Integrating Diabetes Self-Management into Daily Life: Exploring Process, Habit, and Occupation

Heather Fritz

A dissertation submitted to the faculty of the University of North Carolina at Chapel Hill in partial fulfillment of the requirements for the degree of Doctor of Philosophy in the Department of Allied Health Sciences (Occupational Science).

Chapel Hill
2013

Approved by:

Brian Boyd PhD

Antoine Bailliard PhD

Diane Berry PhD

Virginia Dickie PhD

Ruth Humphry PhD

ii

ABSTRACT

HEATHER FRITZ: Integrating Diabetes Self-Management into Daily Life: Exploring
Process, Habit, and Occupation
(Under the direction of Dr. Brian Boyd)

The incidence of type II diabetes continues to increase worldwide. Individuals

diagnosed with diabetes must engage in diabetes self-management (DSM), which

involves developing health promoting behaviors. At issue is that scholars do not yet fully

understand the key dynamics that lead to long term engagement in such behaviors. The

purpose of this qualitative research study was to explore the process by which low

income women with type II diabetes integrate DSM into daily life, the conditions through

which integration occurs, and the role of habit and occupation in the process. The

Transactional Perspective was the theoretical framework that guided the study. A multi-

methods approach, using semi-structured interviews, photography, Time Geographic

Diaries, and a standardized assessment, was used to collect data on ten low income

women, ages 45-64, with type II diabetes. A Grounded Theory approach to data analysis

facilitated the development of the Transactional Model of Diabetes Self-Management

Integration, which depicts the theorized process of DSM integration. Based on the data,

the following primary phases of DSM integration emerged: *Potential Uptake, Inquiry,*

Practice, Contingent Integration, and *Reconfiguration*. These five phases describe the

process whereby individuals accept aspects of diabetes education and training as

congruent with their circumstances, act on them, and practice with them until they

become a more integrated part of their daily lives. Individuals then continue to modify their habits, change their situations, and develop strategies to further facilitate DSM integration. Once habituated, these components may remain an integrated part of daily life until destabilizing life events necessitate reconfiguration. The integration process is a temporally contiguous process that unfolds through time, and is influenced by individuals' past life experiences, habits, and situations. Key findings demonstrate that individuals develop the skills and abilities to modify their habits and the corresponding aspects of their situation that support those habits through inquiry and practice, and this leads to integration. The study findings also suggest the importance of occupation in DSM integration because inquiry and practice are situated within occupational engagement. The implications of this work for both occupational therapy and occupational science are discussed.

ACKNOWLEDGEMENTS

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

Figure

Chapter One: Introduction

Patricia (or Pat) wasn't diagnosed with type II diabetes mellitus (T2DM) until her 60s. At that time she was married, the mother of six children, and living in a rural town in the Midwest. In the beginning stages of her diabetes Pat received education about her medications, including what they were for and how she should take them. Pat also was periodically told that she should try to be more active and watch her diet, and she genuinely tried to manage her diabetes. Nevertheless, her habits had solidified and were fiercely resistant to change. In fact, it seemed that all of the habits Pat had developed over the course of her life, including a general disdain for exercise and healthy foods, were in direct conflict with her diabetes management efforts.

 Occasionally Pat would make gains in one area of her diabetes management, such as losing a few pounds or eating less sweets, but these changes were often short-lived. To her frustration, Pat's gains in one area were usually synonymous with neglecting a different area. Pat was unable to make the multiple changes that were necessary for her to effectively manage her disease, or to sustain those changes for a reasonable length of time. Moreover, neither Pat nor her care providers ever produced a plan for her diabetes self-management (DSM) that would properly address her clinical needs as well as effectively integrate diabetes management into her lifestyle.

As the years went on, Pat's diabetic condition slowly worsened. Her care providers responded to these changes by adjusting the types and dosages of her

medications and by telling her repeatedly that she needed to exercise and eat better. At some point, although no one could seem to pinpoint exactly when, Pat crossed the threshold of what her body could take. Her years of poorly controlled diabetes led to peripheral neuropathy, fatigue, weight gain, and cognitive deficits. It was clear that Pat needed to make drastic changes. Unfortunately, Pat was now in her mid-70s: she was elderly, set in her ways, and, despite her efforts, was unable to make the much-needed changes that could have prolonged her life. Pat's family struggled to find ways to help her manage her diabetes. They tried to get her more information, although the resources they found were often confusing or seemed irrelevant to someone in such a progressed state. Pat's family also tried to get her services such as home health care, and even purchased adaptive equipment for her.

At times their frustration turned to blame. There was never any question about the love and devotion that Pat's family felt for her. Still, they fluctuated between understanding how hard it is to manage diabetes (and how ill-prepared they were to help her), and accusing her of being "lazy" and "unmotivated" to change.

Pat was my grandmother. During the last 15 years of her life, with little success, she struggled to incorporate DSM into her lifestyle. While she lived, my family and I also struggled to understand why her disease was so difficult to manage. That struggle did not stop for us in 2011, when Pat became one more of the more than 200,000 people who die every year in the United States from diabetic complications (CDC, 2011).

Unfortunately, Pat's case is not unique. Individuals worldwide continue to develop diabetes at ever-increasing rates. Currently, 25.8 million people just in the United States have diabetes, and the CDC projects that as many as 1 in 3 American adults

could have diabetes by 2050. Although medical and pharmaceutical advances have allowed more individuals to live longer with the disease, these seeming improvements have contributed to a considerable public health dilemma as a significant population cohort faces the lifelong task of DSM.

Diabetes has long been the purview of clinical and biomedical sciences, which have pursued pharmaceutical approaches to controlling it. As a subject of academic inquiry, however, DSM represents a progression in scientific inquiry that extends beyond biomedical and pharmaceutical research to include psychological, educational, and socio-cultural influences on the disease process. DSM is therefore as much a clinical necessity as it is a socio-cultural phenomenon. The rampant progression of diabetes in the U.S., and around the world, has been linked to lifestyle changes associated with modernity (until the latter part of the twentieth century) and now with globalization. Lifestyle and socio-cultural issues such as poverty, poor diet, obesity, lack of exercise, public policy, and perceptions of morality all shape what we call DSM.

The Rise of Self-Management

The term "self-management" is not the exclusive property of any particular discipline. It is associated with a variety of chronic illnesses, including arthritis and asthma (Lorig, & Holman, 2003). In the broader illness self-management literature, the process has been defined as the efforts patients make to optimize their own health, prevent complications, control symptoms, use medical information, and reduce the intrusion of their disease(s) into their daily lives (Burrows-Hudson, Curtin, Mapes, & Schatell, 2005). More simply, self-management can be thought of as the day-to-day tasks an individual must complete to control or reduce the impact of disease on health status.

In a similar vein, DSM can be thought of as the day-to-day tasks that individuals must perform to adequately manage their diabetes and associated risks. Under the DSM paradigm, patients are responsible for the daily management of their illness. This change in assignment of responsibility is a result of changes in the patient/provider relationship that gained momentum in the last quarter of the twentieth century (Lorig & Holman, 2003). Traditionally, the patient/provider relationship was characterized as largely prescriptive, with a physician (or, later, a primary care provider) directing patient care. Scholars eventually began to critique this relationship, especially with regard to issues of power; terms such as *compliance* gave way to more patient-oriented terms of *adherence* and *concordance* (Horne, 2006). The concept of self-management is commonly used to depict a more collaborative relationship and the responsibility and control possessed by individuals, rather than medical care providers, over their daily disease management.

Challenges to Diabetes Self- Management

DSM requires individuals to change long-held habits while also incorporating health-promoting behaviors (e.g., improved diet, effective stress management, and regular exercise) into daily life (Gomersall, Maddill, & Summers, 2012). Because diabetes is a chronic illness that requires lifelong management, people also must find ways to integrate healthy habits into their lives over the long term. This challenge has proven to be difficult; statistics indicate that more than 50% of individuals with diabetes have self-management deficits (Leeman, 2006). Particular groups face even more challenges with DSM. For example, racial minority status, female gender, and poverty have all been associated with worse diabetes-related health outcomes, increased risk of

early morbidity and mortality from the disease, and resource restrictions that make it difficult to engage in DSM (CDC, 2011; Narayan, Boyle, Thompson, Sorensen, & Williamson, 2003).

Age can also further complicate DSM. Traditionally, individuals aged 65 and older have carried the bulk of diabetes diagnosis; however, the demographic composition of the population with T2DM is shifting. Current estimates show individuals aged 40–64 will experience the largest increase in new diabetes diagnoses compared to both pediatric and elderly populations (CDC, 2011). Individuals in this age group must engage in DSM while balancing competing responsibilities typical for their life stage (e.g., working, caring for children or aging parents, and preparing for retirement). DSM, already a challenging endeavor, can be further complicated by social and economic factors.

Scholars have recognized the difficulties associated with DSM and have worked to further understand how to better facilitate it. Interventionists have used these understandings to develop programs to provide the knowledge, skills, and abilities necessary for engagement in DSM (Newman, Steed, & Mulligan, 2004). DSM scholarship demonstrates that although individuals may be able to initiate changes, they struggle to sustain them long-term (Norris, Lau, Smith, Schmid, & Engelau, 2002). Further exploration of the DSM literature reveals that cognitive and psychological means of affecting behavior changes are the most commonly used, whereas contextual influences are frequently ignored. In light of these findings, scholars have called for the scientific community to further explore the dynamics involved in sustaining health behavior changes through time and across changing circumstances (Glasgow, Goldstein,

Ockene, & Pronk, 2004). Such research is especially important for people who must engage in DSM for the rest of their lives.

Occupational Science and DSM

Scholars in the occupational therapy and science field have also sought to understand the DSM process more clearly, in order to assist their clients. Unfortunately, at the time of this study only a small body of occupational science/therapy scholarship was focused on DSM. Nonetheless, in 2011 the American Occupational Therapy Association (AOTA) produced a fact sheet for practitioners and consumers that described the role of occupational therapists in DSM that included seven recommendations for how occupational therapists can assist clients with DSM:

1. Promote healthy food choices and safe cooking methods.

2. Instruct in safe and appropriate ways to incorporate exercise and physical activity into daily routines.

3. Provide techniques to organize and track medications.

4. Instruct in the use of low-vision and nonvisual devices to draw up and measure insulin.

5. Instruct and provide strategies to successfully use a talking blood glucose monitor or use any blood glucose monitor one-handed.

6. Incorporate protective techniques and compensate for peripheral sensory loss in activities that involve exposure to heat, cold, and sharp objects.

7. Educate in techniques to structure time and simplify activities to cope with depression such as breaking down dietary changes and an exercise program into manageable steps and incorporating them into present daily routines.

As an occupational scientist and practicing therapist, I could appreciate these recommendations. However, as I pondered the official list I found it problematic that many of the recommendations were simply carried over from the American Association

of Diabetes Educators' (AADE) list of seven core behaviors that I questioned the unique contribution of occupational therapy to DSM. After all, with the exception of the fourth and sixth points, nurses, nutritionists, pharmacists, physicians, and physical therapists have been addressing most of these issues for decades and even longer. As I further considered the list, I struggled with identifying the real role of occupational scientists and therapists for individuals with diabetes (aside from addressing sensory and visual deficits and post-amputation care).

Eventually, I began to contemplate the role of occupation in a complex process such as DSM. This dissertation, and the research study that preceded it, are the products of this contemplation. They are the results of the convergence of my own interest, personal history, and professional life.

Of course the fact sheet was written for therapists, not occupational scientists. AOTA's adoption of the AADE's guidelines meets therapists' need for clear-cut, evidenced-based clinical guidelines for their interventions. Although not all therapists and scientists agree on the nature of this relationship (Atwal, Morley, & Spiliotopoulou, 2011), the originators of occupational science envisioned a functional relationship between therapy and science (Hocking, Wright-St. Clair, 2011; Yerxa et al., 1990). Occupational scientists would, in theory, develop a body of scholarship about occupation, and therapists could use these understandings of occupation to better facilitate their clients' occupational engagement. Because so few occupational scientists have explored DSM, however, there is a dearth of information for therapists to draw from even if they desire to do so. This realization caused me to wonder, *what might come from applying an*

occupational science perspective to the problem of DSM? In turn, that question provided the impetus for this study.

The Purpose of the Study

Issues with DSM are complex. They exist and persist because of the dynamic and inextricable transactions of the people, socio-cultural environments, institutions, and systems that make up everyday existence. DSM, a process undertaken by the individual, has consequences for the individual, the medical community, and society at large.

Facilitating adults' long-term engagement in DSM activities requires an understanding of how individuals with T2DM integrate DSM into their daily lives. In other words, it requires an understanding of the processes that lead to habit development. The ability of scholars to understand this process is limited by the overuse of psychological and cognitive theories of health behavior that minimize contextual influences on the DSM integration process. Much theorizing that supports self-management research applies a reductionist perspective that excludes the dynamism and complexity which are at the heart of DSM. The purpose of this study was to understand both the process by which low-income individuals with T2DM integrate DSM into daily life and the conditions that influence this process.

<div align="center">

Research Questions

</div>

1) **What is the process by which individuals with T2DM integrate DSM into daily life?**

The purpose of Question One was to explore the key dynamics of the DSM integration process. I also designed the study to elicit how habits and occupations operate

in the integration process, in order to understand how established habits interface with situational features to facilitate or inhibit DSM, how habits change over time in the context of becoming more experienced with managing T2DM, and what the key situational features are that facilitate these changes.

2) **What are the key temporal, spatial, and social conditions that affect DSM in this population?**

The purpose of Question Two was to understand how time, space, and social spheres influence the DSM integration process. Specifically, I think it is important to understand the distribution of DSM efforts across these factors, and how they influence the DSM process.

Significance of the Study

This dissertation details a multiple-methods study of how middle-aged, low-income women with T2DM have, successfully and unsuccessfully, integrated aspects of DSM into their daily lives. This exposition illustrates the role of habits and occupation in the DSM process. In fact, as the account unfolds, it becomes apparent that this work is as much a narrative of daily life management as of DSM. It is an account of women with diabetes and the daily situations through which they attempt to engage in DSM, including the challenges, opportunities, and strategies that are inherent in this process. This study was guided by the transactional perspective, which influenced both how I designed and implemented it as well as my analysis and presentation of its findings.

The study narrative reveals how habits and the qualities of everyday life frame a process of inquiry, evaluation, integration, and reconfiguration. This process not only transcends time, space, and social spheres, but also strongly suggests occupational

engagement as an effective means to growth and development that result in the ability of T2DM patients to integrate DSM into daily life across ever-changing contexts.

Document Overview

In Chapter Two I present the transactional perspective (Dickie, Cutchin, & Humphry, 2006) and explicate its influence on the study through informing my worldview and orientation to the problem. In Chapter Three I provide a review of the literature, with a particular focus on diabetes as a clinical problem addressed through DSM, limitations in the current DSM paradigm, and ways that scholars can advance our understanding of DSM integration. Chapter Four contains an outline of the multiple methods used in the study of 10 low-income women diagnosed with T2DM. Per the University of North Carolina's Institutional Review Board, I use pseudonyms for participants' names to protect their confidentiality.

In chapters Five through Seven I present the findings from the study, including the transactional model of DSM that depicts the theorized process of DSM. The presentation of findings begins in Chapter Five with a discussion of the three experiential histories that emerged from the data that illustrate (a) the similarities and differences in the participants' experiential histories, and (b) how these influenced, and manifested in, their DSM approaches. Chapter Six contains an overview of the conditions that influenced the DSM integration process (i.e., time, past life experiences, habits, and routines) while also introducing the transactional model of DSM integration. In Chapter Seven I also present and discuss the primary domains of the transactional model (i.e., potentials, inquiry, practice, contingent integration, and reconfiguration). Finally, in

Chapter Eight, I situate the relevance of these findings within existing DSM scholarship and the field of occupational science.

Conclusion

DSM is shared intellectual property that is influenced and investigated by a variety of disciplines that seek to understand and eventually resolve its challenges. For those in the medical and pharmaceutical sciences, progress on the biomedical frontier brings a cure for diabetes ever closer. Scholars with a social sciences orientation seek to understand how people's actions, and the reasons for their actions, can shape the development and management of diabetes. For those in fields such as occupational science, that are uniquely positioned between the biomedical establishment and the social sciences, with this dissertation I seek to contribute a unique understanding of the DSM phenomenon and process in the hopes of ameliorating its negative effects on human health. Ideas about treatment and cure evolve alongside stories of meaning and experience, both of which are required if life is to improve for people who struggle with DSM.

This study represents one step in the development of an occupational science perspective on DSM. As such, its findings provide insights about key dynamics in the integration process as well as suggestions for additional lines of inquiry. This study is significant in that it illustrates the utility of the transactional perspective for understanding complex health behavior processes. This study also provides insights into why DSM integration is such a difficult, time-consuming process. Perhaps most importantly, this study suggests that occupation is an important part of the DSM integration process, and therefore has the power to influence individuals' health.

11

Chapter Two: Theoretical Framework

The notion that theory should not only serve science but be evaluated by how it makes a difference in the real world is the main concern of the philosophical tradition called pragmatism (Cutchin & Dickie, 2013b, p. 23).

The Transactional Perspective

The issues surrounding the process of DSM integration are complex and varied. The transactional perspective influences my worldview and how I think about the problem of DSM integration. Therefore, the focus of this chapter is to provide an overview of the transactional perspective. The chapter begins by explaining the transactional perspective, via a genealogical approach that begins with the philosophical tradition of American pragmatism, specifically, the works of John Dewey (1941, 1957, 1960), and then discusses the application of the transactional perspective in the discipline of occupational science. The chapter concludes with an outline of the core conceptual pillars of the transactional perspective that served as "sensitizing concepts"[1] (Bowen, 2006) throughout the design, data collection, and analysis in the study.

Philosophical Foundation

The philosophical tradition known as pragmatism dates back to the 1870s and is associated with the formation in 1872 of the Metaphysical Club in Cambridge,

---

[1] Sensitizing concepts guide an individual's thinking by suggesting items of possible importance. They do not dictate what lines of inquiry are pursued or what elements are abstracted from the data for analysis.

Massachusetts. Its genealogy continues with the teachings of notable American

pragmatists Charles Sanders Peirce and William James at Harvard University in the late

1890s and early 1900s. Building on the work of Peirce and James, George Mead

extended pragmatist ideas and served as one of the key originators of symbolic

interactionism[2] (Hickman, 1998). From 1984 to 1904, Mead and John Dewey would

work together at the Chicago School of Pragmatism, which Dewey founded during his

10-year tenure at the University of Chicago; in 1905 he would direct another pragmatism

center at Columbia University. Dewey was and remains known as the premier American

pragmatist philosopher (Hickman, 1998). His esteemed position within the history of

American pragmatism stems from his substantial corpus of work, in which he addressed a

variety of philosophical issues including, but not limited to, education, democracy,

experience, and inquiry (Shook, n.d.).

      Dewey's refinement of the tradition of pragmatism is the philosophical foundation

for the study. In its most general sense, pragmatism views theorizing as an innate and

necessary part of everyday life. Theory and practice are not separate entities within this

philosophy but instead are the means by which individuals make sense of and function in

a changing world (Hickman, 1998). The transactional perspective, a theoretical

perspective founded on Dewey's pragmatist writings, views action as integral to and

assimilated within person-environment relationships (Cutchin & Dickie, 2013b).

---

[2] Symbolic Interactionism is a theoretical framework that seeks to explain how individuals use the
meanings of cultural tropes and indicators to interact with each other and within society.

