Time</th>
<th>Printed Name</th>
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Person Explaining the Research: Your signature below means that you have explained the optional part of the research to the participant/participant representative and have answered any questions he/she has about the research.

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<th>Signature of person who explained this research &amp; obtained informed consent</th>
<th>Date</th>
<th>Time</th>
<th>Printed Name</th>
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Melinda R. Whetstone

INSTITUTIONAL REVIEW BOARD
FEB 1 5 2011
APPROVED AT TMH

FSU Human Subjects Committee Approved 2/21/11. Void after 2/20/12 HSC#2010.4408
APPENDIX D

APPROVED STUDY PROTOCOL
POST PRE-TEST MODIFICATION

Institutional Review Board at Tallahassee Memorial Healthcare, Inc.

Modifications Request

Changes (amendments/modifications) to a protocol may not be initiated without prior IRB approval except when necessary to eliminate immediate hazard to subjects. Click on Modifications for guidance (Section 8.6).

This form must be typed or it will be returned.

Date: 02/10/2011

Study Coordinator: Melinda Whetstone
Phone: (352) 264-3360
Email: mwhetstone@fmh.edu

IRB #: 2010-13
Study Title: The Situational Relevance of Kept Personal Health Artifacts: An Exploratory Study of Kept Articles as Expressions of Need By Adults Living With Type 2 Diabetes

Check items submitted for IRB approval. Attach revisions/amendments as appropriate.

☐ Personnel changes: Indicate which personnel are to be added or removed from the study. If NEW PERSONNEL are added provide documentation indicating the individual's qualifications to participate in research, Medical Staff Office Privileges and signed Conflict of Interest Questionnaire IRB Form 3 for each new person.

Action Obtaining Informed Consent Name Resume/CV Submitted
☐ Remove ☐ Add ☐ Yes ☐ No ☐ Yes ☐ No
☐ Remove ☐ Add ☐ Yes ☐ No ☐ Yes ☐ No
☐ Remove ☐ Add ☐ Yes ☐ No ☐ Yes ☐ No

If this is an investigator initiated study involving an Investigational drug, submit a revised FDA Form 1572.

☑ Protocol Updates/Amendment(s): It is REQUIRED that you attach:
  • A detailed summary from the investigator describing the changes and how they impact on the patient care/treatment.
  • If minor changes only, please summarize.
  • A complete copy of the revised protocol with revision date of 04/26/2011
  • Any relevant documentation.
  ☐ Consent form changes: It is REQUIRED that you attach:
  • A copy of the revised consent form with revision date of
  • A summary of changes:
    ALL CHANGES MUST BE HIGHLIGHTED (Strike through and Underline).

☐ Investigator Brochure - CHANGES MUST BE HIGHLIGHTED (Strike through and Underline). If changes are more than minor in detail, attach a detailed summary of the changes requested. Pharmacy received a copy of the investigator brochure [Yes] [No] Comments:

☒ Other (recruitment materials, survey instruments, etc): Recruitment - researcher will be available at support group meetings when study is announced, process to acquire "signature" by means of initials to indicate receipt of compensation dispensed from grant funds; added questions to the data sheet to determine if individuals have smart phones with Internet access and have diabetes-related apps installed

☒ The modifications, if approved and implemented, will not result in a change of the risk/benefit ratio nor will they affect a change in the study's overall objectives.

Signature of Principal Investigator: Melinda R. Whetstone / 04/26/2011
Print Name/Date

The above changes have been reviewed by Expedited Procedures [x] Convened Full Board [ ]
☒ Approved ☐ Deferred ☐ Referred for further review by

Joel F. Kramer, IRB Vice-Chair
IRB Form 8a Rev 5-09
Date: 4/28/11

217
Institutional Review Board at Tallahassee Memorial Healthcare, Inc.

Modifications Request

Changes (amendments/modifications) to a protocol may not be initiated without prior IRB approval except when necessary to eliminate immediate hazard to subjects.

This form must be typed or it will be returned.

Date: 02/10/2011
Phone: 850-263-1362
Email: mwhelston@tmc.edu

IRB #: 2010-03
Study Title: The Situational Relevance of Kept Personal Health Artifacts: An Exploratory Study of Kept Articles as Expressions of Need by Adults Living With Type 2 Diabetes

Check items submitted for IRB approval. Attach revisions/amendments as appropriate.

☐ Personnel changes: Indicate which personnel are to be added or removed from the study. If NEW PERSONNEL are added provide documentation indicating the individual's qualifications to participate in research, Medical Staff Office Privileges and signed Conflict of Interest Questionnaire IRB Form 3 for each new person.

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This is an investigator initiated study involving an investigational drug, submit a revised FDA Form 1672.

3 Protocol Updates/Amendments: It is REQUIRED that you attach:
- A detailed summary from the Investigator describing the changes and how they impact on the patient care/treatment,
- If minor changes only, please summarize,
- A complete copy of the revised protocol with revision date of 04/26/2011,
- Any relevant documentation.

☐ Consent form changes: It is REQUIRED that you attach:
- A copy of the revised consent form with revision date of
- A summary of changes.

ALL CHANGES MUST BE HIGHLIGHTED (Strikethrough and Underline).

☐ Investigator Brochure - CHANGES MUST BE HIGHLIGHTED (Strikethrough and Underline). If changes are more than minor in detail, attach a detailed summary of the changes requested. Pharmacy received a copy of the Investigator Brochure. Yes [ ] No [ ] Comments: [ ]

☐ Other (recruitment materials, survey instruments, etc.): Recruitment - researcher will be available at support group meetings when study is announced. Process to acquire "signature" by means of initials to indicate receipt of compensation. Dispensed from grant funds. Added questions to the data sheet to determine if individuals have smart phones with internet access and have diabetes-related apps installed.

☐ The modifications, if approved and implemented, will not result in a change of the risk/benefit ratio nor will they affect a change in the study's overall objectives.

Signature of Principal Investigator: [Redacted]
Print Name/Date: Melissa R. Wheelston 04/26/2011

The above changes have been reviewed by Expedited Procedures [ ] Convened Full Board [ ]

Approved [ ] Deferred [ ] Referred for further review by [ ]
Protocol Summary

IRB Number: 2010-32  Protocol Name: The Situational Relevance of Kept Personal Health Artifacts: An Exploratory Study of Kept Articles as Expressions of Need By Adults Living With Type 2 Diabetes

Principal Investigator: Melinda R. Whetstone

Check all that apply:  ☒ Human Subjects  ☒ Males  ☒ Females
☐ Competent Adults Only  ☐ Chart Review
☐ Anonymous Tissue Samples  ☐ Minors (Under age 18)
☐ Decisionally Impaired Adults  ☐ Prisoners

SUMMARY.