An Overview of the Transactional Perspective

The transactional perspective is a relational theory; at the heart of a transaction lies the functional relationship of person and world (Garrison, 2001). The term "transaction" denotes that individuals do not simply interact with their environments but rather transact through them. As framed by the transactional perspective, experience is temporally situated and evolving because people exist in a world that is constantly shifting. Because humans exist in an inherently uncertain and changing world, they must constantly engage in dynamic person-environment transactions that are functionally coordinated and re-coordinated, often with the intent of maximizing well-being (Cutchin, 2007). For example, an individual with T2DM may know that he or she needs to reduce carbohydrate intake; however, such people may have to negotiate a range of situational aspects such as the availability of funds to purchase fresh foods, existing knowledge of carbohydrate exchanges, availability of appropriate options at local groceries, and skills to prepare these foods in order to reduce their carbohydrate intake.

The relational focus of the transactional perspective accounts for the existence of individuals within a shared socio-cultural context that shapes them and to which they contribute (Campbell, 1995). As individuals exist within families, communities, and societies, they come to embody aspects of all these contexts. Because of the co-constitutive nature of their development, in many ways individuals can be thought of as embodied communities (Aldrich & Cutchin, 2013, p. 16). Viewing individuals as transacting through their world rather than merely interacting with it or reacting to it, and understanding that human development is a co-constitutive process within particular socio-cultural worlds, is essential to developing a sufficiently complex and nuanced

understanding of how "situatedness" affects health behavior and health management. Humans are situated in particular environments that shape their individual and collective habits, for better or for worse, and these situationally influenced habits are enacted in the process of DSM.

The perspective presented by many popular theories of health behavior commonly used in DSM research is rather different. Perhaps the most commonly used approach, social cognitive theory (Bandura, 1997), emphasizes that individuals develop through interacting with their environments. Although Bandura did use the term "transaction" in his 1997 text, *The Exercise of Control*, its meaning differs from the one assigned to it within the transactional perspective. A thorough reading reveals that although Bandura used the term, he believed that humans develop a sense of self-efficacy through acting on (i.e., manipulating) the environment. For example, humans act upon an object (e.g., when an infant pushes a ball) and then respond to the consequences of such actions; one response is the inference that they have the power to manipulate their environment.

By contrast, the transactional perspective goes beyond a simple back-and-forth scenario in which humans either act on or react to the environment. Its focus instead is the organism-in-environment relationship; specifically, how humans act through their environments to coordinate and re-coordinate this relationship. Thus, the emphasis is less on human dominance of contexts than on human coordination with environments. This difference in perspective is significant because it impacts how scholars and researchers view the problem of DSM and how they approach solutions to it. Focusing on individuals' ability to control their situation is not inherently bad, but it does become

problematic when scholars ignore or marginalize the contextual influences that drive health management.

   The transactional perspective in occupational science. Scholars of occupational science have utilized the transactional perspective, which allows them to understand the complexity of human occupational engagement while avoiding the restrictions imposed by dualistic and individual-focused theories of action and behavior (Cutchin & Dickie, 2013b). The introduction and uptake of the transactional perspective in occupational science reflects the field's maturation in terms of how its central feature, occupation, is theorized and conceptualized.

   The founders of occupational science first conceived of occupation in terms of its meaning for individuals as they experience it (Yerxa et al., 1990). Because the analytical focus was placed upon the individual, the personal experience of engaging in occupation was privileged above not only the occupation itself but also the myriad of social and contextual influences that shape occupational engagement. As the discipline advanced, scholars such as Hocking (2000) began to encourage occupational scientists to study occupations in and of themselves rather than continuing to focus solely on individual experiences of them. Humphry's article, "Model of processes transforming occupations: Exploring societal and social influences" (2005), not only increased our understanding of occupation as co-constructed but also foregrounded the social and cultural forces that drive occupations and human occupational engagement. Building on this momentum and acknowledging a clear need to move occupational science beyond its individualistic orientation, Dickie, Cutchin, and Humphry (2006) introduced the transactional perspective to the occupational science community. This new theoretical perspective,

based upon the work of John Dewey, offered an alternative framing of experience as relational, co-constructed, and influenced by larger socio-cultural, situational contexts. Thus it was also a more holistic framework than the discipline had previously used.

As occupational science has continued to change within the contexts of globalization and multiculturalism, scholars have become more interested in applying the concept of occupations at the community and population levels to issues caused or aggravated by the forces of neoliberalism, globalization, structural violence, and social inequities (Frank, 2011). Scholars have also begun to question core assumptions surrounding the discipline's central concepts; these include issues of taxonomy, the privileging of Western perspectives on occupation, and the discourse surrounding occupational possibilities (Hammell, 2009; Jonsson, 2008; Kantartzis & Molineuz, 2010; Rudman et al., 2008). These developments within the discipline challenged scholars to (a) reflect on existing conceptions of occupation; (b) create avenues for occupational scientists to extend their inquiries to larger social problems; and (c) incorporate additional populations and areas of study that had previously been overlooked. Diabetes, and how individuals attempt to manage their diabetes, is one such overlooked area. Until recently, it has not been a focus for occupational scientists.

Applying the Transactional Perspective to Diabetes Self-Management

Diabetes self-management (DSM) is most often identified as the "process of facilitating the knowledge, skills, and ability necessary for diabetes self-care" (Funnell et al., 2012). This process requires particular skills and abilities; is embedded in the complexity of daily life; changes over time; and is influenced by larger socio-cultural forces. In short, DSM is occupational. Historically, DSM research has focused on

determining barriers and facilitators and how to empower individuals to overcome them. As previously noted, psychological and educational theories—e.g., social cognitive theory (Bandura, 1988), the health belief model (Janz & Becker, 1984), and the trans-theoretical model (Prochaska & DiClemente, 1983)—have often provided the frameworks for these studies (Jeffery, 2004; Newman, Steed, & Mulligan, 2004; Painter, Borba, Hynes, Mays, Glanz, 2008). To date, scholarship that utilizes psychological constructs such as self-efficacy has been useful in facilitating individuals' engagement in certain DSM activities; however, these studies show that results typically wane after approximately six months (Norris, Lau, Smith, Schmid, & Engelgau, 2002). In order to advance DSM scholarship, scholars must develop programs and interventions that produce sustainable results, a goal that may require a deeper understanding of how individuals integrate DSM into daily life.

Understanding the integration process requires moving beyond the individual and incorporating the features of daily life that influence DSM. Although some scholars have begun to call for an expanded focus within DSM research, few have seriously explored the situational context that influences the day-to-day processes of DSM. Because the transactional perspective can be used to understand DSM in a way that is more holistic and congruent with the dynamism of daily experience, it was utilized for the conceptualization and design of this study. Here, the transactional perspective includes the individual's experience of DSM integration and also goes beyond the individual to incorporate the socio-cultural situations of daily life.

Transactional Perspective as a Meta-theory for DSM

Cutchin and Dickie (2013a) indirectly suggested the fit of the transactional perspective for problems such as DSM. The transactional perspective provides an appropriate meta-theoretical orientation because, first of all, it rejects the traditional dualisms of person/environment or subject/object that have limited the inclusion and understanding of contextual factors on DSM. Pragmatists have argued that other theoretical traditions, such as subjective/objective or inner/outer, have also created false dualisms as well as the illusion that humans are essentially independent of their environments. The transactional perspective, by contrast, focuses on the wholeness of everyday experience; it does not depend upon the extraction of individuals from the environment that they develop in and depend upon. In other words, the transactional perspective includes the individual as a necessary, integrated component of an experiential whole (Dickie, & Cutchin, 2013a). This view of humans as organism(s) in the environment emphasizes that throughout their lives, humans must engage in coordination with an unstable world (Aldrich & Cutchin, 2013).

The transactional perspective provides a frame through which to understand the DSM integration process in a way that is more holistic and congruent with this dynamism. In essence, the transactional perspective was chosen as the meta-theory for this study because it is broad enough to handle the complexity of DSM, which exists because of the dynamic, inextricable transactions among persons and the socio-cultural environments, institutions, and systems that influence their everyday existence. Key concepts of the transactional perspective (e.g., habit and situation) were used as sensitizing concepts (Blumer, 1954) during data collection and analysis (Bowen, 2006).

Sensitizing concepts supply people with "a general sense of reference and guidance in approaching empirical instances" (Blumer, 1954 in Bowen, 2006). In other words, sensitizing concepts suggest initial directions for inquiry and analysis without dictating or confining analytical directions. The following key conceptual pillars of the transactional perspective were incorporated as sensitizing concepts within the study: *habit*, *situation*, and *occupation*. Sensitizing concepts are also congruent with the grounded theory approach that was used to guide data collection and analysis for the study.

Key Sensitizing Concepts

Habit. In *Human Nature and Conduct,* John Dewey (1922/1957) defined habit as "an acquired predisposition to ways or modes of response" (p. 45), meaning that habits are more than routines, regularly repeated actions, tics, or addictions (Clark, Sanders, Carlson, Blanche, & Jackson, 2007). Habits do not arise from and exist solely inside of an individual; rather, habits are acquired over a lifetime from transacting with the social and material world as a result of associated living (i.e., living as social beings in a shared culture).[3] Thus, habits reflect the mental and physical ways that people incorporate their environments. Society, as part of the environment, is both "a source and function of habit" (Aldrich & Cutchin, 2013, p. 16). Through the process of living, individuals develop personal habits of being in the world, acquiring "heritable interpretive structures such as symbol systems, stories, beliefs, myths, metaphors, virtues, gestures, prejudices, and the like" (Fesmire, 2003, p. 10). In other words, tendencies, virtues, and ideas (e.g., valuing hard work, prioritizing family over self, or particular food preferences) that we

---

[3] Associated living provides the conditions for individual habit formation while also determining the channels within which it operates (Aldrich & Cutchin, 2013).

believe to be our own creation are largely products of our enmeshment in a socio-cultural matrix. Although we may believe that we are acting independently, "we act based in a large part on predispositions we may not even be aware of, often evaluating consequences based on if they seem congruent with our experience of how the world should or should not be" (Fritz, 2012). In short, as Garrison (2002) notes, our culture has us before we have it. Our beliefs, traditions, and perspectives, which we may believe originate within us, are instead derived from and bound up with the communities we inhabit. Habits are both products of our enmeshment within our socio-cultural matrix and the tools that we have at our disposal to coordinate with it.

Human action, however, is not simply the application of one habit at a time, in stepwise fashion, in response to a situation. Instead, habits function as transactions in relation to the environment and each habit contributes to the total configuration, in turn, the configuration reciprocally affects the functioning of any particular habit (Kestenbaum, 1977). In the context of DSM, different habit configurations may be at play as individuals engage in physical activity versus when they administer their insulin. More specifically, the context of a fitness center may channel the manifestation of different habits than the context of one's home.

Situation. If habits are the social tools at our disposal for coordinating person-world transactions, situations are the contexts in which such transactions occur. Situations comprise the specific materials and qualitative contexts through which specific experiences occur; they are "both familiar to us and pregnant with possibilities and uncertainty, through which we reflect and act to gain knowledge" (Cutchin, 2004, p. 305). In other words, situations exist because we live in a world that is constantly changing; the

21

perpetually shifting nature of everyday life creates situations in which people must coordinate with their environment to maintain some degree of stability. Dewey (1938/1960) referred to the challenges that life situations present people on a regular basis as "problematic" or "indeterminate" situations (p. 218). His application of these terms did not convey negative judgment, but rather a description of reality: some situations are equivocal and need to be brought to determinacy.

Problematic situations are most evident to us when "change occurs and individual or social habits of thought and behavior prove to be inadequate or ineffective" (Dickie & Cutchin, 2013b, p. 424). Habits and situations are intricately linked in that habits exist and persist because situational qualities support them. For example, within the United States, individuals develop differing habits of language within environments that sustain them and support their use. A disjuncture in the relational whole occurs when a change in the qualities of a situation renders existing habits ineffective. The resultant problematic situation must then be re-coordinated to re-stabilize it with influences "that may or may not have benefit for others or the environment" (Dickie & Cutchin, 2013a). The outcome of this re-coordination is dependent on how habits and situational features interface. For an individual diagnosed with diabetes, existing habits may prove ineffective in coordinating this new situation (i.e., being a "person who must manage diabetes"); therefore, modifications to situational qualities as well as habits may be required to bring the new situation to stability and determinacy. Even individuals who have lived with diabetes for some time may experience life changes that require them to re-coordinate with new situations.

Occupation. Occupations are defined as all the things we do in the course of daily life that attract our attention and take up our time, energies, and minds (Cutchin & Dickie, 2013b). The transactional perspective emphasizes the importance of occupation as a means of coordinating person-environment transactions and thereby bringing problematic situations to determinacy. Occupations provide the means for such coordination because they provide opportunities for individuals "to balance intellectual and practical phases of experience" (Aldrich & Cutchin, 2013, p. 20). In other words, through occupational engagement individuals have experiences. As individuals repeatedly appraise their accruing experiences, they make determinations about the meaning of their engagements and how to better engage next time. In this way, the process of subsequent engagements can lead not only to a person's growth and development within his or her environment but also to changes within the environment itself.

The meaning that individuals glean from their occupational engagement is situated, meaning that it is derived from the outcome of the current occupation while also being associated with past experiences. The evaluation of prior experiences contributes to what Dewey (1941) termed "warranted assertability" (p. 170). *Warranted* refers to a prior outcome that provides fodder for future experiences, while *assertability* points to a future task (Hickman, 1998). This term then indicates the reach of experience both forward and backward in time, facilitated by occupational engagement. Occupations contribute to growth and development because they allow for the joining and refinement of situated meaning and experience over time.

In reference to DSM, it is through engagement with it that facts (e.g., the recommended number of minutes of physical activity, the optimum blood glucose range, etc.) are placed in daily contexts that give them meaning. For example, being told to participate in 30 minutes of moderate physical activity five times each week can be seen as a "fact." However, it is the sore muscles, fatigue, exhilaration, frustration, or other things that individuals experience as they actually engage in 30 minutes of moderate physical activity that give meaning to this "fact." Over time, this meaning may change with repeated engagements as individuals grow and develop their ability to participate in the occupation of managing DSM.

Summary

The purpose of this study was to understand the process by which individuals with T2DM integrate DSM into daily life and the conditions under which this integration occurs. The transactional perspective offers an alternative way of understanding DSM integration because the individual engaging in DSM is considered to be part of a larger relational whole. In turn, this relational whole is a functional unit, parts of which flexes and shift from time to time, and must therefore be coordinated and re-coordinated. The holistic and relational orientation of the transactional perspective is more useful than other theories that have been applied to DSM because it emphasizes the fact that individuals, through their environments, do not interact with only one variable at a time. Rather, in the course of day-to-day living, individuals negotiate and coordinate with and through a multitude of relational influences for an end product that is congruent with their circumstances. The same processes occur as individuals attempt to integrate DSM into their daily lives: DSM activities coexist with other everyday influences and become part

24

of the constant coordination and re-coordination of daily life. In order to advance DSM

scholarship, this dissertation seeks to address this complexity and help make sense of it

through thoughtful theorizing of the problem that incorporates the individual as part of

the situational whole.

Chapter 3: Literature Review

The predominance of type II diabetes mellitus (T2DM) in the United States situates this research study as both timely and relevant. As discussed in Chapter 1, the magnitude of the T2DM problem is compelling researchers to not only search for a cure but also to determine the best practices for individual management. Despite the necessity of practicing diabetes self-management (DSM; i.e., the constellation of behaviors that individuals engage in in order to achieve better diabetes outcomes), individuals struggle to appropriately perform it. Therefore, this review begins by situating the need for DSM scholarship as a result of the growing diabetes epidemic and the difficulties individuals have with engaging in DSM. Next is a discussion of how DSM has been conceptualized and how diabetes education and interventions have been used to improve DSM outcomes. This exposition is followed by a discussion of the limitations of the existing DSM paradigm, including the inability of existing health education and interventions to produce and maintain positive behavioral changes in the long term. After a discussion of three pathways that scholars could take to advance the DSM scholarship, the chapter ends with a summary and discussion of key points including how the study could advance the DSM scholarship.

Situating the Study: Type II Diabetes as a Clinical Problem

Type II diabetes (T2DM) is a metabolic disorder that affects how the human body uses sugar (glucose) from food. Under normal conditions, the food that humans eat is

broken down into sugar, which is transported to the body's cells for use as fuel. Insulin is essential for this transport. Most people with T2DM are initially able to produce sufficient insulin but their bodies are unable to use it effectively, a condition known as insulin resistance. When sugars cannot be transported into cells for use, they remain, undigested, in the bloodstream, where they cannot be efficiently used as fuel. The resultant sugar build-up then causes a myriad of micro and macro vascular complications. For this reason it is vitally important for individuals with T2DM to maintain control of their blood glucose levels (BGL).

Unfortunately, T2DM rates continue to rise. According to the Centers for Disease Control and Prevention (CDC), 8.3% of the U.S. population had diabetes in 2012 and an additional 35% were thought to be pre-diabetic. Moreover, since the 1980s the annual rates of newly diagnosed diabetes cases in the adult population has more than tripled, from 493,000 in 1980 to 1.9 million in 2010 (CDC, 2011). The rise in diabetes diagnosis is a particularly salient concern for North Carolinians. The rates of diabetes diagnosis in North Carolina exceed the national average at 9.8% of the state's population having diabetes (Barker, Kirtland, Gregg, Geiss, & Thompson, 2011).The sequelae of diabetes includes micro and macro vascular complications that significantly increase the risk of complications such as heart disease, stroke, high blood pressure, blindness, and kidney disease. CDC estimates for 2011 put the total cost of diabetes in the U.S. at $218 billion, an amount that rivals costs associated with other major diseases such as cancer ($263.8 billion in 2010). The aforementioned incidence rates reflect total diabetes diagnosis (both type I and type II); however, an estimated 90–95% of these diagnoses are type II (CDC, 2011).

For individuals with T2DM, the potential for complications is high. Fortunately, many risk factors associated with the disease can be reduced or eliminated through a combination of medical management and lifestyle changes. Medical management includes taking oral hypoglycemic agents and insulin in order to maintain appropriate blood glucose levels (Cramer, 2004). Lifestyle changes typically focus on changing a person's habits and behaviors to become more health-promoting. Several studies have demonstrated the benefits of lifestyle changes. In particular, the 2008 Diabetes Prevention Program study (DPP) was paramount in establishing that "lifestyle changes", modest weight loss achieved through exercise, and dietary changes resulted in improved BGL management. The DPP stands out because it was a large, multicenter study. Other studies, such as the Diabetes Control and Complications Trial (1993) and the Stockholm Diabetes Intervention (Reichard, Nilsson, & Rosenqvist, 1993) have also shown that lifestyle changes can have a substantial impact on diabetes management.

Overview of Concepts and Recommendations

Individuals diagnosed with T2DM must engage in DSM to reduce their risk of early morbidity and mortality. The following section provides an overview of how self-management has been conceptualized both across chronic conditions, and explicitly within the DSM scholarship. More specifically, the section includes a brief overview of the development of the seven core behaviors as the foundation of DSM; a foundation that influences the focus of many DSM education and interventions.

Concept and education. Individuals with T2DM engage in a variety of behaviors to reduce their risks of acute and chronic complications. The term "self-management" is used to describe the efforts individuals make to optimize health, prevent complications,

control symptoms, use medical information, and reduce the intrusion of the disease into their daily lives (Burrows-Hudson, Curtin, Mapes, & Schatell, 2005). Although the specific tasks and skills needed for self-management vary by condition, there are commonalities of self-management; these include the need to use medications effectively, understand and take appropriate actions in response to symptoms, and deal with the psychological consequences of the illness (Strauss et al., 1984; Lorig & Holman, 2003; Wagner, Austin, Davis, Hindmarsh, Schaefer, & Bonomi, 2001).