This protocol summary was revised April 26, 2011 after the pilot test was conducted.

Hypothesis (Exploratory Research Goal)

This is an exploratory study that is based in the premise that the health information items which adults living with Type 2 diabetes keep in their homes can inform diabetes educators and personal health information tool developers regarding information needs and uses of kept health information items that they deem relevant to their context of managing life with diabetes. For the purpose of this study kept health artifacts, i.e., information items, are considered physical and digital items that are on the individual’s premises at the time of the interview. These artifacts may include paper based items, such as books or notes of references that are consulted, but not maintained in the home; additionally, the items are inclusive of electronic items that are maintained on glucose meters or the individuals’ computer, such as spreadsheets, bookmarked URLs.

Aims

The objectives of the study are: to identify the health artifacts that are kept, thereby determining an individual’s personal information collection specific to the study’s context; to explore the use of the artifact and the precipitating information need; to assess the artifact’s situational relevance, which is the relation between the individual’s context, e.g., knowledge and beliefs, relative to the
kept artifact and the information need; and to explore possible expressions of need reflected by the kept health information items.

Methods
This investigation will be conducted within the naturalistic framework using participants (pilot test n = 3; study n = 25) who are recruited from support groups offered through the Tallahassee Memorial Diabetes, Bariatric, and Lipid Center. The diabetes educators will announce the study using a script provided by the researcher that states:

A local doctoral student at Florida State University is conducting a study of the information items that you keep in your home that help you manage your diabetes. She asked that we pass out a flyer that has more information about the study. If you are interested in participating in her study you may sign-up on the sign-up sheet or contact her. Her information is on the flyer.

The doctoral student who is also the study’s principal investigator will be available at the support meetings where the study is announced to answer any questions that potential participants may have. This step is added per the request of the diabetes educators after the initial solicitation that was conducted for the pilot study. The educators will make flyers (approved by TMH IRB) available that the study’s researcher has provided and provide a sign-up sheet. The potential participants may either provide their contact information on the sign-up sheet or take a flyer which has the researcher’s contact information. The researcher will gather the sign-up sheets following the support group meeting and contact the potential participants to ensure that they would like further information about the study, which includes a consent form and a letter of introduction (approved by TMH IRB). After the participant has received the information and had time to consider it, the researcher will call to see if there are any questions and if the individual is still interested in participating in the study, schedule an interview time.

Data will be collected using semi-structured interviews conducted in the participants’ homes. The interviewer will take copious notes and the occasional note into an audio recorder. The focus of the interviews is on the types of health artifacts kept, the participant’s use of these items, and the information needs that are associated with the items. The researcher is not interested in the content of the artifacts.
Participants will be compensated $30 for their time. The researcher has received a dissertation research grant which will be used to fund the participant’s compensations. In order to receive reimbursement, the researcher will have the participants initial a receipt that has their subject ID on it. FSU will be provided a list of subject IDs and copies of the receipts. The FSU graduate office will not be given any means to determine the identification of the participants by using the list of subject IDs. This grant money was not used to compensate three individuals who participated in a pilot test.

Significance
The significance of this study is that it provides insight into personal health information items, which adults keep in their home to help manage their life with diabetes serves. This information may be useful for diabetes educators to know what information items individuals have at their disposal in their home with regard to the key educational areas that serve to promote self-management. Additionally, knowledge of kept items can inform development of health information management technology, such as personal health records (PHRs). This study differs from past literature in that it diverges from information-seeking studies and focuses on the uses and needs of kept personal health artifacts that individuals living with diabetes deem relevant. It is further unique in that it focuses on items that are currently maintained in the home, i.e., established personal collections, and recognizes that individuals also keep electronic items, such as spread sheets and data on glucose meters.
Date of Interview: ____________

Subject ID: ____________ Pseudonym: ____________

The subject ID is created using the date of the interview and the individual's initials, e.g. Jane Doe interviewed on November 1, 2010 would be coded as 110110JD.

Interview Start Time: ____________ End Time: ____________ Interview duration: ____________

Dissertation Data Gathering / Interview Script

Will you please take a moment to look over this consent form? After you have a chance to look through it, I will highlight the important areas.

The study that you are asked to take part in is a research study of personal health items that you keep in your home with regard to your diabetes. In studying the items that you keep in order to manage your life with diabetes, you will be asked questions about your information needs related to the items and how you use the items. The items of interest for this study are any items that you think helps you manage your life with diabetes. Potential items may include calendars, books, news clippings, journal articles, printouts from an Internet site, files that are you store on a computer in the house, such as spreadsheets, bookmarked URLs, etc., glucose meters, or notebooks of sugar levels.

Before you sign the consent form I'd like to ensure you understand the requirements of this study. Please answer the following question?

- Can you explain what this study is about?
- Can you tell me about the risks and benefits of this study?

If you are comfortable, will you please now sign the consent form?

Before we begin with our discussion of the health information items, we will take a moment to gather some general information about you and your health. You are free to pass on answering a question at any time.

Read and fill in the Participant Informational Sheet
Subject ID: __________________________  Pseudonym: __________________________

PARTICIPANT INFORMATIONAL SHEET

ABOUT YOU

Are you?: □ Male □ Female

Birth Yr: __________

What is the highest level of education you have completed? Mark only one.

□ Grade 8 or less  □ Completed 2 yr degree
□ Grades 9-11  □ Graduated college (4 yr degree)
□ Graduated high school  □ Some Graduate classes
□ Some college courses  □ Completed Graduate Degree

What is your current occupational status? Mark only one.

□ Employed: __________________________
□ Unemployed  □ Retired
□ Homemaker  □ Student
□ Disabled  □ Other: Please specify __________________________

What is your marital status?

□ Married  □ Living as married
□ Divorced  □ Widowed
□ Separated  □ Single, never been married

How many children under the age of 18 live in your household? __________

Which one or more of the following would you say is your race?

□ American Indian/Alaska Native  □ Asian/ Pacific islander
□ Black/African American  □ Latino/ Hispanic
□ White/Caucasian  □ Other: Please specify __________________________

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APR 28 2011
APPROVED AT TMH
Subject ID: ___________________________ Pseudonym: ___________________________

Are there others in your family, living or deceased, with diabetes:  □ Yes  □ No

Please rate your overall current health?
□ 1 (Poor)  □ 2  □ 3  □ 4  □ 5  □ 6  □ 7 (Excellent)

What hobbies and/or activities do you participate in: _______________________________________

Is there anything that you would like to tell me about yourself? (optional):
________________________________________________________

Thinking about members of your family living in this household, what is your combined annual income, meaning the total pre-tax income from all sources earned in the past year?
□ $0 to $14,999  □ $15,000 to $29,999
□ $30,000 to $49,999  □ $50,000 to $74,999
□ > $75,000

Do you currently rent or own your home?
□ Own  □ Rent  □ Occupy without paying monetary rent

ABOUT YOUR DIABETES

Diabetes diagnosis date / Duration of disease: ___________________________

Please indicate:
   Currently: □ Controlled  □ Not controlled

Means of control (e.g., insulin shots, pump, medform, etc.): ___________________________

Is your diabetes care covered by insurance:  □ Yes  □ No

Who referred you to the diabetes center? ___________________________

How would you describe your life with diabetes?

Quote:

Initial if may use________________
ARTIFACT INFORMATIONAL SHEET

Artifact ID: ___________ Subject ID: ___________ Date: ___________

Artifact description:
Please select the description that best describes the type of item:

Audiotape
Calendar
Printed reports of lab report:

Specific news clipping
Specific magazine clipping
popular magazines (e.g., health/diet, cooking, women’s, African-American interest)
Diabetes specific magazines (e.g., Diabetes Forecast, Diabetes Self-Management)
Internet site (give name or address)

Blog (give name or address below)

Nutrition labels on food packages

Nutritional information pamphlet, fast foods
Product information (e.g., Glucerna, information in insulin kit)
Diet information (e.g., Atkins, South Beach diets, Reader’s Digest “Change One” program)
Phonebook
Cook book
Books (other than phone book or cook book)
Exercise videos
notebook
self-care brochure

Other:

Title: ____________________________
Author: ___________________________
Date: ___________
Journal Title: ______________________
URL: _____________________________
Other: _____________________________

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APR 9 8 2011
APPROVED AT TMH
Artifac ID: 

Acquisition Time
Did you get this information in the:
☐ Past _______ week
☐ Past _______ month
☐ Past _______ year
☐ > _______ year ago
☐ Don’t recall
☐ At _______ diagnosis
☐ In _______ class

What do you remember about the time you found the item or it was given to you?

Acquisition
Did you get the information by yourself or did someone give it to you?

Self / Other / Don’t recall

If the information was given to you, by whom?

Please select an option from the list below the item that best describes where the health information came from.

- Physician
- Nurse, nurse practitioner
- Dietitian
- Diabetes educator
- Pharmacist
- Dentist
- Eye doctor, eye laser surgeon
- Health care professional(s), specific role not indicated
- Hospital-based diabetes center
- Insurance company nurse, nurse, dietician, educator, wellness program personnel
- Workplace nurse, health professional or wellness program
- Family, including family members with diabetes
- Friends, neighbors, coworkers, acquaintances, other patients, personal interaction, “word of mouth”
- Classes or seminars
- Support groups
- Participation in research study
- Comprehensive weight loss program
- Health fair or similar event
- Media
- Internet (Web sites, search engines)
- Information from organizations (eg, American Diabetes Association, American Kidney Foundation), other than from their Web sites
- Booklets, brochures, etc, from clinic or health professionals
- Booklets, brochures, newsletters, e-mail newsletters, etc, from miscellaneous sources (“in the mail”)
- Information from pharmaceutical company, drugstore, medication supplier
Artifact ID: __________

Information Need

Tell me about what information you needed that prompted you to search for or to use this item.

Quote:

Initial if may use __________
Artifact ID: ____________

Information Use and Usefulness
I used the item: yes / no
Can you tell me about how you used the item?

Quote:

Initial if may use ____________

Please indicate how useful artifact was using a scale of 1-10, whereby 1 is of no use at all to 10 meaning maximum usefulness:

<p>| | | | | | | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
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<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
<td>10</td>
</tr>
<tr>
<td>none</td>
<td>max</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Is there a time that you used the item in a different way? Please tell me about it.

Quote:

Initial if may use ____________

Please indicate how useful artifact was using a scale of 1-10, whereby 1 is of no use at all to 10 meaning maximum usefulness:
Artifact ID: ________

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Describing the diabetes disease process and treatment options</td>
<td>The item is stated to pertain to and describe the diabetic condition or treatments that are applicable for the disease.</td>
</tr>
<tr>
<td>Incorporating nutritional management into lifestyle</td>
<td>The item is stated to pertain to applying nutritional management into one's lifestyle. This may include diet information as well as nutritional labels that have been kept from food items.</td>
</tr>
<tr>
<td>Incorporating physical activity into lifestyle</td>
<td>The item is stated to pertain to applying physical activity into one's lifestyle.</td>
</tr>
<tr>
<td>Using medication(s) safely and for maximum therapeutic effectiveness</td>
<td>Information about medication that is specific to diabetes, as well as information pertaining to its usage.</td>
</tr>
<tr>
<td>Monitoring blood glucose and other parameters and interpreting and using the results for self-management decision making</td>
<td>Information about means to monitor blood glucose levels and other diabetic specific parameters, as well as information that describes the usage of this information.</td>
</tr>
<tr>
<td>Preventing, detecting, and treating acute complications</td>
<td>Information about short term complications that arise as a result of living with diabetes.</td>
</tr>
<tr>
<td>Preventing detecting, and treating chronic complications</td>
<td>Information about long term complications that arise as a result of living with diabetes.</td>
</tr>
<tr>
<td>Developing personal strategies to address psychosocial issues and concerns</td>
<td>Information about behaviors for dealing with psychological or social issues or concerns that arise in managing life with diabetes.</td>
</tr>
<tr>
<td>Developing personal strategies to promote health and behavior change</td>
<td>Information about activities and behaviors that are related to health and behavior change.</td>
</tr>
<tr>
<td>Other:</td>
<td>This category will be used if none of the other categories.</td>
</tr>
</tbody>
</table>
APPENDIX E
CODING SHEETS

The following coding sheets were used during the data analysis process to code the data collected during the home interviews.