For individuals diagnosed with T2DM, DSM is the dominant medical paradigm for addressing the combination of medical and lifestyle recommendations that they are advised to follow in order to optimally manage their diabetes (Funnell et al., 2011). The most widely accepted and commonly used conceptualization of DSM comes from the American Association of Diabetes Educators (AADE), which has produced the 7 Self-Care Behaviors™ program. These core behaviors, which are considered to be the foundation of successful DSM, include "healthy eating, being active, monitoring, taking medication, problem solving, healthy coping, and reducing risks" (Mulcahy et al., 2003). The program is based upon the 1995 National Standards for Diabetes Self-Management Education (Peeples, Tomky, Mulcahy, Peyrot, & Siminerio, 2007), which provided empirical evidence about the activities that most strongly impacted metabolic control.

Along with establishing the seven foundational behaviors of DSM, the AADE has put forth recommendations for researchers about corresponding clinical outcomes (Mulcahy et al., 2003); these are classified as immediate, intermediate, post-intermediate, and long-term. Immediate outcomes include measuring learning; intermediate outcomes focus on the behavior changes associated with the seven core behaviors; post-

29

intermediate outcomes include clinical measures such as A1C,[4] lipids, and weight; and

long-term outcomes include measures of improved health status such as cost,

productivity, and quality of life.

Engagement in diabetes self-management. Engagement in the seven core

behaviors represents an intermediate-level outcome (Mulcahy et al., 2003). The education

that individuals receive after being diagnosed with T2DM focuses on facilitating the

knowledge, skills, and abilities necessary to achieve this outcome (Funnell et al., 2011). It

is challenging to engage in DSM. Scholars note that approximately 50–80% of diagnosed

individuals lack the appropriate knowledge, skills, and abilities to manage the disease

(Norris, Lau, Smith, Schmid, & Engelgau, 2002). Additionally, rough estimates of

adherence to DSM activities have substantiated that the majority of individuals struggle

in least one area of their DSM. The American Association of Clinical Endocrinologists

survey of more than 157,000 individuals with T2DM found that more than 65% of them

failed to maintain safe glucose levels (State of Diabetes Health, n.d.). Leeman (2006)

reported that as few as 44% of individuals actually achieve their DSM goals.

Moreover, the literature demonstrates that making necessary changes is even

more problematic for certain groups. In particular social and economic factors, such as

race, income, education levels, and gender shape an individual's approach to daily

engagement in DSM. For example, racial or ethnic minority status is associated with

increased risk of diabetes diagnosis, while minority status, having less education, lower

incomes, and being female are associated with higher rates of suboptimal DSM outcomes

---

[4] The A1c level reflects an individual's average blood glucose control over the preceding
two to three months; it is a more reliable measure than daily blood glucose tests of overall
blood glucose management.

30

(CDC, 2011; Narayam, Boyle, Thompson, Sorensen, & Williamson, 2003). The literature suggests that low SES and less education influence suboptimal outcomes in several ways. First, having fewer financial resources restricts individuals' access to quality primary care, necessary medications, and at times, healthy foods (Agency for Healthcare Research and Quality, 2004). Meanwhile, having less formal education can affect people's abilities to use health related information which is essential for DSM (Agency for Healthcare Research and Quality, 2004). Furthermore, low income and less educated minority women often act as surrogate caregivers for grandchildren while also caring for elderly family members. These women, (often referred to as the sandwich generation) may experience further restrictions on time, energy, and resources available to balance both the competing demands of the caretaker role and performing their own health management (Riley, 2005).

DSM scholarship has contributed to an evidenced-based framework for assessment, intervention, and outcome measurement of the behaviors most significantly linked to successful metabolic control. However, despite having specified framework individuals continue to struggle with modifying their lifestyles to accommodate changes across multiple behaviors. The literature therefore suggests, that continued research needs to be done to explore how people eventually accommodate a myriad of health promoting behaviors into daily life. It also suggests that the complex circumstances of low income, less formally educated minority women, further complicate DSM efforts; and therefore warrant added examination of how DSM unfolds in more vulnerable populations.

Education and interventions to improve DSM. Researchers and clinicians have recognized that individuals with diabetes need education and support to successfully

engage in DSM. The primary means of addressing clients' needs are through Diabetes

Self-Management Education (DSME; Funnell et al., 2011). Historically, DSME and

chronic illness management programs in general have focused largely on didactic

education (Newman, Steed, & Mulligan, 2004). However, the didactic presentation of

even the most necessary knowledge is insufficient to effect lasting behavior change

(Glasgow & Anderson, 1999; Funnell et al., 1991).

The new era of DSME included interventions that incorporated additional skills

and strategies (e.g. behavior change goals, treatment self-efficacy, and barrier

management/resolution strategies) (AADE, 2011). As behavior change was adopted as

the primary outcome of DSME, scholars began to import theories and constructs from

psychology and the cognitive sciences (Newman, Steed, & Mulligan, 2004). For

example, Glanz (2002) found that the health belief model (Janz, & Becker, 1984), the

theory of reasoned action (Ajzen & Fishbein, 1980), social cognitive theory (Bandura,

1977), and the transtheoretical model (Prochaska & DiClemente, 1983) were most

commonly used to explain health behavior change and to guide behavior change

interventions. DSM scholarship has continued this trend as researchers incorporate

components such as empowerment, problem solving, and self-efficacy into DSME

interventions (Clark & Dodge, 1999; Hill-Briggs & Gemmell, 2007).

Although DSME interventions have become more sophisticated, DSM

scholarship has revealed some areas of concern. First, each of the seven core behaviors

has not received equal attention. In fact, most DSM interventions focus on only four:

medication management, blood glucose monitoring, healthy diet, and exercise. A meta-

analysis (Gary, Genkinger, Guallar, Peyrot, & Brancati, 2003) of educational and

behavioral interventions in T2DM found that 70% of the randomized control trials RCTs included in the analysis targeted diet, 57% focused on exercise, and 56% focused on either medication or blood glucose self-monitoring[5]. Some interventions have focused on less-commonly considered psychosocial aspects of DSM including anxiety, depression, and quality of life (Steed, Cooke, & Newman, 2002).

The second concern, and probably the most significant one, is that even after a substantial body of intervention work has been developed, DSME programs and interventions still produce mixed results. A meta-analysis (Gary, Genkinger, Guallar, Peyrot, & Brancati, 2003) of the effects of educational and behavioral interventions on glycemic control and weight reduction found that DSME-focused interventions were effective in producing a moderate, statistically significant decline in glycohemoglobin (GHb). However, the changes in participants' weight and fasting blood glucose levels were not significant. Similarly, Ismail, Winkley, and Rabe-Heketh's investigation (2004) of whether or not psychological interventions were effective in improving DSM demonstrated that although the interventions were successful in reducing psychological stress, they did not produce significant changes in weight or blood glucose concentration. Furthermore, a meta-analysis (Norris, Lau, Smith, Schmid, & Engelgau, 2002) of the effects of DSM education on glycemic control showed that DSME interventions produced clinically significant changes in GHb in the short term but that these effects deteriorated after six months. Evidently, DSME interventions sometimes facilitate individuals' engagement in the seven core behaviors, yet this engagement quickly unravels.

---

[5] Some studies had more than one focus such as targeting dietary and physical activities changes at the same time.

The third concern is that the majority of DSM scholars focus their interventions on addressing engagement in the seven core behaviors. These behaviors are valuable; nonetheless, a myriad of additional intrapersonal and extra-personal influences and sub-processes also influence DSM, and therefore, metabolic control. For example, the qualitative meta-synthesis Gomersall, Madill, and Summers (2011) conducted concerning the self-management of T2DM produced four themes that provide insights into additional processes and influences that have significance for how people approach DSM. The four themes generated from the meta-analysis were: self-management in context, gender and self-management, self under attack, and intervention and regulation of the self. Of particular relevance to this study, the authors noted that self-management is influenced by multiple, complex, and often times competing factors including specific social and cultural influences on self-management processes.

The authors also noted the influence of gender on self-management. For instance, the authors founds that women felt more individual responsibility for their DSM and tended to subjugate their own needs, in order to manage the needs of their families, more so than men. This in turn contributed to how they approached their DSM. The authors also noted (with the theme: self under attack) that the inherent complexity of DSM regimens and the burden of making the changes necessary to accommodate DSM sometimes threatened participants sense of self and bodily integrity, whereby causing them distress.

Moreover, within the theme *regulation of self*, the authors found a tendency for researchers to place responsibility solely on the individual's to modify and control their behavior in order to manage their diabetes. They also noted that many studies explored

cognitive or affective means of improving an individual's self-regulation. The authors did criticize this viewpoint noting that self-management tended to be seen as located within the individual, stating, "the idea of diabetes self-management as a set of situated, constituent parts—and the awkward questions this raises for dealing with the social, economic, and political determinants of diabetes—is glossed over by such a conceptualization" (p. 686). These four themes provide insights into additional influences and sub-processes that contribute to how people engage in DSM, that have been previously under studied and that should therefore, continue to be further explored.

Limitations of the DSM Literature

Diabetes is a significant chronic illness that involves following medical regimens while also making lifestyle changes. Individuals struggle to make the behavioral changes necessary to appropriately manage their diabetes. The work of DSM scholars has produced educational approaches and intervention supports that can facilitate positive behavior change. However, limitations in the DSM scholarship have affected scholars' ability to suggest much-needed behavioral changes in all components of DSM.

Although researchers are free to choose the focus of their interventions, their disproportionate focus on diet and exercise is a matter of concern. The meta-syntheses presented above demonstrate that an important component of DSM is learning how to reconcile the psychological and emotional consequences of living with a chronic condition. Individuals will have a better chance of engaging in the highest number of core behaviors if their emotional and psychological needs are addressed; yet, these continue to be underrepresented in the literature.

Perhaps the more significant issues arise from the apparent inability of DSM interventions to produce longer-term behavior change. I argue that this issue is related to the overuse of the seven core behaviors as well as psychological and behavioral theories to guide DSM interventions. I also argue that these two issues are connected. For example, emphasizing behavioral changes in the core behaviors may have led to the privileging of psychological and cognitive theories to guide interventions. Focusing on an arbitrary number of broad behaviors and relying on individualistic theories of behavior change obscures the additional contexts, processes, and skills that are necessary for DSM.

The qualitative meta-syntheses presented above provide alternative conceptualizations of DSM that go beyond the seven core behaviors. In other words, there are additional processes that people take part in to enable their engagement in DSM. These themes, domains, and processes are not behavior-specific but instead transcend the DSM process. Scholars should seek ways to facilitate longer-term behavior change across a wide variety of DSM activities. With this goal in mind, it may be more beneficial and useful to understand the underlying processes and skills that are at play across a variety of DSM activities, rather than to focus on pre-specified behaviors.

DSM scholars are not alone in their struggle to produce lasting behavioral changes. Other scholars who are interested in health behavior change have noted the limits of existing approaches, for example that they are rarely sustained in the long term. Scholars have also begun to note that that the initiation and maintenance of behavior are two similar but separate phenomena and that their dynamics require further exploration (Nilsen, Haverkos, Nebeling, & Taylor, 2010). Researchers have also suggested that scientists need to develop new models of behavior change that address sustained

36

engagement in the context of constantly shifting personal, social, and environmental circumstances (Glasgow, Goldstein, Ockene, & Pronk, 2004).

DSM interventions, as a subset of treatments that are meant to facilitate health behavior change, have followed the general trends of related theories and have focused on psychological and behavioral approaches. Although these theories are useful for understanding how people initiate engagement in behaviors, they may be ill-suited to the understanding of how people sustain such behaviors over the long term. Whereas theories of health behavior change can consider behavior at the individual, group, community, or organizational levels, most of the theories that are used to guide interventions focus on the individual (Noar & Zimmerman, 2005; Crosby, Kegler, & DiClemente, 2002). To some degree, these theories share the belief that people will change their behavior based on some combination of capability perceptions, expectations, and the risks/benefits of their actions (Jeffery, 2004; Newman, Steed, & Mulligan, 2004). Critics, however, question the usefulness of these theories in guiding interventions that address behavior change in real-world environments that continue to become more complex (Crosby & Noar, 2010). This critique stems in part from the realization that psychological and educational theories leave little room for consideration of the circumstances that influence how individuals choose to or are able to engage in DSM: the "substantial majority of health behavior theories exist at the individual level, thereby neglecting contextual realities that shape behavior" (Crosby & Noar, 2010, p. 259).

Brief Summary of DSM Scholarship

Diabetes researchers seek to help people who have the disease engage in health-promoting behaviors and achieve better outcomes, including positive change across

multiple behaviors. Nonetheless, DSM has been shown to entail processes and skills that are not reflected in the seven core behaviors. If the goal is to facilitate initiation of one of the core behaviors, then psychological or cognitive theories may be warranted. However, sustaining long-term behavior change has been shown to be a different enterprise—one that requires the use of alternative theoretical approaches. In the following section I offer three suggestions that can increase our understanding of the key forces at work in DSM. One is that scholars could begin to frame DSM in terms of DSM integration, which draws attention to how behaviors are habituated into daily life. The second is that scholars could apply an occupational perspective to DSM integration and, in doing so; utilize the role of occupation in DSM to generate more-powerful interventions. Third, scholars could work to further theorize how contextual forces function in DSM integration, and how their influence changes over time.

Illness Self-Management Integration

Chronic illness self-management integration (CISMI) has been the focus of researchers who try to understand the impact that chronic conditions have on lifestyle and sense of self over the course of illness trajectories. CISMI has been defined in a variety of ways; one way presents it as a chronological process through which individuals develop their self-management skills while determining how to balance illness self-management within their daily lives (Hibbard, Mahoney, Stock, & Tusler, 2005). Other scholars have placed less emphasis on the chronological nature of CISMI in favor of defining it as a more fluid process characterized by transitions of life circumstances and illness change (Horsten, Jutterstrom, Audulv, & Lundman, 2010).

The majority of CISMI research has focused on the psychological, spiritual, and emotional aspects of integration whereby past roles, identities, and experiences are reconciled as the person takes ownership of his or her condition (Hernandez 1995, 1996; Whittemore, 2002). For example, CISMI has been presented as the process by which one makes psychological adjustments (Whittemore & Dixon, 2008) or comes to terms with a new identity (Asbring, 2001), as well as the process within which body, mind, and spirit achieve harmony within a constantly changing environment (Dungan, 1997).

Recent scholarship has begun to focus less on the inner world of CISMI and more on the actions and circumstances that the person works through while integrating illness self-management into daily life. For example, Audulv, Asplund, and Gustaff-Norbergh, (2012) divided the CISMI process into phases of (a) seeking effective self-management strategies, (b) considering costs and benefits, (c) creating routines and plans of action, and (d) negotiating self-management that fits into one's lifestyle. Hornsten, Jutterstrom, Audulv, and Lundman (2011) depicted phases of the integration process as (a) suspecting/being diagnosed with an illness, (b) understanding and explaining an illness, and (c) negotiating illness and taking stands about self-management. The authors noted that the CISMI process changes through time and is influenced by key turning points.

The overarching focus of CISMI involves trying to understand how self-management components are assimilated into and sustained within daily life. CISMI scholarship demonstrates that self-management integration includes aspects of the self-management experience (e.g., time, change, and negotiation) that are currently under-theorized in the DSM literature. However, the majority of CISMI scholarship is still

focused on the psychological and emotional aspects of integration; more work is required to understand the role of person-context relationships in the CISMI process.

The Contribution of Occupational Science to the Study of DSM and DSM Integration

To date, DSM interventions have largely focused on getting individuals to modify their behavior in order to achieve better diabetes outcomes. Scholars have turned to psychological and cognitive theories to facilitate engagement in these behaviors. However, human action remains under-examined as it relates to the management within, and integration into, the broader sphere of daily life.

A form of action that has relevance to DSM is occupation, generally defined as the things we do that attract our time energy and attention. People's occupations reflect aspects of their identity, such as their particular habits, history, geography, life experiences, life circumstances, education, beliefs, values, interests, roles, relationships, and personal and socio-cultural meanings (Cutchin, 2007; Dunn & Hocking, 2001; Yerxa, 1990). Occupations serve as organizers of time and resources (Christiansen & Matuska, 2006; Clark, 1997) and often supply the means through which individuals experience personal and social change in the world. Occupations both require and lead to skills, abilities, knowledge, and access, and are subject to time and resource constraints, policy restrictions, and cultural norms (Hocking, 2009). Some occupations are enacted out of necessity (e.g., food provision) while others are done for pleasure (e.g., visiting with friends and loved ones). Therefore, the effects and consequences of occupational engagements extend beyond the meanings that individuals ascribe to them; they draw from and affect communities and society at large (Dickie, Cutchin, & Humphry, 2006).

Occupational scientists study occupation in all its forms and functions (Yerxa, et al., 1990) and are concerned in particular with the relationships among occupation, health, and well-being (Scaffa, Van Slyke, & Brownson, 2008). Not only do a person's occupational needs and choices influence her health (Wilcock, 2006), such choices are made in the face of multiple daily demands. Occupational therapists use their understanding of occupation to help people achieve engagement in their valued occupations, to assess and determine when difficulties arise, and how to remediate problems through rehabilitation, modification, and adaptation (Scaffa, 2008).

Occupational scientists and occupational therapists have long been concerned with chronic illness, especially with regard to how living with chronic illness affects occupational engagement. Areas of investigation have included the effect of chronic illness upon occupational choices (Nagle, Valiant-Cook, & Polatajko, 2002; Pyatak, 2011) and changes and losses in occupational engagement (Kerr & Ballinger, 2010). Occupational scientists have also explored the meanings that occupations hold for persons with chronic illness (Reynolds, 2004), how chronic illness affects life balance (Matuska & Erickson, 2008), and how individuals make sense of living with a chronic condition (Clair, 2003).

A growing interest in DSM also has become evident within the occupational therapy literature, as shown by the American Occupational Therapy Association's fact sheet on the role of occupational therapy in DSM (AOTA, 2011). Occupational therapy scholars have explored issues related to DSM, such as interventions for secondary conditions including Raynaud's disease (Riley, 1998) and peripheral neuropathy (Raztan,

Futeran, & Isakov, 2010). Additionally, scholars have examined the cultural relevance of interventions to promote DSM in Mexican-American older adults (Haltiwanger, 2012).

Although this growing body of scholarship has increased our knowledge and understanding of how the experience of living with a chronic illness affects occupation, the reversal of this relationship remains under-researched (i.e., how occupational engagement facilitates or inhibits management of a chronic illness). Most relevant to the purposes of this dissertation, scholars still know relatively little about the role of occupation in DSM. Perhaps the primary reason for this gap is that scholars in both occupational science and occupational therapy have persisted in conceptualizing DSM as a phenomenon that affects how individuals engage in valued occupations rather than looking at DSM itself as a form of occupational engagement.