<table>
<thead>
<tr>
<th>Category</th>
<th>Value</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Electronic information</td>
<td>No</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Yes</td>
<td>1</td>
</tr>
<tr>
<td>Internet bookmarks</td>
<td>No</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Yes</td>
<td>1</td>
</tr>
<tr>
<td>Gender</td>
<td>Male</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>1</td>
</tr>
<tr>
<td>Birth Year</td>
<td>This date were converted to age</td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td>Grade 8 or less</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Grades 9-11</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Graduated high school</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Some college courses</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Completed 2 year degree</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Graduated college (4 year degree)</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>Some Graduate classes</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>Completed Graduate Degree</td>
<td>8</td>
</tr>
<tr>
<td>Diabetes diagnosis date</td>
<td>This is converted to the number of years the participant claims to have lived with diabetes</td>
<td></td>
</tr>
<tr>
<td>Control</td>
<td>Controlled</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Not controlled</td>
<td>1</td>
</tr>
<tr>
<td>Health Status</td>
<td>The participant indicates on the scale</td>
<td>1-10</td>
</tr>
<tr>
<td>Life description</td>
<td>This is a free text variable</td>
<td></td>
</tr>
</tbody>
</table>
Each item was given a code that includes the subject ID and an indication of the type of item. For example, the first identified electronic bookmark for Jane Doe who was interviewed on November 1, 2010 was identified as bm01-110110JD.

<table>
<thead>
<tr>
<th>Item ID:</th>
<th>Description</th>
<th>Item ID:</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Category</td>
<td>Description</td>
<td>Code</td>
<td></td>
</tr>
<tr>
<td>-------------------------------------------------------</td>
<td>-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>------</td>
<td></td>
</tr>
<tr>
<td>Audiotape</td>
<td>An audio recording that offers information pertaining to diabetes management or training</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Calendar</td>
<td>This is a calendar where events pertaining to managing life with diabetes are kept</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Printed reports of lab report</td>
<td>These are reports from medical facilities with information that is specific to managing life with diabetes.</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Story clipping</td>
<td>This is a clipping or a printout from a news source or magazine of a specific story related to managing life with diabetes.</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>popular magazines</td>
<td>Magazines that are referenced for general information pertaining to managing life with diabetes.</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Diabetes specific Magazines (e.g., Diabetes Forecast, Diabetes Self-Management)</td>
<td>Magazines that deal specifically with diabetes</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>Internet site (give name or address)</td>
<td>Any internet site name or address as written in the bookmark that is stored on the participant’s computer.</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td>Blog (give name or address below)</td>
<td>An online weblog title or address that is bookmarked on the participant’s computer.</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>Nutrition labels on food packages</td>
<td>Package labels that are kept once the item is used and the package is disposed of</td>
<td>9</td>
<td></td>
</tr>
<tr>
<td>Nutritional information pamphlet, fast foods</td>
<td>Documents outside of food packaging that contain nutrition information.</td>
<td>10</td>
<td></td>
</tr>
<tr>
<td>Product information (e.g., Glucerna, information in insulin kit)</td>
<td>Documents that come with products that contain diabetes management related information</td>
<td>11</td>
<td></td>
</tr>
<tr>
<td>Diet information</td>
<td>Diet related information that the participant states are related to managing their life with diabetes. Longo et al. reported that this could include Atkins, South Beach diets, or Reader’s Digest “Change One” program.</td>
<td>12</td>
<td></td>
</tr>
<tr>
<td>Phonebook or Address book</td>
<td>Books that contain address or phone information for sources that participant’s state are related to managing their life with diabetes</td>
<td>13</td>
<td></td>
</tr>
<tr>
<td>Cook book</td>
<td>Books that provide recipes that participants state are related to managing their life with diabetes</td>
<td>14</td>
<td></td>
</tr>
</tbody>
</table>
## ARTIFACT INFORMATIONAL SHEET - continued

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Books (other than phone book or cook book)</td>
<td>Books that are deemed relevant to managing life with diabetes</td>
<td>15</td>
</tr>
<tr>
<td>Exercise videos</td>
<td>DVDs, VHS tapes, or online exercise and activity items</td>
<td>16</td>
</tr>
<tr>
<td>notebook</td>
<td>Personally kept notes of health data that relates to life with diabetes, such as blood sugar readings</td>
<td>17</td>
</tr>
<tr>
<td>self-care brochure</td>
<td>Brochures and handouts that provide guidance as to how to perform self-care activities</td>
<td>18</td>
</tr>
<tr>
<td>Other:</td>
<td>This space were used for additional categories not anticipated</td>
<td>19</td>
</tr>
</tbody>
</table>

### Item MetaData

<table>
<thead>
<tr>
<th>Field</th>
<th>Description</th>
<th>Type</th>
</tr>
</thead>
<tbody>
<tr>
<td>Title</td>
<td>This is the title of the item</td>
<td>Free text</td>
</tr>
<tr>
<td>Author</td>
<td>This is the person(s) or agency who authored the item</td>
<td>Free text</td>
</tr>
<tr>
<td>Date</td>
<td>The is the publication date</td>
<td>Free text</td>
</tr>
<tr>
<td>Journal /Publication Title</td>
<td>If the item is an article or clipping, this is the title of the parent document</td>
<td>Free text</td>
</tr>
<tr>
<td>URL</td>
<td>This is the address of electronic items</td>
<td>Free text</td>
</tr>
<tr>
<td>Other</td>
<td>This space were used for additional identifying metadata not anticipated</td>
<td>Free text</td>
</tr>
</tbody>
</table>
ACQUISITION INFORMATIONAL SHEET

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acquisition Time</td>
<td>Free text</td>
<td></td>
</tr>
<tr>
<td>Acquired</td>
<td>Self</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Others</td>
<td>1</td>
</tr>
<tr>
<td>Source</td>
<td>Physician</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Nurse, nurse practitioner</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Dietitian</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Diabetes educator</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Pharmacist</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Dentist</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>Eye doctor, eye laser surgeon</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>Health care professional(s), specific role not indicated</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td>Hospital-based diabetes center</td>
<td>9</td>
</tr>
<tr>
<td></td>
<td>Insurance company nurse, nurse, dietician, educator, wellness program personnel</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>Workplace nurse, health professional or wellness program</td>
<td>11</td>
</tr>
<tr>
<td></td>
<td>Family, including family members with diabetes</td>
<td>12</td>
</tr>
<tr>
<td></td>
<td>Friends, neighbors, coworkers, acquaintances, other patients, personal interaction, “word of mouth”</td>
<td>13</td>
</tr>
<tr>
<td></td>
<td>Classes or seminars</td>
<td>14</td>
</tr>
<tr>
<td></td>
<td>Support groups</td>
<td>15</td>
</tr>
<tr>
<td></td>
<td>Participation in research study</td>
<td>16</td>
</tr>
<tr>
<td></td>
<td>Comprehensive weight loss program</td>
<td>17</td>
</tr>
<tr>
<td></td>
<td>Health fair or similar event</td>
<td>18</td>
</tr>
<tr>
<td></td>
<td>Mainstream Media</td>
<td>19</td>
</tr>
<tr>
<td></td>
<td>Internet (Web sites, search engines)</td>
<td>20</td>
</tr>
<tr>
<td></td>
<td>Information from organizations (e.g., American Diabetes Association, American Kidney Foundation), other than from their Web sites</td>
<td>21</td>
</tr>
<tr>
<td></td>
<td>Booklets, brochures, etc., from clinic or health professionals</td>
<td>22</td>
</tr>
<tr>
<td></td>
<td>Booklets, brochures, newsletters, e-mail newsletters, etc., from miscellaneous sources (“in the mail”)</td>
<td>23</td>
</tr>
<tr>
<td></td>
<td></td>
<td>24</td>
</tr>
<tr>
<td>Information from pharmaceutical company, drugstore, medication supplier</td>
<td>25</td>
<td></td>
</tr>
<tr>
<td>---------------------------------------------------------------</td>
<td>-----</td>
<td></td>
</tr>
<tr>
<td>Information from insurance company</td>
<td>26</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>27</td>
<td></td>
</tr>
<tr>
<td>Categories of information needs</td>
<td>Description</td>
<td>Source</td>
</tr>
<tr>
<td>--------------------------------</td>
<td>--------------------------------------------------------------------------------------------------------</td>
<td>-------------------</td>
</tr>
<tr>
<td>Access to resource/services</td>
<td>Refers to the needs to get access to resources or services, such as time, money and free counseling</td>
<td>Song, 2007</td>
</tr>
<tr>
<td>Cause of problem</td>
<td>Refers to the reason that caused the medical condition to arise</td>
<td>Song, 2007</td>
</tr>
<tr>
<td>Complications</td>
<td>Refers to information or descriptions about complications, such as amputation, that may occur due to the presence of diabetes</td>
<td>Google Top Health</td>
</tr>
<tr>
<td>Coping skills/strategies</td>
<td>Refers to specific ways a person uses to cope with illness, cognitive, physical or emotional</td>
<td>Song, 2007</td>
</tr>
<tr>
<td>Diagnosis</td>
<td>This was originally diagnosis &amp; tests. Refers to the information that is kept that deals with the diagnosis of diabetes</td>
<td>WebMD</td>
</tr>
<tr>
<td>Facilities</td>
<td>Refers to locations where diabetes management care is offered</td>
<td>Google Top Health</td>
</tr>
<tr>
<td>Health insurance concerns</td>
<td>Refers to issues relating to health insurance in a health situation, such as looking for affordable health care and dealing with medical bill payment</td>
<td>Song, 2007</td>
</tr>
<tr>
<td>Healthy behaviors</td>
<td>Refers to positive behaviors that help a person to maintain a healthy lifestyle, such as eating or exercise habits</td>
<td>Song, 2007</td>
</tr>
<tr>
<td>Impacts on life/family</td>
<td>Refers to impacts that illness has on personal and social life, such as mobility, family relationship, and lifestyle</td>
<td>Song, 2007</td>
</tr>
<tr>
<td>Issues on recovery</td>
<td>Refers to issues relating to the recovery of a medical condition, such as prognosis and chance of cure</td>
<td>Song, 2007</td>
</tr>
<tr>
<td>Categories of information needs</td>
<td>Description</td>
<td>Source</td>
</tr>
<tr>
<td>---------------------------------</td>
<td>-------------</td>
<td>--------</td>
</tr>
<tr>
<td>Living &amp; Managing</td>
<td>Refers to life activities and behaviors, and life management strategies</td>
<td>WebMD</td>
</tr>
<tr>
<td>Magazines and E-zines</td>
<td>Refers to paper and online popular press material</td>
<td>Google Top Health</td>
</tr>
<tr>
<td>Nutrition</td>
<td>Refers to food or supplement information pertaining specifically to diabetes</td>
<td>Google Top Health</td>
</tr>
<tr>
<td>Organizations</td>
<td>Refers to groups that provide diabetes support, care, information, activities, etc.</td>
<td>Google Top Health</td>
</tr>
<tr>
<td>Overview &amp; Facts</td>
<td>Refers to content that simply provides descriptions of diabetes and facts/statistics about diagnosis, care, complications, population size, etc.</td>
<td>WebMD</td>
</tr>
<tr>
<td>Patient care needs</td>
<td>Refers to needs to take care of a patient throughout the illness process, such as home care and rehab needs</td>
<td>Song, 2007</td>
</tr>
<tr>
<td>Personal Pages</td>
<td>Refers to private web sites that individuals maintain with regard to diabetes.</td>
<td>Google Top Health</td>
</tr>
<tr>
<td>Potential diagnosis</td>
<td>Refers to the nature and circumstances of a medical condition</td>
<td>Song, 2007</td>
</tr>
<tr>
<td>Products</td>
<td>Refers to items that can be purchased over the shelf, rented, or are available as medical items.</td>
<td>Google Top Health</td>
</tr>
<tr>
<td>Psychological/emotional impact</td>
<td>Refers to the impact that the health problem has on a person’s psyche, feelings and emotions</td>
<td>Song, 2007</td>
</tr>
<tr>
<td>Research</td>
<td>Refers to research studies and findings that are specifically related to diabetes.</td>
<td>Google Top Health</td>
</tr>
<tr>
<td>Categories of information needs</td>
<td>Description</td>
<td>Source</td>
</tr>
<tr>
<td>---------------------------------</td>
<td>-------------</td>
<td>--------</td>
</tr>
<tr>
<td>Support Groups &amp; Resources</td>
<td>Refers to groups that offer support for individuals who are dealing with diabetes and places where useful information may be found</td>
<td>Combination of Google Top Health &amp; WebMD</td>
</tr>
<tr>
<td>Symptoms &amp; Types</td>
<td>Refers to the symptoms of and the types of diabetes</td>
<td>WebMD</td>
</tr>
<tr>
<td>Treatment options &amp; Care</td>
<td>Refers to all possible ways or methods of dealing with a medical condition, such as medication and surgery</td>
<td>Combination of Google Top Health &amp; WebMD; Song, 2007</td>
</tr>
<tr>
<td>Tests</td>
<td>Refers to medical tests that are conducted specific to diabetes medical treatment</td>
<td>WebMD</td>
</tr>
<tr>
<td>Type 1</td>
<td>Refers to information pertaining specifically to Type 1 diabetes (this category is maintained, although it is not expected to be used as the study’s focus is on Type 2 diabetes)</td>
<td>Google Top Health</td>
</tr>
<tr>
<td>Type 2</td>
<td>Refers to information pertaining specifically to Type 2 diabetes</td>
<td>Google Top Health</td>
</tr>
<tr>
<td>Working of treatment</td>
<td>Refers to the details or process of how a specific treatment works, such as how a medicine works or the procedures of a surgery</td>
<td>Song, 2007</td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Information Use and Usefulness