Hocking (2009) offered parameters for the study of occupation that included looking at the specific knowledge, skills, abilities, temporal dimensions, normative standards, and socio-cultural meanings of occupational engagement. Diabetes self-management integration (DSMI), certainly, requires specific knowledge, skills, and abilities. Moreover, the performance of DSM activities is routinely compared to normative standards. In addition, DSM holds personal and social meanings, especially for those who must engage in it. These parameters, which suggest that scholars should also conceptualize DSM as a form of occupational engagement, are augmented by scholarly suggestions that occupations provide opportunities for growth and development (Aldrich & Cutchin, 2013; Cutchin, 2013). Integrating DSM into daily life requires individuals to grow in their skills and abilities. Occupational engagement provides opportunities for individuals to act, practice, and evaluate related skills and abilities. For all of these

reasons, I believe that understanding DSM integration as an occupational endeavor can provide important insights into how people grow and develop their integration efforts.

Framing DSM as a form of occupational engagement, and applying an occupational perspective to the study of DSM, allows for a more comprehensive understanding of DSM. Moreover, such a frame subsumes existing avenues of scholarship that focus on (for example) issues of meaning, value, and occupational choices, while also opening avenues to explore how people use occupation to grow and develop in their DSM efforts. The problem of DSM creates opportunities for occupational scientists to contribute to DSM scholarship and the larger field of illness self-management.

General Summary

DSM represents a complex process that involves a mix of medical and lifestyle recommendations. People who develop T2DM must engage in DSM in order to reduce their risk of related health complications. Optimum DSM is characterized by maintaining a healthy diet, engaging in moderate physical activity, self-managing of medications and BGL, and self-monitoring to prevent complications (Funnell et al., 2011). Engaging in these DSM activities, which are many and varied, takes place within daily life contexts that are already complex. Accordingly, the changing nature of daily life is often the issue that makes DSM engagement difficult to sustain.

Diabetes interventions have been somewhat successful in facilitating the initiation of DSM behaviors. Interventions have also been valuable in adding to the understanding of which variables or constructs are most important in DSM (DPP, 2008; King, et al., 2010; Newman, Steed & Mulligan, 2004), which variables are most reliable predictors of

43

behavior change (Bandura, 1998; Noar & Zimmerman, 2005), and desirable areas of focus and primary domains of interventions (Futeran, 2010; Burrows-Hudson, Curtin, Mapes, & Schatell, 2005; Lorig, & Holman, 2003; Lorig et al., 1999). Existing DSM scholarship also provides guidelines for future DSM research. These guidelines indicate that optimum DSM programs must be comprehensive and contain content that affects the three main areas of DSM management: medical, life and role, and psychological (Burrows-Hudson, Curtin, Mapes, & Schatell, 2005; Lorig, & Holman, 2003).

Diabetes interventions have not, however, demonstrated the ability to consistently facilitate behavior change across all DSM behaviors or to sustain long-term behavior change. In acknowledgement of this failure, scholars have suggested that long-term behavior change may necessitate different theoretical approaches than those that are currently guiding many SMIs. Specifically, scholars have stated that understanding long-term behavior change will include exploring how individuals and their environments function together in DSM and how that relationship changes over time.

I suggest that one way to address these limitations is increase the focus on DSM integration. DSMI studies have already revealed not only the presence of additional behaviors and processes that influence behavior maintenance, but also that these areas should be given further study. I also suggest that scholars need to further theorize how contextual forces shape DSM integration, and how their influence changes through time. This study represents a step in this direction by further theorizing the DSM integration process.

The purpose of this dissertation is to explore the process by which some low-income women have integrated DSM into their daily lives and the conditions through

which this integration has occurred. I have approached integration as a long-term process by which individuals grow and develop in their ability to maintain engagement in DSM across contexts and over time. I have done so to contribute to much needed theorization of how and why people do and do not engage in DSM and how the integration process changes over time. An additional study goal is to understand how life transitions affect DSM efforts at sustained management as well as how individuals use occupation to grow and develop in DSM. In other words, the form of DSM integration I present entails the understanding of how individuals and their situations both co-constitute DSM integration.

The benefit of exploring DSM integration is that it incorporates the actions associated with DSM under the environing conditions within which integration occurs. This investigation therefore emphasizes how situational qualities, habits, and occupations work together in this process. Recognition of this cooperation is an essential first step in meeting the need for a new kind of DSM scholarship, one that aims to understand the key dynamics of long-term DSM. Thus, the specific research questions posed in this study were as follows: (1) what is the process by which individuals with T2DM integrate DSM into daily life and (2) what are the key temporal, spatial, and social conditions that affect DSM in this population? In the following section (Chapter 4) I explicate the methodological approach used to answer these questions.

Chapter Four: Methods

The overarching aim of this study was to explore the process by which individuals with type II diabetes (T2DM) integrate diabetes self-management (DSM) into daily life and the conditions through which this occurs, with the larger goal of developing a theoretical model of the DSM integration process. A multiple case study design was used to explore the process individuals with T2DM use to integrate DSM into daily life, the conditions through which this integration occurs, and the roles of habit and occupation in this process. As I pursued this line of inquiry, it became clear that a multiple-methods approach was needed in order to see and make sense of the problem from a variety of angles, as well as to achieve a depth of understanding within individual cases and across cases. Utilizing multiple methods also provided welcome opportunities for convergence, corroboration, and triangulation of the data, which in turn led to a more valid and comprehensive understanding of the findings than would have been achieved via singular methods (Creswell, 2011).

Grounded theory, which guided both the data collection and analysis, is consistent with the overall study aim of developing a theoretical model of the process of DSM in daily life. In the following sections I will further discuss the grounded theory approach used in this study as well as the study design, recruitment, data collection, and data analysis. Specifically, I provide a rationale for selecting the data collection methods and describe the data collection process for each method that was selected. Finally, I discuss

the analysis of each method and how a grounded theory approach facilitated integration of the multiple data sources throughout the research process.

Study Design

Rationale for methods. I hypothesized DSM integration as a transactional process, which meant I also anticipated the need to collect data that would provide insight into how habits, occupations, and the relevant conditions of everyday life function in DSM integration over time. Because I determined early on that no one method would be sufficient to allow an in-depth understanding of these various factors, I selected four complimentary methods of data collection: the Diabetes Care Profile (DCP), semi-structured interviews (SSIs), photo-elicitation, and time geographic diaries (TGD).

Diabetes Care Profile. The Diabetes Care Profile (DCP; Michigan Diabetes Research and Training Center, http://www.med.umich.edu) is a self-administered questionnaire used in DSM research to assess the psychological and social factors that affect diabetes care. The DCP consists of 16 scales that assess individuals' self-reported diabetes care, attitudes, beliefs, and difficulties with self-care, in addition to participant demographic data and information on individuals' diabetes-care practices. In the study, participants used specific sections of the DCP to self-report data on their demographics, self-care practices, and understanding of diabetes-care activities (e.g., BGL management and exercise). I did not deem the full DCP necessary for this study because I anticipated that additional information would be gathered during the SSIs. Participants completed the DCP in conjunction with their first SSI.

Semi-structured interviews. DSM integration is a process that occurs through time. Therefore it was necessary to elicit participants' personal biographies to understand

47

how their habitual ways of being in the world developed over time and shaped their DSM integration processes. I determined that semi-structured interviews (SSI) would be the best way to capture participants' experiences of living with and attempting to integrate DSM over time.

SSIs are structured in that the content to be covered with each participant is consistent. In other words, all participants in a given sample are asked the same questions that cover the same content, although the sequence of questions may vary from person to person. SSIs utilize open-ended questions, which allow participants to elaborate on subjects that are particularly meaningful and relevant for them (Britten, 1995). For this study, I chose SSIs to ensure that all participants would respond to the same foundational questions, and to allow exploration into additional topics that participants introduced.

Photo-elicitation. The photo-elicitation method (Wang & Burris, 1997), which has been successfully used in community-based participatory action research, involves facilitating reflective dialogue about community issues based upon photography and photographs. The photo-voice method, which is a more formalized approach to photo-elicitation research, involves training participants in basic photography techniques and then directing them to take photographs within their context as it relates to the focus of the study. After the photos are developed, researchers typically discuss them with participants, either individually or in groups.

A review of the literature revealed that photo-voice and similar methods had been used successfully in a variety of studies about process and situations that affect certain processes (e.g., the process of increasing daily life engagement for individuals with stroke, or how transsexual access health care) (Catalani & Minkler, 2010). My prior

clinical experience also led me to believe that the participants in the study would possibly have complicated home lives and peripheral situations (e.g., work and school) that would affect their attempts to integrate DSM into their daily lives. Therefore, I expected that photo-elicitation would allow these individuals to document these and other situations in their daily lives that I could not directly access. I also chose the photo-voice method because of its potential to empower participants in terms of their control over what they would photograph and discuss with me.

Time-geographic diary. The time-geographic diary (TGD) method was used in this study to highlight and understand the role of occupation in people's lives from a contextual perspective. I expected that occupation would influence DSM integration because what individuals do—along with where, how, why, and when they do it—effects health (Wilcox, 2006). The TGD method allows for analysis of the multiple contexts of an individual's daily occupations, with a focus on the use of time and space throughout a day in combination with analysis of social networks as the person moves through his or her everyday lives (Kroksmark et al., 2006).

The TGD method employs a type of temporal-use journal that includes a physical location component. This type of record has the potential to elicit a variety of activity data such as type, location, duration, time period, and presence of other participants, as well as to capture the affective domain of the activity. The diary method has been widely used in large multinational time-use studies, is cost effective, and can be analyzed qualitatively or quantitatively depending on the diary's design (Pentland & Harvey, 1999). The TGD provided a method by which to foreground the structural influences of daily life on DSM (e.g., the sequence of daily activities and the relative rigidity or

flexibility of one's daily routine) along with the distribution of DSM across time, space, and social spheres.

Study Setting, Recruitment and Sampling Framework

Setting. The study was conducted in an urban setting in North Carolina. The county in which recruitment occurred has a mixed population that represents multiple ethnicities, ages, and socio-economic statuses. I chose a recruitment site in N.C. because of logistical considerations (e.g., driving distance from the primary investigator's home) and because the current rate of diabetes in N.C. is greater than 9% (Barker, Kirtland, Gregg, Geiss, & Thompson, 2011).

Recruitment and informed consent. Participants were recruited from local, community-based primary care clinics that offer accessible services through use of a sliding scale with minimal co-pays. The specific clinic was chosen as a recruitment site because it met feasibility criteria (i.e., a substantial number of its clients met the desired social and economic sampling parameters for the study).

The recruitment goal was 10 participants, a sample size that has been deemed sufficient for a grounded theory study using multiple methods of data collection (Miles & Huberman, 1994). Initial inclusion criteria included (a) self-identify as African American, (b) household income at or below the 200% federal poverty guideline (HHS, 2012), (c) self-identity as female, (d) self-reporting of a diagnosis of T2DM, and (e) self-reporting of being between the ages of 40 and 64. The age requirements reflected the CDC's 2010 projections that individuals between the ages of 40 and 64 represent the fastest-growing cohort of diabetes diagnoses. Exclusion criteria were: (a) not having T2DM, (b) having a cognitive impairment that resulted in a proxy performing DSM, (c) being outside of the

age range, or (d) inability to read and understand English at the third-grade level. The last criterion was included to ensure that participants would be able to complete all study activities.

Recruitment began with the posting of IRB-approved flyers at the clinic (Appendix A). In addition, I recruited participants from group-based diabetes educational classes at the clinic that I attended as part of a larger study associated with the University of North Carolina at Chapel Hill. I was granted time at the end of each class to distribute recruitment flyers, briefly describe the study, and obtain contact information from people who expressed interest. I used an IRB-approved script (Appendix B) to screen potential participants via a follow-up telephone call. If people were deemed eligible and were still interested in participating, I then met with them to discuss the study in more detail and obtain informed consent.

A total of 16 individuals provided study contact information; of these, four did not return follow-up calls and two agreed to participate, but then decided to withdraw because of personal issues/crises that would have made it difficult for them to complete all of the required activities. In total, 10 women were enrolled in the study (see Appendix C for consent form). Demographic information for the 10 individuals who completed the study, based on the DCP demographics subscale (Michigan Diabetes Research and Training Center, http://www.med.umich.edu) (Appendix D) is presented in Table 4.1. The collected demographic data was considered in data analysis to determine if additional situational factors affected how participants managed their diabetes.

Table 4.1. *Participant Demographic Data*

ID#	Age	Years With Diabetes	Race	Marital Status	Housing	Family Size	Edu. Level	Emp.	Income	Federal Limit Reference Range 200%
ID 01	59	20	W	S/D	HOME/ APT	1	HS	U/L	< $5k	$22,340
ID 02	58	14	W	M	HOME/ APT	3	HS	U/L	$30k–$39k	$38,180
ID 03	63	18	B	S/D	HOME/ APT	5	SC	D	$15k–$19k	$54,020
ID 04	48	18	B	M	HOME/ APT	5	SC	U/L	$30k–39k	$54,202
ID 05	58	5	B	NM	HOME/ APT	2	SC	FT	$20k–$29k	$30,260
ID 06	64	30	B	M	HOME/ APT	2	SC	FT	$20k–$29k	$30,260
ID 07	47	6	B	M	HOME/ APT	2	SC	FT	$20k–$29k	$30,260
ID 08	58	3	W	S/D	HOME/ APT	7	HS	FT	$20k–$29k	$69,860
ID 09	45	6	B	M	HOME/ APT	2	SC	FT	$20k–$29k	$30,260
ID 10	60	14	B	S/D	HOME/ APT	2	HS	FT	$15k–$19k	$30,260

*Key: **S/D** = Single or Divorced   **M =** Married   **NM =** Not married **W =** White
B = Black   **U/L =** Unemployed/looking,   **D =** Disability assistance
FT = Working ≥35 hrs. /wk. **HS** = High school education   **SC** = Some college

Sampling framework. Purposive sampling was used to recruit low-income (i.e., at or below the 200% federal poverty guideline) African American women who were (a) between the ages of 40 and 64 years at the time of study initiation, and (b) had been diagnosed with T2DM. During participant recruitment, several White women expressed interest in study participation. After enrolling the first five African American study participants, I decided to open recruitment and include White women to ensure that the recruitment goal could be met (recruiting sufficient numbers of African American women was becoming more difficult). As it happened, changing my recruitment strategy provided a unique opportunity to explore if and how race/ethnicity affected the DSM integration in this sample.

Data Collection

This section describes the four data collection processes used in the study; they are presented separately for maximum clarity. Data collection activities began with the administration of the DCP and the first SSI, but subsequent data collection activities were staggered to facilitate the enrollment and graduation of participants.

Data Collection Sequence

Utilizing a multi-methods approach to data collection entailed planning a data collection sequence that would allow each method to build upon and compliment the others. The proposed data collection sequence was: (1) administration of the Diabetes Care Profile (DCP) and semi-structured interview (SSI), (2) use of participant-generated photos together with a semi-structured photo-elicitation interview, and (3) time-geographic diaries (TGD) and semi-structured TGD interview.

The logic for the data collection sequence was as follows. First, it would be essential to understand the individual's experience and history with DSM in order to appropriately situate additional data; therefore, the DCP and initial SSI began the data collection sequence. Second, I decided that whether photo-elicitation preceded or followed TGD was not especially crucial but did anticipate that participants would face more challenges in completing the TGDs than the photo-elicitation phase. Therefore, I decided to have participants complete the TGD last to maximize the amount of data that could be more easily collected, i.e., the DCP/SSI and photos. Figure 4.1 depicts the sequence of data collection methods.

Figure 4.1. Data Collection Sequence
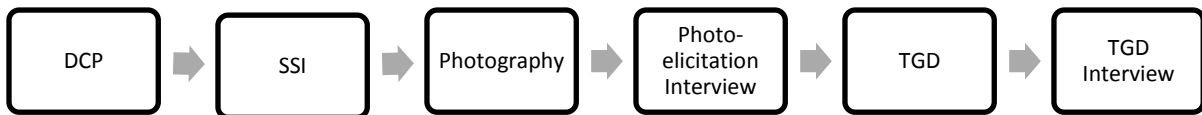
Data Collection Procedures

As the primary investigator (PI), I completed all data collection activities. After participants were assigned an identification number, all identifying information was removed from their files to maintain their anonymity. Potential participants provided their names and telephone numbers to the PI at diabetes group class meetings, but all study-related contact with them was conducted outside of the diabetes classes to protect their privacy. I assigned pseudonyms to participants for any quotations included in this dissertation.

Participant protection. To protect the participants' privacy and in accordance with IRB protocol, all sources of data were de-identified. Only the PI had access to the master file of participants' names and telephone numbers, which were stored separately from other data. All data were stored on a secure, university-maintained server and accessed and analyzed using an encrypted computer located in the PI's office. In addition, the PI and participants sometimes communicated via text message to coordinate meeting times, but these messages were deleted from the investigator's phone immediately after sending, along with any reply texts from participants. Data sharing was limited to the PI's communications with her doctoral advisory committee.

Semi-structured interviews (SSIs). The SSIs were primarily conducted at the clinic, where a private space was reserved for this purpose. This private space was a small room containing a desk and two chairs, a sink, a box of tissues, and various notepads and training manuals for clinic staff and volunteers. As the interviews, informal conversations, and photographs progressed, it became clear that the clinic represented a safe place for participants, a place where they were cared for and valued. Apparently the participants' positive associations with the clinic facilitated their highly noteworthy openness during all study phases.

Other options were pursued for participants who could not meet during normal clinic operating hours; for example, a private study room at a public library branch was sometimes reserved. This arrangement became problematic once, when adverse weather caused a power outage. In this instance the participant suggested we continue the interview in my car, because there was also no power at her home.

The SSI guide for the initial interview (Appendix E) was constructed to elicit data on the following aspects of the DSM integration process: (a) experience of DSM through time, specifically from diagnosis onward; (b) past and current process of integrating DSM tasks into daily life; (c) facilitators and inhibitors of DSM from the participant's perspective; and (d) aspects of decisional processes, such as negotiating competing activities/circumstances, handling contingencies, and creating/modifying routines. Subsequent SSIs were modified from their original content to match the nature of both the participant-generated photographs and the TGDs. In all, study participants completed three SSIs (paired with DCP, photos, and TGDs), for a total of 30 interviews.

Nine of the 10 participants agreed to be audio-recorded during all interview sessions. One participant requested not to be audio-recorded during the second interview, without providing a reason, but agreed to be recorded for the third interview. The initial SSI was typically the longest, ranging in time from 80 to 125 minutes. The second and third SSIs, which occurred in conjunction with discussions of the photographs and TGD, respectively, ranged from 50 to 85 minutes. I remained at the clinic after the interview sessions to write and/or dictate my field notes and impressions. These field notes, included but were not necessarily limited to initial impressions, hypotheses, self-critiques, and thoughts on aspects of the interviewing process that could be changed or improved before the next interview.

Audio recordings (including field notes) from the interview sessions were transcribed for analysis. I felt that it was particularly important to transcribe recordings and listen to dialogue from the initial SSI to determine additional lines of inquiry for subsequent SSIs. I often listened to the audio files of the interviews on a headset while

exercising or doing other daily tasks. Repeatedly listening to the interviews allowed me to generate additional thoughts which I wrote down and added to the field notes. This early evaluation of the interview process also allowed me to reflect upon and modify my interview technique. Twenty-one of the 30 interviews conducted were transcribed; the remaining nine were not transcribed because participants did not provide permission to record them or because I determined that my field notes were sufficiently representative of their content after listening to the audio and comparing it to my written notes.

Photo-elicitation. Before terminating the first interview, participants were instructed on the photo-elicitation process and handed a Kodak disposable digital camera with 27 exposures and a pre-addressed, postage-paid mailer with which to return it. Participants were given two weeks to take photographs of "things that you associate with integrating diabetes self-management in daily life." The instructions were deliberately kept general in order to avoid limiting participants' perspectives on integrating DSM into their daily lives. Nor was DSM defined ahead of time for participants. For these reasons, I am more confident that the photographs participants took in the study revealed both aspects of their lives that influenced their DSM integration, and how they defined the DSM process. To maintain anonymity, participants were instructed to not take pictures of their own or others' faces.

Five of the 10 participants returned the disposable cameras on time. Those who needed more time to take photographs cited unexpected illness, out-of-town training for a new job, and family or personal crises. Individuals kept the cameras for periods of one to six weeks. Participants who required additional time for taking photographs were

contacted weekly (with their permission) to determine if they had any problems or concerns about the photographic process.

After all of the cameras were returned, I took them to a local pharmacy to develop the film. After picking up the developed photographs, I reviewed them and made notes on my initial impressions before meeting the participants for the second SSI (i.e., the photo-elicitation interview). This second interview was structured similarly to the photo-voice method interviews (Wang & Burris, 1997); in other words, at the beginning of the interview individuals were instructed to select the photographs that they wanted to discuss. I gave each participant time at the beginning of the interview to review their photographs and make their selections. This process, in and of itself, was often enlightening in terms of the prioritization and rationalization that participants applied to their photos.

Interview process. The second interview began when participants had selected their photos of interest. Participants presented each photograph individually and were asked to describe the content of the photo. This was important because at times it was difficult for me to discern the nature of a photo; at other times, the participant's explanation turned out to be different than my initial impression. For example, the import of a photograph of a participant's grandchild may seem obvious; however, when I asked this particular participant about this photo, she described it as a representation of temptation because of a can of soda at the bottom of the frame. Participants also were asked why a photo was taken (e.g., its meaning, value, or representation), where it was taken, and, if applicable, with whom the photo was taken. Throughout the interview, I made notes about the relationships between photos and additional follow-up questions,

58

among other things, and also noted any themes that were similar to themes that had been discussed in other interviews. When each participant had gone through all of her photos, I presented additional photos of my own selection for discussion.

Participants were also asked to reflect and elaborate upon anything that they had wanted to take a picture of but did not. This aspect of the photo elicitation interview was particularly useful at compensating for the primary limitation of photographic methods; that is, the participant must have access to the subject of interest in order to photograph it. As it turned out, lack of access often precluded participants from capturing phenomena that for them would have represented "potentials," "if-thens," or "going-tos," all of which could have been important components of their DSM integration processes.

Time-geographic diary. At the end of the second (photo-elicitation) interview, participants were given a TGD packet which included a diary, instructions for completing the diary, and a pre-addressed, pre-paid return mailer. I reviewed the TGD packet instructions with the participants and gave them the opportunity to ask any clarifying questions. The TGD was preformatted in intervals of 15 minutes; this length was selected because time studies have demonstrated that there is no appreciable difference between the quality of data collected in this time increment versus smaller increments (Harvey, 1993; Pentland & Harvey, 1999). Additionally, increments of 15 minutes allowed the participants to record their daily activities in sufficient detail without being overwhelmed (Harvey, 1993). The TGD was formatted to collect data on (a) primary activity performed, (b) secondary activity performed, (c) location these activities took place, (d) the person or people who were present, (e) activities that were forfeited because of having to perform either primary or secondary activities, and (f) miscellaneous thoughts

or comments. Tables 4.2 and 4.3 depict the TGD format used in the study along with the definition of each data category.

Table 4.2. *Sample Time Geographic Diary (TGD)*

Time	Activity	Secondary Activity	Location	Persons Present	Forfeited Activities	Miscellaneous
7:00–7:15 a.m.	Breakfast	Child care	Home	Child	Morning exercise	Felt rushed
7:15–7:30 a.m.	Dressing	Child care	Home	Child	Morning exercise	Spouse not home yet to help

* Definition of category content below

The TGD packet included instructions about each category along with a sample segment of a TGD (similar to the one in Table 4.2.) for reference purposes. Each category was described in enough detail that participants would understand the type of data to be recorded in each cell.

Table 4.3. *TGD Categories and Definitions*

Category	Definition
Activity	The activity that dominates the majority of that time interval in sequential order starting with the first activity done upon waking.
Secondary Activity	Additional activities that may be occurring at the same time, but to a lesser degree compared to the primary activity.
Location	The location of the activity completed for the given time interval (e.g. home, work, school, grocery store, etc.).
Person Present	Respondents will fill in persons present, or with whom they are performing a given activity in a given time interval.
Forfeited Activities	Any activities that had to be forfeited due to situational circumstances, if applicable.
Miscellaneous	An open column in which respondents can narrate any other pertinent information that occurred during the time interval.

Participants were instructed to complete the TGD for one "typical" weekday and one weekend day. A weekday and weekend day were selected because time use and daily routines tend to vary from weekdays to weekends, and incorporating a weekend day helps to capture that variation (Pentland & Harvey, 1999). The participants were given a 14-day period to complete the two days of data collection. According to time-use scholars, there is no significant difference in data collected via assigned versus elected days (Pentland & Harvey, 1999); therefore, participants were allowed to select the particular weekday and weekend days they would record during this 14-day window. The same individuals who had required additional time to complete the photo-elicitation portion of the study also typically required more time to complete the TGDs, due to illness or personal/family crises. Following similar procedures, participants who required additional time with the TGDs were contacted by phone once a week (with their permission) to remind them of the TGD completion tasks, answer any questions, and help ensure completion of the TGD. One participant experienced great difficulty in completing her TGD. Per her request we arranged an extended TGD interview in which she completed her TGD while discussing each aspect of it. See Appendix F for a sample of the TGD used in the study.

Interview process. After the TGD was returned, I reviewed the diaries for completeness so that I could follow up on any missing/incomplete data with participants. The third interview was then scheduled to discuss the TGD. In preparation for the TGD interview, I transferred the participants' handwritten TGDs into an Excel spreadsheet.

The interviews were used to review the TGD and to elaborate upon as well as clarify aspects of the diaries. Participants were asked if the recorded day was a typical

day for them, and the total time use was also discussed. Participants were asked specific questions regarding the structure of their day, how long they had adhered to the daily routine depicted in the TGD, and what aspects of their daily schedule they perceived as beneficial or problematic to DSM. The TGD interviews were the least structured of the three SSIs. Although participants were asked the same initial questions, follow-up questions varied because of the array of daily activities in which participants engaged. Because the TGD interview was the last one, time was allotted at the end of this interview to discuss any additional aspects of DSM integration that needed to be clarified before participants exited the study.

Special and Ethical Considerations

Because this study focused on individuals diagnosed with T2DM, participants were offered a beverage and a snack to enjoy during the interviews, especially as several interviews occurred during mealtimes. Accommodations were made for snack breaks to ensure that participants could address their DSM activities while participating in the SSIs. A participant who initially refused a snack later experienced symptoms of low blood sugar and was then provided with a granola bar and juice. This participant's symptoms resolved within a few minutes and she was able to continue the interview.

I anticipated that discussing the topic of DSM could be emotional for some participants. I was surprised, however, at how often participants experienced strong emotional reactions to the life events that co-occurred with their diagnosis of diabetes. As participants discussed their histories of DSM, they wove together the positive moments in their lives (e.g., the births of grandchildren) but also many painful and sad influences on

their DSM (e.g., divorce, loss of a parent, and loss of a job). During these times, I offered the participants tissues and leant a sympathetic ear.

I believe participants were allowed to address their feelings in a safe, non-judgmental atmosphere during the interviews. Many commented that they were surprised by their emotional responses, but felt the process was "like therapy." It became apparent from participants' responses that they saw the interviews as not only a time to discuss the more "serious diabetes stuff" but to also connect, "check in," and talk about their general daily life concerns and struggles. In many ways, these unstructured conversations helped me reach a much deeper awareness of and appreciation for the complexities of these women's daily lives, in particular how much effort they must expend to manage DSM in these complex and dynamic contexts. When these informal conversations occurred outside of the interview for example, during phone contacts, or while walking out to the clinic parking lot, I made field notes as soon as possible and combined them with the interview transcripts.

Terminating data collection. Total data collection lasted from July 2012 through December 2012 resulting in 182 photographs, 30 interviews, ten TGDs, ten DCPs, ten sets of field notes and 71 memos. In addition, my involvement in the group diabetes classes provided additional insights into the integration process. Because my interactions with the women during these group sessions were not included in the IRB I did not include the insights gained from these conversations in the data analysis. Nonetheless, the group discussions served to further stimulate my thinking during the data analysis process; as they sometimes challenged while at other times supported themes emerging from the data.

During the progression of the study I came to know these women as more than mere "study participants." I had the opportunity to meet several of their family members, who often drove them to the clinic and waited for them during the interview sessions. When necessary, I provided transportation for them to and from the clinic to facilitate their participation in the study. This allowed me to see their homes and neighborhoods, albeit briefly. On one occasion I provided transportation for one participant to a Walmart so she would not have to spend two hours completing her errand by bus. During this time, our conversation did not focus on diabetes but instead on her kids, grandkids, birthday parties, and church services, along with many other topics. In many ways it was these moments, spent simply talking about the stuff of life, which helped me understand how life management is DSM.

The final interview with each participant was bittersweet. By this time these women were no longer just study participants, yet moves toward true friendships had not yet occurred. In the final interview moments we would talk about how much the study meant to both of us, how much we both had learned, and how we would miss meeting with each other. Sometimes we would exchange a handshake, but more often it was a heartfelt hug. Fortunately, my involvement in the group diabetes classes at the clinic ensured that I would get to see the participants again in the weeks and months to come. The group diabetes classes provided a way for participants and me to continue to connect, if we wished to do so.

Data Analysis

The data analysis process is explicated below, including (a) the grounded theory approach (b) the analytical steps applied to each method, and (c) the integration of findings from multiple methods to produce the DSM integration model (see Chapter 7 for the actual model). It is important to note that the grounded theory process was used to approach the entire data analysis process, including the DCP, interview transcripts, photos, and TGDs. Therefore, data analysis was both iterative and comparative and involved referring to new data, previously coded data, and different types of data. This back-and-forth process continued throughout the study.

Grounded Theory

Grounded theory is an approach to data that leads to the development of theory without a particular commitment to a line of inquiry or theoretical interest (Strauss, 1987, p. 5). Grounded theory is based in a constructivist epistemology and thus emphasizes the co-creation of knowledge. This approach to data analysis involves distinct features such as theoretical sampling, constant comparisons, and the use of a coding paradigm to ensure systematic development of a conceptually dense theory drawn directly from data. These features of grounded theory make it particularly useful for capturing the complexity of social processes (Charmaz, 2006; Strauss, 1987). Grounded theory also has proven useful in the study of human action and occupation, which makes it congruent with the purpose of the study. The integration of DSM into daily life is conceptualized in this dissertation as a complex process that transcends the individual and extends into the larger social sphere; capturing this process requires data analysis that is both systematic and intensive. Furthermore, because grounded theory is founded in pragmatism, it is

65

particularly applicable to multi-method studies and the theoretical perspective of

transactionalism used to frame this study[6].

Analysis Procedures

Grounded theory analysis is characterized as an iterative process that includes

making constant comparisons within and between cases. This approach to the data

requires engaging in data analysis throughout all phases of data collection. The analysis

of each data collection method presented in this section is presented independently.

However, throughout the study, the data from each source were compared within each

case and among all cases.

Analysis of SSIs

The Atlas ti. software package (Scientific Software Company, 2012) was used to

analyze interview transcripts and field notes (see Charmaz, 2006). The stages of data

coding were line-by-line coding, focus coding, axial coding, and theoretical coding. I

performed the line-by-line coding on the first three SSI transcripts and analyzed the codes

to determine if additional questions should be added to subsequent interviews. Across

participants, this process was repeated after every third interview. This step of reviewing

transcripts and coding them before continuing allowed me to incorporate theoretical

sampling in the form of modifying or adding questions to foreground areas that I felt

should be pursued in the remaining interviews. For example, reviewing the first three

---

[6] Charmez (2006) suggests that it is impossible to enter into the research process without being influenced by past theories, literature reviews, or particular world views, and it is therefore acceptable to identify those influences, and concepts to which one is sensitized, ahead of time (p. 168-170). The theoretical perspective introduced in chapter 2 (transactionalism) influences my worldview and how I think about DSM integration. It also provided sensitizing concepts that influenced initial analytical directions.

interviews revealed that destabilizing events were important themes in the women's DSM

trajectories. Therefore, in subsequent interviews I began to ask them about destabilizing

life events. In addition to reviewing transcripts, starting line-by-line coding (see tables

4.4., 4.5., and 4.6.) early in the process allowed me to engage in constant comparisons

within and across participants' transcripts (Charmaz, 2006; Strauss, 1987). The initial

line-by-line coding produced more than 250 codes.

Table 4.4. *Example: Line by Line Coding*

Code		Corresponding Text
Creating an environment for my health condition		"I need to pick all this crap up, I know I can't move in here, I got to manage this mess better for me"
Starting out in denial		"You just act like nothing is going on for a while"
Changing approaches		"At first I jumped all in, but then later I slacked off"

The data were focus-coded after all transcripts had been coded line by line

(Charmaz, 2006). Focused coding involves taking initial analytical directions developed

from the line-by-line coding and applying them more selectively to larger chunks of text

(Strauss, 1987). This stage was necessary so that I could sift through the data and

determine the adequacy of the existing codes. This focused coding stage reduced the

initial list of codes by almost half.

Table 4.5. *Example: Focused Coding*

Code	Text Example
Substituting to make it healthier	"I use the fat- and sugar-free syrup. I use Smart Balance butter. I said I was going to use the olive oil one but I haven't tried that yet. I just got the one they used in the hospital, the yellow one with yellow top.

After focused coding was completed, the first SSIs were analyzed a second time to develop axial codes. Axial codes reconnect fragmented data by conceptualizing how categories are linked (Strauss, 1987). Focus codes may include phrases that refer to or directly state concepts such as: substituting to make foods healthier, eliminating the "bad stuff," and changing methods to save time and effort. These three codes could be combined into the axial code of "using occupation-level strategies" because they are all strategies that participants use during the occupation of cooking to meet the end goal of creating healthier meals. Finally, theoretical codes were developed. The benefit of developing theoretical codes is that they allow the conceptualization of linkages between codes as preliminary hypotheses that can be integrated into a theory (Charmaz, 2006). Theoretical coding allowed me to hypothesize relationships between axial codes.

Table 4.6. *Example: Theoretical Coding*

Theoretical Code	Contributing Codes
* The benefits of practice in DSM	Becoming aware of needing to change Developing strategies Striving for Consistency Becoming Self-aware

Analysis of Photographs

Photo analysis occurred in several steps across multiple levels. The first step was taken in preparation for the photo-elicitation interview. As previously mentioned, I reviewed each participant's photos and wrote field notes regarding my initial interpretations. I also indexed and prioritized the photos; for example, taking aesthetic liberties, I rated the photos that I thought were the most provocative or that I was most

68

interested in having the participants discuss. My rationale for this level was to create a record of my preconceived notions that could be compared to participants' interpretations of the photographs.

The second level of analysis, which occurred after the photo elicitation interviews were completed, coincided with transcription of the interviews. Specifically, I read the transcriptions while viewing the photographs and made notes on the back of the photos to indicate what they represented to the participants. If a particular photograph was not discussed or alluded to during an interview, I did not write any information on the back other than an ID number.

After my secondary analysis of the photographs, all of the photos were combined and sorted by content area for content analysis. First, each set of photos was laid out as a complete group. Then each group of photographs was divided into content categories (e.g., animals, children, adults, etc.). Next, the photographs were analyzed according to the participants' interpretations (which I had already written on the backs of the photos) and regrouped into subcategories based on their interpretations. I repeated this double analysis of content focus and narrative focus for each subgroup of photos. This sorting revealed 11 major content categories. Table 4.7 presents a sample of the major categories and subcategories that I found during my content/narrative analysis of the photographs.

Table 4.7. *Categories of Photographic Content*

Category	Content subcategories	Narrative subcategories
Media (15)	Computer screen shots (4), books & magazines (4), newspapers & coupons (2), signs & banners, (3), paper (1), electronics (1)	Tools, resources, strategies, relaxation, connection, work
Places (22)	Places of worship (5), hotels (2), public parks (2), medical clinics (3), places of employment (1), restaurants (9), sky (2)	Support, relaxation, help, supplies, temptations, strategies
People and Pets (21)	Pets (4), photographs of people in public (3), family members (13), other (1)	Trouble, support, triggers
Exercise (13)	Places for exercise (2), people exercising (6), equipment and supplies for exercise (5)	Inspiration, supplies, strategies

Time-Geographic Diary Analyses

The TGDs were analyzed at several levels to yield different perspectives on how time-use and the sequence of daily activities affect DSM integration. First, I analyzed the TGDs for each case to determine (1) types of primary and secondary activities each participant engaged in during a typical day; (2) total time use of activities; (3) types and frequencies of co-occurring activities; and (4) routine structures. Second, I combined the cases and analyzed them as a group according to the same four parameters. Table 4.8., which presents a segment of a TGD from a participant's diary, places this analysis in context.

Table 4.8. *Segment of Participant TGD*

Time a.m.	Activity	Second Activity	Location	Person Present	Missed Activity	Misc. Remarks
5:30–5:45	Assemble church clothes	Iron church clothes	Own bedroom	Alone	None	None
5:45–6:00	Take blood	Take blood pressure	Own bedroom	Alone	None	None
6:00–6:15	Set granddaughter's clothes out	Wake up granddaughter	Granddaughter's room	Granddaughter & father	None	I'm tired
6:15–6:30	Send granddaughter to bathroom	Comb own hair	Bathroom	Granddaughter & father	None	None
6:30–6:45	Shower self	Partially dress	Own bedroom	Alone	None	None
6:45–7:00	Fix breakfast	Call father to eat	Kitchen	Family	None	None

After the quantity and types of activities had been determined for a given participant across a 24-hour period, this list of activities was consolidated into categories. For example, the category of home maintenance included multiple related activities such as cleaning, yard work, laundry, ironing, and so forth, which were grouped together for the total time spent in these types of tasks in a given day. Participants' individual time uses were then translated into a bar graph which was shared with them during the TGD interviews.

The TGD interviews were crucial to completing the TGD analysis because which category a particular activity belonged to was often unclear. For example, determining whether certain activities should be categorized as paid work or as child care for participants who provided in-home child care was difficult for me. In addition to analyzing total time use per category, I analyzed each block of time with regard to the ratio of secondary activities occurring within a primary-activity time block. For example, if the primary activity was meal preparation, I would link this category to how many secondary activities co-occurred with it and why they co-occurred. During the next TGD interview, I would ask this participant to explain why she performed these activities together or in a particular sequence. After I had separately analyzed each participant's TGD, I combined the cases to explore the most common co-occurring primary and secondary activities for the group (Table 4.9.).

Table 4.9. *Co-Occurring Activities for the Group*

Secondary activity	Media use	Child care	Adult care	Household maintenance	Meal prep	Work
Primary Activity						
Cooking	4	6	2			
Sleep	3	1				
Self-care		1				
Eating meals	8	1		9		1
Taking meds	1			2	1	
Work	4			2		

Finally, I analyzed the TGD for differences in the structure and use of time. Two prominent types of time use emerged: open time and closed time. A block of time was considered open if general activities were anticipated (e.g., grocery shopping on a Saturday morning). However, open time blocks easily accommodated unforeseen, new, or spontaneous engagements such as last-minute get-togethers with friends or family. A block of time was considered closed if daily order and stability required that certain activities be completed within it (e.g., waking up at a specified time immediately followed by bathing and dressing for work). Closed time blocks did not accommodate unforeseen or spontaneous events well.