<table>
<thead>
<tr>
<th>Categories of information needs</th>
<th>Description</th>
<th>Source</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Use</td>
<td>No, the item was not used</td>
<td></td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Yes, the item was used</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Usefulness</td>
<td>Scale</td>
<td>Song (2007): initial list of major categories of item uses from sensemaking studies, from the perspective of “help,”</td>
<td>1-10</td>
</tr>
<tr>
<td>How used</td>
<td>got pictures, ideas, understandings</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>able to plan</td>
<td></td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>got skills</td>
<td></td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>got started, got motivated</td>
<td></td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>kept going</td>
<td></td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>got control</td>
<td></td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>things got calmer, easier</td>
<td></td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>got out of a bad situation</td>
<td></td>
<td>8</td>
</tr>
<tr>
<td></td>
<td>reached a goal, accomplished</td>
<td></td>
<td>9</td>
</tr>
<tr>
<td></td>
<td>things</td>
<td></td>
<td>9</td>
</tr>
<tr>
<td></td>
<td>went on to other things</td>
<td></td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>avoided a bad situation</td>
<td></td>
<td>11</td>
</tr>
<tr>
<td></td>
<td>took mind off things</td>
<td></td>
<td>12</td>
</tr>
<tr>
<td></td>
<td>relaxed, rested</td>
<td></td>
<td>13</td>
</tr>
<tr>
<td></td>
<td>got pleasure</td>
<td></td>
<td>14</td>
</tr>
<tr>
<td></td>
<td>got support, reassurance, confirmation</td>
<td></td>
<td>15</td>
</tr>
<tr>
<td></td>
<td>got connected to other</td>
<td></td>
<td>16</td>
</tr>
<tr>
<td></td>
<td>other</td>
<td></td>
<td>17</td>
</tr>
</tbody>
</table>
Situational Relevance
Select the category that best reflects the stated participant’s view of the health information item with regard to managing their life with diabetes. This list comes from the suggested diabetes curriculum content areas listed in the diabetes education standard (Funnell et al., 2009).

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Describing the diabetes disease <strong>process</strong> and <strong>treatment</strong> options</td>
<td>The item is stated to pertain to and describe the diabetic condition or treatments that are applicable for the disease.</td>
<td>1</td>
</tr>
<tr>
<td>Incorporating <strong>nutritional</strong> management into lifestyle</td>
<td>The item is stated to pertain to applying nutritional management into one’s lifestyle. This may include diet information as well as nutritional labels that have been kept from food items.</td>
<td>2</td>
</tr>
<tr>
<td>Incorporating <strong>physical activity</strong> into lifestyle</td>
<td>The item is stated to pertain to applying physical activity into one’s lifestyle.</td>
<td>3</td>
</tr>
<tr>
<td>Using <strong>medication(s)</strong> safely and for maximum therapeutic effectiveness</td>
<td>Information about medication that is specific to diabetes, as well as information pertaining to its usage.</td>
<td>4</td>
</tr>
<tr>
<td><strong>Monitoring blood glucose</strong> and other parameters and <strong>using the results</strong> for self-management decision making</td>
<td>Information about means to monitor blood glucose levels and other diabetic specific parameters, as well as information that describes the usage of this information.</td>
<td>5</td>
</tr>
<tr>
<td>Preventing, detecting, and treating <strong>acute complications</strong></td>
<td>Information about short term complications that arise as a result of living with diabetes</td>
<td>6</td>
</tr>
<tr>
<td>Preventing detecting, and treating <strong>chronic complications</strong></td>
<td>Information about long term complications that arise as a result of living with diabetes</td>
<td>7</td>
</tr>
<tr>
<td>Developing personal strategies to address <strong>psychosocial</strong> issues and concerns</td>
<td>Information about behaviors for dealing with psychological or social issues or concerns that arise in managing life with diabetes</td>
<td>8</td>
</tr>
<tr>
<td>Developing personal strategies to promote health and behavior change</td>
<td>Information about activities and behaviors that are related to health and behavior change.</td>
<td>9</td>
</tr>
<tr>
<td><strong>Other:</strong></td>
<td>This category was used if none of the other categories are suitable.</td>
<td>10</td>
</tr>
</tbody>
</table>
APPENDIX F

DIABETES CLASS INFORMATIONAL PACKET:
THE ITEMS

These items were provided by diabetes educators to every participant.