Integration of Results

The aim of the study was to generate a theoretical model describing the process by which individuals with T2DM integrate DSM into daily life. As previously noted, using and then integrating multiple methods was essential to understanding this process. In this section I describe how the results of the multiple methods explained above were integrated to produce the conceptual model that I discuss in detail in Chapter 6.

Using an iterative grounded theory approach to data analysis ensured integration of the multiple data sources throughout the analysis phase via constant comparisons.

Using multiple-case methods and a multiple-method approach required me to analyze data within each case and to make comparisons across cases. The constant comparison process was key to the construction of the model because each data type contributed essential components.

The initial SSIs provided the foundation for the integrative process by supplying histories and narratives of the participants' experiences with engaging in DSM over and through time. Data from the initial SSIs produced many codes that held up through subsequent rounds of analysis and therefore became part of the conceptual model. In particular, the first SSI produced codes related to participants' past experiences with diabetes, their maturation (i.e., growing-up) processes, their general habits related to physical activity and "foodways", and their general health awareness. Additionally, during the first SSIs, participants spoke about their current DSM and contexts, which allowed me to link past to present for each case and then compare across cases. Each subsequent phase of data collection resulted in additional codes and refinement of existing codes, both of which contributed to the formation of categories.

Table 4.10. illustrates the different types of data that were collected and core findings unique to each data collection method. Intentional overlap among different methods allowed each phase of data collection to contribute important pieces to understanding the integration process.

Table 4.10. *Method-Specific Data Contributions*

Data Type	Key Contributions*
DCP	Demographics, income, family structure, diabetes related services, understanding of DSM, and frequency of diabetes related complications.
Initial SSI	The time it takes to "get" DSM, how past experiences with diabetes frame the initial approach to DSM, how participants grew up, past experiences and habits related to physical activity, foodways, general health awareness, current DSM, past and current personal situations such as employment and finances
Photo-elicitation	Facilitators and barriers to DSM, situations, places, persons associated with particular aspects of DSM, symbolic representations of ideas yet to be acted on, successes, failures, strategies enacted, potential ideas to improve DSM
TGD	Routines, time use, activity sequences, distribution of DSM activities, types of and frequency of DSM activities

* This table contains only contributions from the specified data sources.

As data collection progressed, my constant comparisons among cases and data sources led to the expansion of key ideas. Earlier memos aided this process because they contained hypothesized linkages drawn from previous data that could be further supported or rejected during new layers of analysis. For example, participants may have spent large portions of their initial SSIs discussing how well they were doing with regularly eating a healthy diet. This information could then be compared with other data sources, such as the DCP, photographs, photo-elicitation interviews, and TGDs, and expanded when appropriate. Such comparisons of the data both within and across multiple data sources revealed contradictions that led to further inquiry and analysis. The need to clarify aspects of participants' daily experiences produced a more nuanced and multifaceted account of the complexity of integrating DSM in daily life, which is illustrated in Figure 4.2.

Figure 4.2 Diagram of the Iterative Process

Data Analysis Example: Integration of Data

| Interview: Participant reports consistently healthy diet and BGL monitoring | → | DCP: Multiple incidents of hyperglycemia |

| Photographs: mixed messages eating habits | → | Additional lines of questioning in photo-elicitation interviews |

| TGD: Multiple entries of eating fast food and skipping BGL monitoring | ← | Participant explains contradictions; expand existing codes |

Inferences:
- Healthy meals as attainable sometimes, but not habitual
- Situations and habits still not supportive of consistent efforts
- Inquiry and ongoing practice

The iterative process of constantly comparing data sources within and among cases provided depth to each conceptual pillar within the developing theory. Applying a grounded theory process enabled the lifting of initial themes, ideas, codes, and inferences from the data. These raw materials were sifted through additional rounds of coding. Some ideas were less supported by subsequent data, while others were enriched.

In this chapter I described how I integrated and analyzed multiple data sources using a grounded theory approach, with the ultimate goal of obtaining a conceptual model. In Chapter 5, I present a description of the different DSM trajectories drawn from

the data. The conceptual model that describes the process by which low-income women

with T2DM integrate DSM into daily life is presented in Chapters 6 and 7.

Chapter Five: Case Presentations

> Really diabetes is a life skill. It's really no different in that way. I mean you have to learn a lot, then things change, you have to adapt and change too. I mean I'm at the point where I can pretty much relax, but at the same time there are still moments when it still keeps me on my toes.   —Lori (diagnosed in 1983)

The complex experiences of low-income women with diabetes who are working toward integrating DSM into their daily lives have received little attention. The following three chapters constitute the study's findings. In this chapter, I present the narratives of the low-income women who participated in this study. The narratives demonstrate how participants' level of integration was a manifestation of their past life experiences, habits, and circumstances. Narratives also show how integration changed through time. This view of the participants' integration experiences is preparatory for the subsequent chapters. In chapter 6, I provide an overview of the conditions that influence the process of DSM integration. In chapter 7, I turn my focus to the Transactional Theory of DSM Integration that depicts the process of DSM integration.

The DSM Integration Trajectory

The participant's narratives served as stories of successful and unsuccessful DSM integration; moreover, they revealed the emergent nature of DSM integration as a manifestation of habits, experiences, and situational qualities. Therefore, the first part of this chapter contains an overview of the general DSM trajectory, as experienced by the participants in the study. Although each of these women is unique, their narratives reveal

some shared experiences that were common across cases. The convergence and divergence of their narratives is a function of individual as well as shared experiences of being situated within a specific historical period, culture, and social space. This brief overview of the initial DSM trajectory is followed by a presentation and discussion of how the participant's different habits and situations influenced their approach to DSM and their subsequent level of integration. In presenting the women's stories I provide examples of how different life experiences, habits, and situations transact through time and manifest in varying approaches to DSM integration, each resulting in varying levels of success. Tables 5.1 and 5.2 contain a summary of characteristics of the low-income women with T2DM who participated in the study. The situational qualities, habit elements, and shared DSM experiences were derived from my analysis of the women's narratives and reflect those experiences that emerged across the group as the most relevant to DSM.

Table 5.1. *Participant Summary: Situational Factors*

Participant*	Glenda	Lydia	Felinda	Alyssa	Aleisha	Lori	Yolanda	Deidra	Diane	Cindy
Situational Factors										
Age	59	58	63	48	58	64	47	58	45	60
Married	N	Y	N	Y	N	Y	Y	N	Y	N
Divorced	Y	Y	N	N	N	N	Y	Y	N	Y
Stable partner relationship	N	Y	N	Y	N	Y	N	N	Y	N
Children/ Grandchild in home	N	N	Y	Y	Y	Y	N	Y	N	N
Caring for elders	N	Y	Y	Y	N	N	N	N	N	N
Caring for others' children/ unpaid	Y	N	Y	N	N	N	N	Y	N	N
Employed	N	N	N	N	Y	Y	Y	Y	Y	Y
Home location	Rural	Rural	Urban	Rural	Urban	Urban	Urban	Urban	Urban	Urban
Currently in school	N	N	N	N	N	N	Y	N	N	N
High school /GED	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Some college	N	N	N	N	N	Y	Y	N	Y	Y
Associates degree	N	N	N	N	Y	N	N	N	Y	N

*The names presented here, and used throughout this dissertation, all are pseudonyms.

Key: **N**=No   **Y**=Yes

Table 5.2. *Habit Elements and Shared Experiences*

Habit elements, shared DSM experiences	Glenda	Lydia	Felinda	Alyssa	Aleisha	Lori	Yolanda	Deidra	Diane	Cindy
Organized	Y	N	Y	Y	N	Y	N	N	Y	Y
Coping style	A	P	A	A	P	A	A	P	A	A
Sets personal boundaries	N	N	N	Y	N	Y	N	N	Y	Y
Temporal preference	AM	PM	AM	PM	PM	AM	PM	PM	AM	PM
History of being physically active	Y	N	N	N	N	Y	Y	N	Y	Y
History of healthy eating	N	N	N	N	N	Y	N	N	Y	N
Approach to tasks	HO	AV	HO	HO	AV	HO	HO	AV	HO	HO
Role of faith in DSM	AS	AS	C	AS	AS	AS	C	AS	AS	AS
Manages finances to meet needs	Y	N	Y	Y	N	Y	N	N	Y	Y
Information-seeking	Y	N	Y	Y	Y	Y	N	N	Y	Y
Years managing diabetes	20	14	18	18	5	30	6	3	6	14
Family history of diabetes	Y	Y	Y	Y	Y	Y	N	N	Y	Y
Experienced critical episode[7]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y

*Key: AM =Morning PM =Night A=Active P=Passive AS=Assistive
C=Central HO=Head-on AV=Avoid

---

[7] A critical episode refers to an acute medical event or worsening of diabetic symptoms (e.g., severe hypoglycemia).

Participants' experiences of DSM began when the women learned that they had diabetes. This knowledge transformed them into individuals with diabetes and, ultimately, propelled their transitions into the realm of DSM. On average, the subjects in the study had been dealing with DSM as part of their reality for 14 years (range 3-30 years). Lori, the most experienced participant, had been managing her diabetes for 30 years at the inception of this study, whereas Deidra had only been engaging in DSM for three years. The years of a participant's experience with DSM tended to be associated with better DSM, but not always. Lydia, for example, had been managing her diabetes since 1999 and continued to have very little success with integrating DSM into her daily life.

DSM is a multifaceted problem; likewise, achieving successful DSM is the product of multiple influences including past experiences, personal histories, personal tendencies, and situational qualities. All of these factors impacted these women's ability to have productive experiences that led to growth and development of their self-management abilities. Further complicating the issue was the fact that their ability to engage in DSM was intimately tied to their ability to engage in daily life in general.

Although this association may seem intuitive, DSM is often approached as a phenomenon that is separate from the prevailing forces of everyday life. However, the same influences that affected participants' everyday life management (e.g., habits, situational qualities, etc.) also influenced how they managed their diabetes. In other words, if a woman's daily life was characterized by disorganization, instability, and inconsistency, these characteristics extended to her engagement in DSM as well.

Each of the women in the study had unique situational aspects. Even so, there were similarities among the cases that shed light on how experiences, habits, and situations can influence DSM.

The trajectory in context. Six of the women who participated in the study were diagnosed with diabetes between 1983 and 1999; four were diagnosed after 2000. The women differed in their initial reaction to the news; for example, Glenda was devastated but Cindy stated that "it was no surprise." The women's life situations at the time of their diagnoses impacted their initial DSM efforts. Five were undergoing major life transitions when they found out they had diabetes. These situations included divorce, job loss, street-drug withdrawal, and moving back home to care for family. Having no health insurance hindered some of the women's ability to receive initial support and guidance.

Glenda's narrative illustrates her difficulty with obtaining initial guidance and support post diagnosis. She obtained her diabetes diagnosis around the time she was also experiencing the dissolution of her marriage and the loss of health insurance.

> It was in 1993 when I went for my yearly check-up, I had no clue, I had no symptoms that were diabetes… I went to my gynecologist for my yearly physical and during my annual blood work they found it.

Glenda's gynecologist attempted to care for her but was unable to provide the necessary specialized services, so she referred Glenda to an endocrinologist (shortly before Glenda lost her health insurance). This combination of circumstances brought Glenda to a crisis point that led her to seek care at the nonprofit clinic where she was still a patient at the time of this study.

> I mean my blood sugar would not register anymore, and I called and I thought something was wrong with the meter and I called the number off the back of the meter, and the lady asked me well have you tested more than once and she went

through the steps and she said well if it's not registering then it's over 700. She said well you need to go to the emergency room! Well of course I didn't do that, I couldn't afford it, so I prayed, and then I found a card for the clinic, and the first time I walked in the door I just cried because I needed help so bad and they were the only ones who would give it to me.

Unfortunately, nearly five years elapsed between Glenda's initial diabetes diagnosis and her discovery of consistent, high-quality care. Other participants were able to receive support for their diabetes sooner, although the quality varied. Felinda reported being told for years that she had "borderline diabetes" (i.e., that she was pre-diabetic) but was not given specific information on what to do about this condition. She learned of her diabetes and received initial guidance on DSM during participation in a community program that recruited individuals at risk for diabetes or diabetic complications.

Well I never had no nutritionist nor educator I never had anyone to talk to me about diabetes or counting calories nobody ever said well… It's been maybe two years maybe three I was almost 300 pounds. And I was doing with that project program with my doctor at a point and that's really when I found out I was diabetic. I was doing it [the program] so basically they were the first to like, that's when I had just went over [from pre-diabetes to diabetes] when the diabetes and stuff and so they started helping me… I started losing weight for a while but after I stopped with them, basically I was on the diabetes medicine by then. But nobody was talking to you about what you need to eat or do or whatever.

Although Felinda was able to receive reasonably prompt support, the support she received was not comprehensive. Eight of the 10 study participants reported that their health care providers focused on medication management with relatively little education about diet, exercise, or other aspects of DSM. In fact, the women reported that for years they focused on medication management because when they did receive guidance on other aspects of DSM, it tended to be delivered in the form of vague instructions such as "Stay away from starches" or "Lose weight." All of the women reported that these general statements were of little use. As they reflected upon their past experiences, many

84

of the women observed that their compliance might have increased in the early stages if providers had given them more information, suggestions, and, in particular, examples. As Aleisha points out,

> You know it's really difficult when they just say stuff, I mean yeah, lose weight, stay away from starches, I didn't even know corn was a starch until like two years ago, I need more to go on than that!

Alyssa and Cindy did not have these experiences. Cindy received her diabetes diagnosis while she was hospitalized for another condition. Before her discharge, hospital staff provided her with patient handouts and pamphlets that detailed dietary and exercise recommendations, and arranged for her to speak with a trained diabetes educator. Alyssa was employed at Kaiser Permanente when she received her diagnosis. Because HMOs have tended to provide their employees with exemplary preventative care, Alyssa was sent for a full diabetes work-up—the most comprehensive one for all the women in the study.

> Well before they sent me to a diabetic nurse, who did the diabetic teaching, they sent me to a podiatrist to get my foot checked. Let's see what else did I do? They sent me to the dentist because I have dental to make sure that my teeth had been cleaned and then they didn't have any gum disease. At the time when I first started out with diabetes I wasn't on any medication it was just my diet. The diabetes people gave me a meter. They gave me a meter and taught me how to check my sugar.

The women reported that the education provided by nutritionists and pharmacists was generally more useful than guidance from their primary medical providers.

> Cindy: Medicine is pretty simple, you know take a pill or whatever, but the diet, I had issues with that because I had a certain way of eating and I just couldn't change all that like poof! Besides it wasn't just me, I had a family too, so what she did was help me look at what I was eating and what I could eat.

The participant's initial trajectories reflect the transaction of their past and current life experiences and their social cultural circumstances. The women's past life experiences

and association (e.g. experiencing a family members diabetic complications), along with the stresses of their current circumstances (e.g. going through a divorce) shaped how they responded to the initial news of their diabetes diagnosis. Their life circumstances and social cultural context (e.g. having insurance, having access to qualified providers) further influenced the type and quality of services and support that they received early on. Thus, the participant's early approaches to DSM could be seen as a manifestation of the multiple forces that shaped their initial trajectories.

Initial approach. Despite differences in the type and quality of services the women received after being diagnosed, they all characterized this initial period as one of "fits and starts." Some, for example Yolanda and Aleisha, reported trying to tackle DSM head-on for a short time, before falling into what was commonly referred to as the "denial period." Many of the women initially disregarded their DSM because they had no symptoms or simply didn't take their diagnoses seriously.

> Cindy: Honestly right in the beginning I never thought about my uses of sugars or molasses and jellies and cakes and pies, all types of desserts because I cooked dessert every day. I was married. I paid the eating part no mind. I had what I want, and ate what I want; I never felt anything because of it.

> Diane: So he [the doctor] put me on Metformin then and honestly, I would say I did not take it. One of the things I seen and heard in some of the classes that I've been in is that myself like a lot of the others we find ourselves in denial about having diabetes. I took seriously the high blood pressure but that diabetes, nah I couldn't have it.

Other women in the study, Alyssa Aleisha, and Diane for example, quickly reduced their DSM efforts because they felt a false sense of security. These women mistakenly viewed DSM as a short-term endeavor rather than a life-long commitment. Alyssa reported that after receiving her diabetes meter and education she continued to use

the meter until she thought her diabetes was under control; after that, she reported just "going by how my body felt."

> When I was first diagnosed it was fasting [blood sugar checks], two hours after the breakfast, before lunch, and two hours after lunch. I think I did that for until my next appointment, which I think was like six weeks or something just to see, to get an idea.

Similarly, Aleisha also found herself reducing her DSM efforts once she became comfortable with her numbers. Aleisha was told by her provider that she needed to maintain her A1C level at or below seven. Once she achieved this milestone, without fully understanding how quickly her number could increase, she lessened her DSM efforts.

> It's a gradual evolution of understanding the lifestyle because it first hit me, I understood it, and I acted and positively related to it, but once I got comfortable with my number, my number was seven. I was educated that the numbers were OK. I mean, I knew I still was overweight which is still… but I didn't take all that into effect the first go-around.

How long the women struggled with this period of fits and starts varied. To some degree, the lifelong management of diabetes can be characterized in this stop-and-go manner. Participants in the study reported periods of being burnt out with managing their diabetes. Their relationships with numbers came across as especially poignant. Although nearly all of the women voiced their frustration with feeling that they had to constantly watch their numbers, Lori and Glenda elaborated most on the issue.

> Lori: You have all these little numbers and all these little things the chores, puncturing yourself and reading numbers it's depressing. It'd be nice to have a free day I could get out of my mind these numbers blood sugar and blood pressure numbers, and all these numbers, that's really depressing. You also don't tell people your numbers because they will blurt them out anywhere. You know you had a family dinner they will say you shouldn't be eating any sugar because your numbers were such and such so they'll blurt them out to everybody, you know how you pull up to get gas and you see those little numbers cha-ching, cha-ching, well that's diabetes, all those little numbers rolling around.

87

Glenda described herself as being "sick and tired of the numbers." Upon viewing one of her photographs (Figure 5.1.), she explained:

> I took this, because this number tells me what my day is going to be like… basically, it tells me how much energy I'm going to have, whether I eat bacon or oatmeal, or just how much I'll be able to get done… sometimes you feel like your life is run by numbers.

Figure 5.1. Participant Photograph: Relationship with Numbers

It must be noted that, for these women, there was a qualitative difference in the fits and starts that characterized their initial years of DSM and the later ebb and flow of their DSM. During the early months and years of their DSM trajectories, the women learned about diabetes in general and, more specifically, what it meant for them. The women reported that their worst and most inconsistent experiences occurred during these early years, as they engaged in what could be accurately characterized as largely

unguided trial and error. As they developed approaches that fit with their lives, the women rapidly made a wide variety of changes to their DSM regimens. By the time they signed up for the study, they had already tried many ways of engaging in DSM and had established approaches that were compatible with their lifestyles, even if these approaches did not result in optimum DSM. Significant changes in the later years of DSM were typically due to destabilizing life events.

   Critical episode and renewed commitment. The most common phenomenon that the women reported as helping to change their DSM trajectories from a stage of fits and starts to one characterized by renewed commitment was experiencing a critical episode. Such an episode could take many forms. For Glenda, Cindy, Lori, and Aleisha, it came after experiencing severe diabetic symptoms that challenged their sense of security and made them reevaluate the impact this disease would have on their lives, if left untreated. For Felinda, Diane, and Alyssa, the renewed commitment came after experiencing the deaths of their mothers.