<table>
<thead>
<tr>
<th>ArtID</th>
<th>Item Title</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>HO1</td>
<td>A1C relationship to Glucose readings</td>
<td>A b/w chart of A1C and glucose (eag) readings</td>
</tr>
<tr>
<td>HO2</td>
<td>Diabetes Medications</td>
<td>A list of various medications that are used to treat Type 2 diabetes. The handout describes how the medications work, when to take them and how to test to ensure their effectiveness</td>
</tr>
<tr>
<td>HO3</td>
<td>Glucose Log</td>
<td>A chart that is to be used during the class sessions. Used to record blood glucose readings at periods before and after breakfast, lunch and supper. Times and dosage of medication are also to be noted.</td>
</tr>
<tr>
<td>HO4</td>
<td>Good Foot Care</td>
<td>Tips for caring for and inspecting feet in order to prevent or care for infections.</td>
</tr>
<tr>
<td>HO5</td>
<td>Routine Problems</td>
<td>Describes the glucose levels that indicate when the doctor needs to be called.</td>
</tr>
<tr>
<td>HO6</td>
<td>Community &amp; Resource List</td>
<td>Contact information for online and local diabetes resources.</td>
</tr>
<tr>
<td>HO7</td>
<td>Fat Facts</td>
<td>Discusses the various types of fats, e.g., saturated, trans fats, etc., and their value in diet.</td>
</tr>
<tr>
<td>HO8</td>
<td>Daily Meal Planning Guide</td>
<td>Includes picture for determining portion sizes, food lists for meal planning, a sample meal plan, and a personal meal plan log.</td>
</tr>
<tr>
<td>HO9</td>
<td>Stress</td>
<td>Discusses how stress affects diabetes, the effect of personality on stress, and ways to reduce mental stress and to relax.</td>
</tr>
<tr>
<td>ArtID</td>
<td>Item Title</td>
<td>Description</td>
</tr>
<tr>
<td>------</td>
<td>------------------------------------</td>
<td>-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>HO10</td>
<td>Diabetes Self-Management Support</td>
<td>Encourages the student to choose a course of action that they will use to manage diabetes – magazine, websites, attend fitness center, health fairs, weight loss program, diabetes support group, and information from insurance company.</td>
</tr>
<tr>
<td></td>
<td>Plan &amp; Action Plan</td>
<td></td>
</tr>
<tr>
<td>HO11</td>
<td>Action Plan Form</td>
<td>Weekly goal sheet to manage diabetes.</td>
</tr>
<tr>
<td>SLIDES1</td>
<td>TEAM Diabetes</td>
<td>B/w handout of 24 slides discussed in diabetes education class; the slides give an overview of diabetes, its symptoms, and its management</td>
</tr>
<tr>
<td>SLIDES2</td>
<td>Nutrition for Diabetes</td>
<td>B/w handout of 29 slides discussed in diabetes education class; the slides cover foods to eat, portion sizes, carbs, fats, alcohol, nutrition labels, meal timing, and weight management. Resources are provided: <a href="http://www.calorieking.com">www.calorieking.com</a> and <a href="http://www.diabetes7.org">www.diabetes7.org</a>.</td>
</tr>
<tr>
<td>SLIDES3</td>
<td>Putting it All Together</td>
<td>B/w handout of 11 slides discussed in diabetes education class; the slides cover eating out and menu options</td>
</tr>
<tr>
<td>SLIDES4</td>
<td>Exercise for Diabetes</td>
<td>B/w handout of 12 slides discussed in diabetes education class; gives video and pedometer recommendations, guidance for starting, implications for hypoglycemia, and tips to make it fun</td>
</tr>
<tr>
<td>SLIDES5</td>
<td>Short term Complications</td>
<td>B/w handout of 12 slides discussed in diabetes education class &amp; hypoglycemia information sheet; discusses hypoglycemia and its treatment, as well as other safety tips, such as when to see the doctor</td>
</tr>
</tbody>
</table>
## APPENDIX G

### THE PARTICIPANTS

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Age</th>
<th>Occupation</th>
<th>Family Status</th>
<th>Race</th>
<th>Diabetes Duration</th>
<th>Means of Control</th>
<th>Health Status (1=poor, 7=excellent)</th>
<th># of items kept &amp; used</th>
</tr>
</thead>
<tbody>
<tr>
<td>Arlene</td>
<td>38</td>
<td>employed - postal service</td>
<td>single with children in home</td>
<td>African American</td>
<td>&lt; 3 months</td>
<td>medication only</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>Kay</td>
<td>79</td>
<td>retired</td>
<td>married</td>
<td>Caucasian</td>
<td>&lt; 6 months</td>
<td>not stated</td>
<td>-</td>
<td>28</td>
</tr>
<tr>
<td>Lisa</td>
<td>53</td>
<td>state employee</td>
<td>living as married, with children in home</td>
<td>Caucasian</td>
<td>&lt; 3 months</td>
<td>no medication</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>Sue</td>
<td>56</td>
<td>state employee</td>
<td>married</td>
<td>Caucasian</td>
<td>&lt; 3 months</td>
<td>no medication</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>John</td>
<td>68</td>
<td>retired</td>
<td>married</td>
<td>Caucasian</td>
<td>&lt; 12 months</td>
<td>medication only</td>
<td>1</td>
<td>11</td>
</tr>
<tr>
<td>Adam</td>
<td>77</td>
<td>self-employed</td>
<td>married</td>
<td>Caucasian</td>
<td>&lt; 3 months</td>
<td>no medication</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>Mary</td>
<td>69</td>
<td>retired</td>
<td>divorced</td>
<td>African American</td>
<td>&lt; 3 months</td>
<td>medication only</td>
<td>6</td>
<td>8</td>
</tr>
<tr>
<td>Jack</td>
<td>49</td>
<td>student</td>
<td>divorced, with children in home</td>
<td>Caucasian</td>
<td>&lt; 3 months</td>
<td>no medication</td>
<td>5</td>
<td>21</td>
</tr>
<tr>
<td>Kathy</td>
<td>70</td>
<td>retired</td>
<td>single, never married</td>
<td>Caucasian</td>
<td>&lt; 3 months</td>
<td>medication only</td>
<td>6</td>
<td>3</td>
</tr>
<tr>
<td>Sandy</td>
<td>57</td>
<td>state employee</td>
<td>married</td>
<td>Caucasian</td>
<td>&lt; 3 months</td>
<td>no medication</td>
<td>6</td>
<td>10</td>
</tr>
<tr>
<td>Renee</td>
<td>62</td>
<td>state employee</td>
<td>divorced</td>
<td>Caucasian</td>
<td>&lt; 12 months</td>
<td>medication only</td>
<td>4</td>
<td>93</td>
</tr>
<tr>
<td>Carla</td>
<td>64</td>
<td>state employee</td>
<td>married with children in home</td>
<td>Caucasian</td>
<td>&lt; 3 months</td>
<td>no medication</td>
<td>5</td>
<td>8</td>
</tr>
<tr>
<td>Pseudonym</td>
<td>Age</td>
<td>Occupation</td>
<td>Family Status</td>
<td>Race</td>
<td>Diabetes Duration</td>
<td>Means of Control</td>
<td>Health Status (1=poor, 7=excellent)</td>
<td># of Items kept &amp; used</td>
</tr>
<tr>
<td>-----------</td>
<td>-----</td>
<td>------------------</td>
<td>--------------------------------</td>
<td>-----------------</td>
<td>-------------------</td>
<td>------------------------------------------------------</td>
<td>-----------------------------------</td>
<td>------------------------</td>
</tr>
<tr>
<td>Dan</td>
<td>60</td>
<td>business owner</td>
<td>living as married</td>
<td>Caucasian</td>
<td>&lt; 3 months</td>
<td>medication combined with diet or exercise</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Janice</td>
<td>57</td>
<td>retired</td>
<td>single - never married</td>
<td>African American</td>
<td>&lt; 3 months</td>
<td>medication combined with diet or exercise</td>
<td>5</td>
<td>9</td>
</tr>
<tr>
<td>Alan</td>
<td>59</td>
<td>state employee</td>
<td>married</td>
<td>African American</td>
<td>&lt; 3 months</td>
<td>medication only</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Louis</td>
<td>48</td>
<td>state employee</td>
<td>married with children in home</td>
<td>Caucasian</td>
<td>&gt; 5 years</td>
<td>medication only</td>
<td>3</td>
<td>9</td>
</tr>
<tr>
<td>Emily</td>
<td>57</td>
<td>employed</td>
<td>divorced</td>
<td>Caucasian</td>
<td>&lt; 3 months</td>
<td>medication only</td>
<td>5</td>
<td>9</td>
</tr>
<tr>
<td>Suzanne</td>
<td>58</td>
<td>disabled</td>
<td>married</td>
<td>Caucasian</td>
<td>&lt; 3 months</td>
<td>not stated</td>
<td>6</td>
<td>5</td>
</tr>
<tr>
<td>June</td>
<td>65</td>
<td>retired</td>
<td>married</td>
<td>Caucasian</td>
<td>&lt; 3 months</td>
<td>no medication</td>
<td>5</td>
<td>28</td>
</tr>
<tr>
<td>Mona</td>
<td>59</td>
<td>nurse</td>
<td>divorced</td>
<td>Caucasian</td>
<td>&gt; 5 years</td>
<td>no medication</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>Sarah</td>
<td>55</td>
<td>state employee</td>
<td>married</td>
<td>Caucasian</td>
<td>&gt; 5 years</td>
<td>medication only</td>
<td>3</td>
<td>24</td>
</tr>
</tbody>
</table>
APPENDIX H
KEPT HEALTH INFORMATION ITEMS
FOUND IN HOMES

Books


CCS Medical. (n.d.). *Simple diabetes recipes*.


Cruise, J. (2010). *The belly fat cure sugar & carb counter: discover which foods will melt up to 9 lbs. this week*. Carlsbad, CA; London: Hay House.


Liberty Insurance. (n.d.). *The healthy kitchen: Delicious recipes for people with diabetes*. 245


Novo Nordisk. (n.d.). *Carb counting and meal planning*.


stPeteFabfamilies. (n.d.). *Total food counter for healthy living*.


Weight Watchers. (2002). *Dining out companion*.


Magazines
Diabetes Focus
Diabetes Forecast
Diabetes Health Monitor
Diabetes Living, a Better Homes & Gardens Special Interest magazine
Diabetes Self-Management
Eating Well
Health Magazine
Rachel Ray
Walgreen’s Heart Health & You
Woman's World

Websites
American Diabetes Association: http://www.diabetes.org/
Cleveland Clinic: http://my.clevelandclinic.org/health/default.aspx
dLife: http://www.dlife.com/
Diabetes Daily - A better life starts today: http://www.diabetesdaily.com/
Diabetic Connect: Diabetes Support Community: http://www.diabeticconnect.com/
Foot Care Express: http://www.footcareexpress.com/
Health Trio Connect (associated with participant’s insurance company):
https://www.healthtrioconnect.com/app/index.page
LifeScan, Inc.: from http://lifescan.com/
The Publix Pharmacy Diabetes Management System:
http://www.publix.com/pharmacy/Home.do
WebMD: http://www.webmd.com/
APPENDIX I

TABLE OF ACRONYMS

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>ADEC</td>
<td>American Distance Education Consortium</td>
</tr>
<tr>
<td>ARRA</td>
<td>American Recovery and Reinvestment Act</td>
</tr>
<tr>
<td>ASK</td>
<td>anomalous state of knowledge</td>
</tr>
<tr>
<td>CDC</td>
<td>Center for Disease Control</td>
</tr>
<tr>
<td>CDE</td>
<td>certified diabetes educators</td>
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<tr>
<td>CMS</td>
<td>Centers for Medicare &amp; Medicaid Services</td>
</tr>
<tr>
<td>CQM</td>
<td>clinical quality measure</td>
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<tr>
<td>DSME</td>
<td>diabetes self-management education</td>
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<tr>
<td>FSU</td>
<td>Florida State University</td>
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<tr>
<td>HER</td>
<td>electronic health records</td>
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<tr>
<td>HIPAA</td>
<td>Health Insurance Portability and Accountability Act</td>
</tr>
<tr>
<td>HISB</td>
<td>health information seeking behavior</td>
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<tr>
<td>HIT</td>
<td>health information technology</td>
</tr>
<tr>
<td>IB</td>
<td>information behavior</td>
</tr>
<tr>
<td>ID</td>
<td>identification number</td>
</tr>
<tr>
<td>INSU</td>
<td>information needs, seeking, and usage</td>
</tr>
<tr>
<td>IOM</td>
<td>Institutes of Medicine</td>
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<tr>
<td>IR</td>
<td>information retrieval</td>
</tr>
<tr>
<td>IRB</td>
<td>Institutional Review Board</td>
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<tr>
<td>IS</td>
<td>information science</td>
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<tr>
<td>IVR</td>
<td>interactive voice response</td>
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<tr>
<td>LIS</td>
<td>library and information studies/science</td>
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<tr>
<td>NAHIT</td>
<td>National Alliance for Health Information Technology</td>
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<tr>
<td>NCVHS</td>
<td>National Committee on Vital and Health Statistics</td>
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<tr>
<td>NHIN</td>
<td>National Health Information Network</td>
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<tr>
<td>NVS</td>
<td>Newest Vital Statistic</td>
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<tr>
<td>ODL</td>
<td>observations of daily living</td>
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<tr>
<td>PDA</td>
<td>personal digital assistant</td>
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<tr>
<td>PHI</td>
<td>protected health information</td>
</tr>
<tr>
<td>Abbreviation</td>
<td>Full Form</td>
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<td>--------------</td>
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<tr>
<td>PHIM</td>
<td>personal health information management</td>
</tr>
<tr>
<td>PHR</td>
<td>personal health record</td>
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<tr>
<td>PIC</td>
<td>personal information collection</td>
</tr>
<tr>
<td>PIM</td>
<td>personal information management</td>
</tr>
<tr>
<td>REALM</td>
<td>Rapid Estimate of Adult Literacy in Medicine Assessment</td>
</tr>
<tr>
<td>RWJF</td>
<td>Robert Wood Johnson Foundation</td>
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<tr>
<td>TILES</td>
<td>tourism-related categories, temporal, identity, location, environmental and social</td>
</tr>
<tr>
<td>URL</td>
<td>uniform resource locator (website address)</td>
</tr>
<tr>
<td>VA</td>
<td>Veterans Affairs</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organization</td>
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</table>
REFERENCES


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Dervin, B. (1992). From the mind's eye of the user: the sensemaking qualitative-quantitative methodology. In J. D. Glazier & R. R. Powell (Eds.), Qualitative Research in Information Management (pp. 61-84): Libraries Unlimited.


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PUBLICATIONS


REFEREED CONFERENCE PROCEEDINGS