> Diane: I gained more weight and I think the turning point was the death of my mom. It wasn't that she died from having complications with diabetes or anything. My mother had a stroke. I guess… I don't know. The emotions of everything, and losing her, and knowing that she had certain ailments and stuff. I know she had high blood pressure, I know she was on a lot of meds for both her high blood pressure and her diabetes. It started me thinking that possibly I need to take care of myself… Then I started on a little small regime of trying to get to the gym a little bit. Heck, I had a gym membership for years and I would use it sporadically. Every once in a while I would go in, and so I finally decided to start using it a little bit more then.

These women reported that the experience of losing their loved one caused them to reevaluate their own lives and health. The occurrences of critical episodes marked periods of renewed commitment in their lives.

Even after experiencing such critical episodes the women still struggled to manage their diabetes; however, they discussed these critical episodes as catalysts that changed their attitudes toward DSM. Whereas the women may not have taken the threat of having diabetes seriously before these critical episodes, their experiences during the episodes ushered in reflective awareness of the very real consequences of ignoring them.

Becoming aware. As the women matured in DSM by gaining experiences over time, they developed strategies to better manage their diabetes and became more knowledgeable and confident in their own abilities. All of the study participants reported that they still engaged in less-than-optimal DSM for periods of time; however, they typically neglected only one area (e.g., exercise or blood glucose testing) and this neglect was of short duration. For example, Aleisha reported that she "had been doing so well with my DSM, but I do slack off a bit every year during my birthday month, I know it's wrong, but hey, that's my one month." Diane reported that she exercised regularly except "when it's really, really hot." These women felt that such temporary periods of suboptimal DSM were normal and expected that such periods would occur. As the women matured in their DSM experiences, they generally managed their conditions better, developed more realistic expectations for themselves given their situations, and were more forgiving of setbacks.

Experiential Histories

Despite the importance these women placed on their critical episode experiences, no singular event changed the course of their DSM trajectories. Instead, the influences of

90

past experiences and habits, the passage of time, and changing circumstances combined and often set the stage for change. In other words, the women's engagement in DSM were manifestations of the culmination of their past and current experiences, developed habits (of thought, action, perception, etc.), and situational qualities. In the following sections, I present different experiential histories derived from the women's narratives that illustrate how habits and situations function to influence DSM integration.

This distinction is important because it has significant implications for how the healthcare community approaches the facilitation of DSM. Each woman in the study grew and developed in a particular socio-cultural matrix that impacted the types of experiences she had, the contexts in which she had them, and her interpretations of them. Therefore, these study participants represent socially entwined and socially constructed experiential histories. The histories are socially entwined because the women engaged in DSM and progressed along the DSM trajectory as parts of social units (i.e., a family, a dyad, or a community that influenced their DSM experience). The histories are socially constructed because the women's socially based experiences (e.g., the quality of the DSM education they received, their past experiences with other diabetes patients, and their other interpersonal relationships) all contributed to the experiential histories they narrated during their study involvement.

Group one: the most integrated. The women in this group reported the least amount of difficulties with DSM, felt less burdened than the other study participants by their condition, and generally reported feeling that DSM had become an integrated, accepted part of their daily lives. This group is presented first to convey how past experiences and habits operating within particular situational qualities can produce an

91

effective DSM style that can then be integrated into daily life. Although DSM integration is a moving target, not a static end point, DSM integration can be improved (or threatened) by how personal habits and situational qualities operate together.

    A snapshot of Lori, Diane, and Cindy. All of the women in this group were raised in medium-to-large families, with at least two other siblings and many aunts, uncles, and cousins, many of whom they continued to maintain contact. Although none of the women grew up very far from an urban area, they all came from families that farmed, sharecropped, or had large family gardens. These participants recounted fond memories of the strong women in their families, the mothers and grandmothers who worked on the land and knew how to produce their own fruits and vegetables. Although these women were never without fresh produce as they grew up, they noted that the food-related habits passed down to them involved heavily seasoned items containing ample amounts of saturated fats, along with a tradition of homemade breads, cookies, pies, and jams. As young women, they were expected to work hard, be independent, and adhere to "Christian" values.

    The women in this group retained strong, supportive ties with their families into adulthood. They relied on the advice and experience of their elders and more mature family members when faced with new situations. These women could be considered curious and analytical. Of all the narratives shared during the study, theirs contained more episodes of trying new endeavors and furthering their job-related education and training. Hence, the women in this group also were the most highly educated study participants. Two had taken college courses and the third held an associate degree. The three women in this group were employed in the child care industry; all worked from

their homes. In addition, they had been employed through the same agency and had

worked with the same families for many years, which added a sense of stability and

predictability to their situations. These women worked consistent hours, Monday through

Friday, with clear delineations between work hours and free time. All three could be

characterized as having strong habits related to organization and planning. Women in this

group reported an active DSM coping style. As Diane stated:

> I think it isn't scary or overwhelming to me because I mean I have some
> education, so I think my classes helped me in that way, because you sort of look
> at the problem and see what's available and try to pick the best solution, I don't
> get carried away in it.

Two of the three women were in long-term, supportive marriages; the third was

divorced and had not remarried. All of the women reported feeling that their interpersonal

relationships were supportive and did not interfere with their DSM. All three had children

of their own and were involved in caring for their grandchildren. One of the more

interesting findings was that, compared to the other women in the study, these women set

clear personal boundaries. Unlike the women in Group Two, who seemed unable to set

aside time for themselves, the women in Group One were clear about what they were and

were not willing to do.

> Cindy: I do help out caring for my grandbaby, but he [her son] pays me. It may
> not be a lot, but I make him pay, I am not going to let him think it's OK to not pay
> me just because I'm family, because he'd have to pay someone else. I've always
> been clear, I will not be raising your kids, and I already raised mine.

The women in Group One all had their own, reliable transportation and lived in

neighborhoods where they could walk safely and readily access a church or community

center for exercise. Not surprisingly, the women in this group reported spending more

time engaged in exercise activities than women in the other two groups. Moreover,

possibly because of their ability to set boundaries and limit commitments, the women in this group also reported being regularly engaged in more leisure pursuits than the other women in the study.

These women shared similar past experiences, habits, and situational qualities. As previously noted, they tended to report better DSM and experienced fewer burdens associated with their DSM. Two advantages this group enjoyed were its number of years living with diabetes and its supportive relationships with others with diabetes or related health conditions. Simply put, these women had more time to engage in DSM. Having sufficient time set up a cycle in which more opportunities to accumulate positive experiences with DSM facilitated their ability to develop numerous and varied strategies, which in turn helped them further integrate DSM into their daily lives.

In addition to time, habits, and experiences, other situations in these women's lives aligned with their habits and facilitated their DSM integration. For example, the predictability and regularity of their work hours and personal relationships allowed them to plan and prepare ahead: they reported having set times for breakfast, lunch, dinner, snacks, medication, and exercise. In addition, because they worked from home, these women had built time into their daily routines for exercise and household chores rather than having to fit it these things in during a less-predictable week. Cindy, for example, integrated her 45-minute daily walk with pushing the child she cared for in the stroller. Because Cindy lived in a safe neighborhood with paved sidewalks, she was also able to visit a nearby friend during these walks.

Long-term, supportive relationships were another positive influence on these participants' DSM integration. The women in this group reported the least difficulty with

making appropriate dietary choices in social situations. Even Lori, who had hidden her diabetes diagnosis from her daughter for 30 years, reported few problems with engaging in healthy behaviors in social situations:

> It's easy really, because it's not like a special diet, it's really just a healthy diet, I mean really everyone should be watching their sugar and carbs you know, so I don't have to say hey it's because I have diabetes, I just say it's because we all need to eat healthy.

Lori's comments illustrate another interesting characteristic these women shared, namely a sense that they needed to set an example by demonstrating a healthy lifestyle. They demonstrated this commitment by not only preparing and serving healthy dishes at church and family gatherings, but also by providing healthy snacks to the children they cared for in their homes.

A final similarity worth noting within this group is its relatively secure resources (e.g., financial, material, and more). This security could be a result of their higher levels of education, more stable employment histories, or the fact that their children are now adults. Lori explained that although she had known for years what a healthy diet was and how to prepare it, when her children were young she had significantly fewer resources at her disposal to spend on healthy options, which were usually more expensive. Cindy reported a similar history, for example when she paid off a vehicle and by doing so created disposable income that she could use to enhance her diet. Diane further explained that having reliable transportation facilitated her consistent attendance at an exercise group.

Group two: inconsistent. Group Two comprised the majority of the women in the study. These participants were not as comfortable with their DSM integration as those in the previously described group, which included women whose habits, experiences, and

situations culminated in their ability to consistently engage in DSM. Instead, these participants were able to engage in DSM, but not with the same degree of consistency.

The narratives produced by the women in Group Two highlighted how they had developed strong habits associated with caring for others while placing their own needs second. For these women, the most valued life skills were based on their ability to maintain a functioning household that included child-rearing and elder care. Having been raised to believe that virtue comes from self-sacrifice, they were extremely hard working, and allowed themselves little time for leisure and rest. These habits facilitated strong kinship ties and orderly homes, but also meant that the women existed in situations characterized by few resources; thus, they were continually being pulled in all directions to help others. All of the women in this group recounted moments of exasperation and feelings of inability to set personal boundaries that would facilitate more opportunities to engage in DSM integration. In short, these women are able to successfully engage in DSM, but struggled to do so consistently—a situation that impeded the process of DSM integration into their daily lives.

A snapshot of Glenda, Felinda, Alyssa, and Aleisha. All of the women in Group Two were recently (within the past two years) either retired or involuntarily unemployed; only Aleisha had recently begun a new job. The general transitional situation of the women in Group Two was captured in their frequent comparisons between their past and present engagements with DSM. For example, they often discussed how their eating schedules had changed from having no time to eat to having too much time to "munch." The women in this group regarded work as extremely important. Having a job not only aligned with their beliefs about being responsible and hardworking but also provided the

96

financial resources necessary for DSM. Paid employment was seen as the primary means of obtaining the medications, testing strips, and healthier foods that were part of their DSM. The women also discussed financial hardship in their narratives, or represented it in their photographs. Financial security may have been a substantial concern for the women in this group because only one had a partner whose income could be counted on for assistance.

These women lamented the loss of their jobs; with the exception of Felinda, who was retired, all had earnestly sought other employment opportunities. Unlike the women in Group One, none of these women were able to work from home; therefore, time and money for transportation were necessary if they were to work outside the home. These women had often worked long hours in low-paying jobs, but because they held such strong habits related to caring for others, they had also felt obligated to come home after working all day and attend to other family members' needs. Except for Aleisha, these women were deeply engaged in the unpaid care of their grandchildren or elderly family members. Being pulled between these commitments and household responsibilities left them little time to engage in DSM. And even though they emphasized the importance of work, the women in this group also elaborated on how their previous employment situations had impeded their DSM integration efforts.

Besides restricting and reducing the available time for these women to engage in DSM, their workplaces at times were environmentally problematic. In other words, their workplaces sometimes supported habits that were not conducive to DSM. Aleisha, who had begun a new job two months prior to study enrollment, elaborated on how her work environment supported any tendency she might have to neglect her DSM.

97

So here I am, trying to be good, man I had been doing so well, and wouldn't you know that the new job I got, well they are always getting all these pastries and stuff from Starbucks, and I mean it's free, so of course I'm not going to pass up free stuff, so here I am stuffing my face with all that stuff, I mean for the last couple of weeks I was doing it every day.

Other routines associated with work could also be problematic. Glenda provided a photograph of a fast food restaurant that she passed on her way to work and where she stopped daily for breakfast, rationalizing that this choice was quick, easy, and convenient. For hard- working women with little spare time, shortcuts become part of daily life even if they mean sacrificing food quality. Felinda would frequently discuss the healthy diet she consumed, yet her TGD revealed that nearly all of her recorded meals were at fast food restaurants. She explained that although she was capable of making good decisions, she was often so pressed for time that she defaulted to these fast, convenient meals even though she knew they were not good choices.

The women faced new situational challenges as they transitioned (at times against their wishes) into retirement and unemployment, and unfortunately, the irony of their new situations became apparent. Whereas before they had had little time but sufficient resources to engage in DSM, now they had few resources but lots of time. The suddenness of this change revealed how having time, specifically unimpeded time, is so essential to effective DSM. Glenda and Alyssa, in particular, provided rich descriptions of how their DSM had been transformed because of the time they now had. Both women reported that they were finally able to "play around with" their DSM, by which Alyssa meant engaging with and trying out new recipes and cooking techniques, reading up on current diabetes information, and experimenting with new exercise programs. For the

women in Group Two, these ideas had been tucked away in the back of their minds until their situations allowed them opportunities to engage with them.

Although increased free time gave the women opportunities to focus on and engage in their DSM more fully, having too much unstructured time also proved detrimental to their DSM. As the women in the group reflected on their experiences, they commented on how they often "got lost in time" during the day. The most common consequence of this was skipping lunch or forgetting their midday doses of medication. Interestingly, the women all reported that they had maintained their usual morning and evening routines through their transitions into retirement and unemployment, but the open expanse of unstructured time in the middle of the day had proved to be problematic.

In addition to having more unstructured time than they could easily fill, diminished resources (e.g., time, energy, money) were other consequences of unemployment and early retirement. Diminished resources were especially significant for the women in Group Two because they tended to be involved in caring for others. Caretaking further restricted their available resources because they spent money and energy as well as time providing for their children's and grandchildren's needs. Glenda shared how, despite her limited unemployment benefits; she had continued to financially assist her daughter until she realized, recently, that she was at risk of not being able to pay her own mortgage. The women in this group admitted more often than the women in the other two groups that they reused diabetes supplies (e.g., needles) more than the recommended number of times, or skipped blood glucose testing because they were unable to afford their testing strips. This group also expressed that they knew what they should be eating, but often could not afford those particular foods.

99

Aleisha: Before I got this new job, it was rough, that's why I took the picture of the ATM, I mean I would love to eat the wheat bread and have the fresh vegetables and stuff, but when you have to pay three, sometimes four dollars for a loaf of bread, that's not possible for me, well at least not when I wasn't working. What's worse, I'll tell you what really drives me crazy, that kid [her adult son] will eat all the good stuff that I buy. He eats garbage, and I try to buy the better stuff for me, but then he eats it and he don't realize that's expensive, it isn't cheap.

The women in Group Two understood how important it was for them to engage in DSM, had demonstrated that under certain conditions they could accomplish DSM, and had succeeded in integrating some aspects of DSM into their daily lives. They also spoke at length about the many strategies they were utilizing to further facilitate their DSM integration. Nonetheless, habits of thought and action, including privileging the needs of others and being unable to set personal boundaries, operated within situational qualities to produce an inconsistent DSM style.

Group three: just trying to get by. The women in Group Three tried very hard to integrate DSM into daily life; unfortunately, many of their habits proved counterproductive and their life situations provided the lowest levels of support for their efforts. The narratives these women produced reflected an underdeveloped DSM approach that was further stunted by the combination of their personal habits that operated in unstable situations. The narratives were characterized by repeated destabilizing life events that derailed their attempts to habituate DSM integration into their daily lives.

A snapshot of Lydia, Yolanda, and Deidra. Two of the women in this group were divorced and remarried and the third had recently undergone a traumatic divorce. Two also had secondary medical conditions that impeded their engagement in valued daily activities. One of the women, Deidra, worked full time (nearly 60 hours per week) while

also attending a certificate program at a community college. In stark contrast, Lydia was unemployed and unable to work because of her health but was not receiving disability benefits. Although these participants' situations varied, they all reported significant problems with DSM integration and felt the most burdened by their condition.

Among the significant destabilizing life events reported by this group were difficulties in their interpersonal relationships; they felt they could not trust or rely on their families for help. While these women's past experiences differed, they shared certain habits related to passive coping styles and DSM avoidance when stressed. Finally, these women reported being more disorganized, using food to cope with stress, and being unable to effectively set or maintain personal boundaries.

Yolanda's narrative revealed that during a long addiction to street drugs she had gone in and out of rehabilitation programs, a pattern that significantly impacted her DSM efforts. Her drug addiction, a significant destabilizing force in her life, affected her interpersonal relationships, educational attainment, resource security, and ability to engage in positive health behaviors. Yolanda reported that she had joined a faith-based program and had been clean since she "found the Lord." Her narrative revealed how she had struggled through several attempts at drug rehab, during which she would quit drugs cold turkey and then become addicted again. After she would get clean, Yolanda would feel a sense of urgency about her DSM integration, as if she had to make up for lost time. Overall, Yolanda's narrative revealed numerous periods during which she would determine that she needed to make a change; make the change suddenly, with no preparation; and then reinstate her previous behaviors. Yolanda had struggled for many years with how to make the necessary changes to better manage her diabetes. She had had

101

little success with her typical all-or-nothing approach, yet, had not developed effective

habits to consistently modify her behaviors. She explained the significance of one of the

photographs she took (Figure 5.2.) in relation to her food habits.

Figure 5.2 Participant Photograph: Mindless Eating

"Everything goes in my mouth," she said. "I mean I just start grabbing and munchin' on

whatever, I don't even care, it's mindless you know, but it just gets on me." The mindless

eating Yolanda refers to is stress eating.

Deidra, who had been diagnosed with diabetes nearly three years before enrolling

in the study, had also struggled with stress eating and interpersonal relationships. She had

been unable to make much progress with her DSM for a variety of reasons, including a

failed marriage that ended in a traumatic divorce, diagnosis with a serious illness (aside

from her diabetes), and a constant overload of stress. She experienced ever-increasing life instability as her brother-in-law moved in with her, followed by her son, his wife, and their three children.

During the 12 months that preceded her involvement in the study, six additional people had begun living in Deidra's three-bedroom home; as a result, she took her medication regularly but engaged in few other DSM activities. Deidra explained that she did not have the ability to focus on her DSM very much, given her chaotic and stressful situation: "I just can't, I know what I'm supposed to be doing, but I just can't right now, maybe when things change a little." Although Deidra had promised to get back to managing her diabetes better, the unrelenting stress of her situation had already robbed months and years from her DSM integration efforts and impeded her ability to further develop the experiences and strategies necessary for DSM integration.

As with Yolanda, Deidra's DSM efforts were further complicated by her heavy work schedule. When asked about the possibility of reducing her workload, Deidra responded that she had no choice in the matter and was continuing to work nearly 60 hours a week, for very little money, at the restaurant she co-owned with her ex-husband. Due to the high number of hours she spent at work, Deidra was unable to consistently make healthy food choices because nearly everything she ate was from the restaurant's menu. Further confounding this situation was the fact that Deidra, even within her own home, felt unable to set personal boundaries with her son and grandchildren. Thus, Deidra performed almost all of the household chores and provided care for the three grandchildren residing in her home.

In contrast, Lydia was unemployed at the time of her study involvement but had worked in low-income jobs most of her adult life. Despite having been diagnosed with diabetes 18 years prior to the study and having received formal DSM education at least three times, Lydia articulated that she still did not really understand what she should do with her diabetes. However, Lydia also commented that she did not care to eat healthy foods or engage in exercise because of another physical condition (debilitating arthritis). Through further questioning it became apparent that Lydia did have some understanding of DSM, but she interpreted the information she received as a list of very general rules (e.g., exercise, eat salads, and don't eat sugar). Lydia was unable to articulate DSM recommendations in detail, use health information well, or seek help with her DSM when she had questions. The photographs she provided of her home revealed mass disorganization and clutter; she confided that her daughter believed she was a hoarder. Lydia's photographs and narrative also revealed her struggles with stress eating.

Lydia's stress came from numerous sources. The low income she had earned required her spouse to work substantial overtime to meet their financial needs; this demand on him had added to her stress. Additionally, her mother had recently become ill and Lydia was obligated to assist with her care. Lydia's coping skills in such stress-inducing situations were relatively poor; she often engaged in what she termed "mass and mindless eating" in response. She also used avoidance and consumption to feel better. When asked what she thought would help her improve her DSM integration the most, she exclaimed, "Going to the beach!" Lydia presented the photograph of a motel (Figure 5.3.) to represent the importance she placed on beach trips. At the beach, she explained, she would feel calm and be able to eat good-tasting foods, an activity that she believed would

help to better manage her diabetes. She went on to explain that being relaxed improved her blood sugar levels. These answers reflected her distorted understanding of DSM as well as her tendency to prioritize escaping it. Lydia was unable to appreciate that the actions that made her feel relaxed were counterproductive to her DSM.

Figure 5.3. Participant Photograph: Going to the Beach

The narratives from Group Three demonstrated experiential histories, characterized by trauma and instability, which significantly impeded these three women's DSM integration. As discussed in Chapter Two, a habit serves as a tool to coordinate the person-world relationship; although the habits these women had developed did support their life situations, they were largely inhibitive of DSM. This group of participants generally shared habits of disorganization, passive coping styles, and the use of food as a coping mechanism. In addition, they tended to react with extreme emotions to their surroundings, yet demonstrated little ability to set boundaries or negotiate their

105

circumstances. Subsequently, they reported having the least successful experiences with DSM integration and few useful strategies to negotiate their DSM needs in the context of daily life.

Implications of the Experiential Histories

The three experiential histories groups described above demonstrate how past life experiences, habits, and situations influenced not only the participants' overall DSM styles but also their abilities to grow and develop their DSM approaches. They also confirm that engaging in DSM requires individuals to negotiate the demands of everyday life. The women had all developed habits over their lives that helped them negotiate daily life, and these were the same habits they relied upon during their initial DSM trajectories. The women's customary ways of responding, however, were not always conducive to DSM. For example, Yolanda's time as an addict was characterized by short-lived but intense efforts to channel the time, energy, and resources needed to frequently reorganize her life. Her addiction necessitated such perpetual reorganization because chronic disarray made it difficult for her to maintain a job or an interpersonal relationship. Although this approach had been useful in the past, it was not supportive of her DSM efforts.

DSM integration requires channeling resources, and these resources must be allocated and negotiated to sustain DSM efforts in the long term. For example, without making appropriate accommodations, it is highly unlikely that a person can sustain drastic, sudden changes such as giving up all carbohydrates, sugars, and caffeine while also beginning to exercise an hour every day. Yolanda had not developed the abilities to create supportive, intermediate plans for her intense all-or-nothing approaches. If DSM

106

was an acute illness, Yolanda's approach would be appropriate. DSM, however, is a lifelong endeavor and Yolanda had not yet developed the ability to take a more measured, sustainable approach to it.

Similarly, Deidra's habit of avoiding tasks when she felt overwhelmed may not have been problematic when she was married and could rely on her spouse for assistance; however, her passive coping style resulted in neglect of her DSM when she was living on her own and dealing with multiple life stressors. The seemingly positive habits of caregiving and serving others that dominated Group Two could also be useful in the context of raising children and maintaining marital relationships. Such habits appear to have negatively influenced these women's DSM, however, when they focused on others to the exclusion of their own health.

These differing experiential histories foreground the importance of how the women in the study responded to certain situational qualities and how their responses affected their DSM processes. For example, they were most consistently able to engage in taking their medications because they could generally afford them (in part due to pharmacy-subsidized medication programs) and there were few barriers to taking them. Blood glucose testing was the second most consistent activity reported; the women associated failure to perform this task with the cost of testing strips.

As activities became more complex, took more time, or required more resources, they became more vulnerable to neglect in the face of changing situations. The women associated restrictions on their time and energy with their reliance on strategies that saved time and labor. A typical manifestation of this association was their reliance on convenience foods. They also tended to respond to financial restrictions by reusing DSM

supplies (e.g., insulin needles). At times the women simply eliminated aspects of their DSM regimen, for example by skipping blood glucose checks or reducing their intake of fresh fruits and vegetables. Stress often led to avoiding DSM almost completely or engaging in self-sabotaging efforts through mindless eating.

Yet, despite these setbacks and inconsistencies, the women in Group One were able to consistently engage in DSM. Like the women in the other two groups, these women had to care for others, maintain martial relationships, and balance work and home responsibilities. Their adaptive habits of organization, planning, active coping, and setting personal boundaries, however, had shaped their situations and proven effective in facilitating their DSM within their particular contexts. That is not to say that their habits were better or worse than the other participants', but simply that their habits in concert with their situational qualities manifested in a more optimal DSM style.

For this reason, individuals' DSM integration efforts should not be considered as the results of their individual personality types as much as the results of their experiential histories. Considering the DSM integration efforts of the women in the study with respect to their experiential history leads one to examine their personal habits and the qualities of their situations and also supplies ways and opportunities to address both. Simply changing context does not automatically change habits, or vice versa; rather, the two forces evolve and change together. For example, because Glenda, Felinda, and Aleisha were unmarried and their children are adults, they may no longer feel obliged to neglect their own needs for the sake of taking care of others. Yet the narratives these women produced illustrated their tendencies to re-acquire caregiving responsibilities and overextend themselves for the sake of others. Yolanda's experience with street drugs and

multiple rehabilitation programs is another example of the interplay between habit and context. Although married and working full-time, she approached changing her own DSM behavior in the same all-or-nothing manner that had been only temporarily successful during most of her attempts at drug rehabilitation. In other words, even when someone can change the qualities of her situation, changes in habits do not always follow automatically.

Integrating DSM into daily life takes time. Past life experiences, habits, and situations, transact in ways that can be facilitative or hostile to integration efforts. Chapter 6 provides a more detailed overview of the conditions that influence the integration process. Chapter 7, through discussing the primary domains of the integration process, illustrates how individuals can become more aware of the effects of their past life experiences, habits, and situations on their integration efforts, and thereby possibly change them.

Chapter Six: The Conditions of Diabetes Self-Management Integration

The participants experiences presented in Chapter Five illuminate how the past experiences, habits, and situational qualities of participants in the study influenced their DSM integration efforts. In this chapter and the next one, I present the product of the study, the transactional model of DSM integration. The model describes the theoretical process by which the participants in the study integrated DSM into their daily lives and the conditions through which this integration occurred. The purpose of this chapter is to provide a more in depth presentation and discussion of the conditions that affected the women's integration efforts throughout the diabetes trajectory. I begin by explicating the nature of DSM integration as revealed through the women's experiences. This exposition then turns to the influence of temporality, habits and situations, and routines on the integration process.

Defining and Conceptualizing Diabetes Self-Management

The women who participated in this study were never provided with an a priori definition of DSM integration; instead, they revealed their definitions of DSM integration through their narratives, photographs, and TGDs. The women defined effective DSM integration as the ability to generate the same or similar outcomes repeatedly, across the same or similar circumstances. Lori perhaps said it best by simply stating that "for me, it means I can do almost all of what I am supposed to do almost all of the time." The women's experiences revealed that optimal DSM integration is (a) transactional, (b) an

occupational process, (c) contingent and ongoing, (d) situated within daily life management, and (e) DSM as distributed across space and social spheres.

The transactional nature of integration. The transactional perspective emphasizes the contingent, relational nature of the person/world relationship. Humans and their actions are part of larger social and cultural systems that reciprocally influence one another. The women's accounts of their DSM integration efforts revealed that for them, the process of integration was long and contingent at best. The women used terms such as "coordinate," "negotiate," "work out," and "finagle" to describe how they had to make continual refinements to their processes in order to achieve and maintain integration. The women's stories also illustrated the many ways that social living, daily life demands, their own tendencies, and larger contextual factors shaped their ever-changing DSM. I characterize DSM integration as transactional, therefore, not only for theoretical purposes but also to reflect these women's experiences and emphasize the elements of contingency, coordination, and change that shaped their stories.

Occupational nature of self-management. The women's descriptions of DSM integration were consistent with existing conceptualizations of what constitutes an occupation (Hocking, 2009, Yerxa et al., 1990). DSM integration requires specified knowledge, skills, and abilities. The women's narratives illustrated that for them, integration was full of personal and cultural meanings, and that they felt their performances were evaluated according to normative standards. At times integration also required the women to use specialized tools and equipment (e.g., syringes and meters). Not surprisingly, they unanimously referred to DSM as a "second job." With this description they framed DSM integration as both an occupation and a constellation of

111

occupations. Moreover, the women reported moving back and forth between engaging in the occupation of DSM integration as a whole and abstracting specific aspects of DSM (e.g., diet and stress management) in order to address them individually. Cindy's comments capture this relationship.

> I mean it's a job, I mean it really is, the whole big mess of it, but then at times I focus on one part of the job and at other times I focus on another part of the job, I mean you sometimes get over[whelmed] by trying to deal with the whole thing but you got to keep the whole thing so you don't forget about stuff.

Cindy went on to explain how, at the beginning of her diabetes trajectory, she became so focused on her diet that she neglected the fact that she also needed to accommodate exercise into her routine. Cindy recognized the need to fluctuate between managing the larger DSM integration as a whole and paying greater attention to a specific DSM component. The women all noted that this back-and-forth movement kept them from becoming overwhelmed or discouraged with the enormity of their DSM responsibilities.

The women's stories demonstrated that phases of the model, such as inquiry and practice (discussed in Chapter Seven), took place during their engagement in the occupation of DSM. They also shared how the occupational engagement of their friends and family resulted in suggestions and ideas that they then incorporated to improve their own self-management efforts. Therefore, their experiences indicate that occupation was an important component of how they grew and developed as self-managers.

Contingency and integration. The findings from the women's narratives, photographs, and TGDs demonstrated the contingent nature of DSM. The women characterized DSM as a "moving target" because they felt that integration was never fully complete. The women referenced many life disruptions that necessitated periodic

adjustments so that they could maintain their integration efforts. They reported how job loss, death of a family member, home burglary, or loss of dependable transportation could temporarily derail their efforts.

The women who participated in the study had realistic expectations for their DSM integration; in fact, they noted that they found the achievement of DSM integration as a whole to be unrealistic. Instead they discussed the stepwise, piecemeal approaches that they relied upon for integration. For example, it was common for the women to have integrated some components of DSM while leaving others virtually untouched. As situations changed, the composition of the integrated components also changed thereby reflecting the uncertain, contingent nature of integration.

The experiences presented in Chapter Five illustrate that some social situations foster more uncertainty than others. The women who participated in this study are the working poor. Their incomes, although meager, often preclude them from receiving assistance reserved for the very poorest of the poor. The women reported that living in an almost-constant state of poverty required them "to make decisions that others take for granted." These decisions were most often associated with the allocation of scarce resources in order to meet daily life demands as well as demands specific to DSM integration. For example, several women discussed how they "juggled" purchasing food and household necessities while trying to ensure that enough money would be left over for diabetes supplies. The women reported that the consequences of these choices sometimes further complicated their integration efforts.

Integration as fluid and situated. DSM is often focused on facilitating individuals' engagement in the ADA's seven core behaviors, the goal of which are to

improve blood glucose control. However, the women's experiences revealed many other aspects of daily life that had to be addressed in order for them to engage in these recommended behaviors. The women's stories revealed how the boundaries between diabetes-related activities and general daily life activities were not only fluid but also shaped by and within larger situations. In other words, the women had to first address daily life management to successfully engage in DSM. This determination blurred the lines between the actions they took to manage daily life and those specifically directed at DSM integration.

Self-management as a distributed activity. The distribution of participants' daily activities through time, space, and social spheres had consequences for their integration efforts. The participants' stories and TGDs provided opportunities for insights into the people and places they encountered during their daily routines and the reciprocal influence of these networks on their integration efforts. In particular, the women's narratives illustrated that social and spatial distribution could assist DSM by extending available resources and support. Conversely, certain aspects of the women's distribution served to perpetuate their engagement in activities that were in conflict with their self-management goals.

Social distribution. Participants' routines provided insights into the distribution of their DSM and daily life activities across social circles. Their narratives illustrated how this distribution at times had to be coordinated and how it affected DSM. Engaging in DSM brought the women into contact with friends, family members, church members, and care providers. In fact, they tended to associate engagement in certain DSM activities with certain social ties. For example, three of the women associated members of their

114

church with their own engagement in exercise. Two other participants, Alyssa and Diane, most commonly exercised with their sisters.

Although the women's social spheres often provided them with social support for their self-management, these could be problematic. For example, participants reported that they ate healthier meals in their own homes or those of close family members. Conversely, they noted that they were less likely to eat well in the presence of church members or associates. Diane, Aleisha, and Alyssa all commented on how difficult it was to stick to their healthy eating plans during church functions. Although this form of social participation was highly valued by the women, it also posed real challenges. The women cited church potlucks and post-service buffets as particularly troublesome because they generally contained few diabetes-friendly food choices. These examples demonstrate that the women associated different social spheres with varying levels of self-management success.

Regardless of the activity, distributing self-management across social spheres required some of the women to coordinate their routines with those of others. This social coordination of routines often allowed the women to access additional resources (e.g., transportation or much needed free time). Unexpected changes in either the women's routines or the routines of others could, therefore, be problematic.

Felinda's case exemplified having to coordinate routines to secure both time and transportation. Because she did not own her own vehicle, she depended upon her sister for rides when running errands or attending doctor's appointments at locations beyond the bus line. Additionally, Felinda cared for her son's two-year-old daughter. For Felinda to engage in some of her DSM activities, she needed to coordinate with her son (to hand

off her granddaughter) while also coordinating with her sister so that she could have transportation. Felinda explained how she had to be aware of not only her own routine, but also of others'.

> Well I mean it's enough for me to just keep track of me, but I have to always be knowing what he's doing [son] and where she's [sister] at because we have to coordinate everything so that I can get done what I need to get done. I mean she's mine [granddaughter], I keep her in my house, but with the other two [grandchildren] he just has to take her sometimes so that I can get stuff done because I only have a small window of time to do those things I need to do.

Felinda remarked that it was easier for her to coordinate her routines with others' when everyone's routines were stable. Conversely, Felinda reported that at times she was unable to maintain DSM integration efforts because her routine, or the routines of others, unexpectedly changed. The more all of the women depended on others, the more important the collective stability of everyone's routines became. Therefore, the social distribution of the women's daily activities had implications for their DSM integration.

Spatial distribution. The women's narratives illustrated the spatial distribution of their DSM integration efforts; specifically, their stories clarify how the distribution of their daily lives impacted their DSM. Just as with social distribution, participants associated engagement in particular DSM activities with certain places. For example, Lori mentioned that when she wanted healthy ingredients, she always went to the Whole Foods grocery store across town. Similarly, Alyssa associated her exercise with the fitness center and Glenda presented the picture in Figure 6.1 to illustrate her association of exercise with the community park near her home.

Figure 6.1. Participant Photograph: Exercise at the Park

The women's stories also demonstrated that the distribution of their general daily

life activities had repercussions for their DSM. Glenda provided an example of how her

distribution through space changed after her employer closed the office where she had

worked for almost 11 years. Glenda, who had driven the same route to her job every

morning, took pictures (figures 6.2. and 6.3.) that helped her explain how her distribution

through space changed after she lost her job, and how this change affected her DSM

Figure 6.2. Participant Photograph: Old Routine

Figure 6.3. Participant Photograph: New Routine

Glenda explained that she had driven past the Bojangles™ every day that she went to work. She described how the restaurant was located right on the corner, at the stop light after she got off at the highway exit: "It was just so easy you know, I mean it was right there." The fact that Glenda's daily routine conveniently took her by one of her favorite eateries made it easy for her to engage in a daily breakfast consisting of a sausage biscuit. Glenda compared this old morning routine to her new morning routine which involved getting up, making coffee, checking her blood sugar, taking her medications, and then fixing herself a bowl of oatmeal. Moreover, because she was barely surviving off her unemployment benefits and gas prices were high, Glenda explained that she simply could not afford extraneous trips. In short, becoming unemployed had changed Glenda's spatial distribution and, this change did have a positive effect on her healthy eating. When asked if she thought she would have changed her breakfast routine on her own had she not lost her job, Glenda replied:

No, I mean I highly doubt it, first I had no time in the morning, second, It was always just so easy to get it on the way to work, so no, I don't think that would have changed until I changed jobs.

It is important to note that although Glenda's new distribution through space improved her DSM via her meal choices; it also caused her many financial difficulties. Glenda was eating healthier, while also reporting that she had to increasingly reuse her diabetes supplies, including insulin syringes. Glenda's situation also restricted her social contacts because she could no longer afford the gas to visit some of her friends. Glenda expressed that at times she felt lonely spending so much time home alone. Glenda's story illustrates how the women's DSM activities and daily routines were distributed through space and how their circumstances could affect this. At times these were associated with supporting their DSM efforts; at other times, they impeded them.

Temporality and Integration

Aleisha: Really I think it just takes time, and I mean sometimes it can take a lot of time, sure the money is important, in some ways more, and in some ways less, but I guess if you don't have the time, who cares how many good ideas you have right?

Life experiences preface the model to draw attention to the cumulative nature of experience. The women's stories demonstrated how, especially in the early stages of their DSM trajectory, time and experience influenced their integration efforts. Some of the women had had a lifetime of experiences prior to being diagnosed with T2DM. Through these experiences, they had developed habits of thought, action, belief, perception, and so forth, with which they entered their DSM trajectories. These habits and situations influenced the time it took for them to become skilled diabetes self-managers and the

time available for them to develop self-management abilities. They also influenced how the women organized their time use within their daily routines.

Time to become a self-manager. One of the most important aspects of DSM, often unacknowledged is that it is a process that unfolds over time. Time flows through the model, as demonstrated by the fact that all of the women felt the influence of time on their integration efforts. Time and past experiences are tied together throughout the entire DSM integration process because the habits and situational qualities that are constructed over time influence present actions. The influence of past time and experiences in solidifying habits and constructing routines shaped how the women initially approached DSM integration and why it took so long for them to feel like effective self-managers.

When the women in the study were asked to reflect on the idea of DSM integration and to specify the point at which they felt they were capable self-managers, their responses varied from four to 11 years. My first inkling that the temporal dimension of DSM was both immensely important and also significantly overlooked by DSM scholars was derived from a participant's narrative. At the time of our first interview, Glenda had been managing her diabetes for 19 years, had attended diabetes management education classes early on in her diabetes trajectory, and was currently attending diabetes classes at the local clinic. At first it appeared that Glenda had a wealth of experiential knowledge from having learned to manage her diabetes over so many years. She appeared as a confident and capable patient-expert who was able to consistently engage in her DSM regimen with minimal problems. But during our second interview, as Glenda and I discussed how she felt about her DSM, her response startled me: "Well, I honestly can say that I just now think I have the hang of it, maybe these last four or five years I felt

121

I have really got it." Other women in the study shared Glenda's perception that becoming an "expert," a bona fide self-manager, or even just feeling comfortable with being in charge of their DSM, was a very long process.

Time and routine: open and closed time. The women's narratives demonstrated how they continually negotiated daily demands in order to make the time to work through aspects of their DSM integration. Yolanda, who worked two jobs and also attended school, showed me the photograph in Figure 6.4 while explaining her struggles to find the time in her schedule to focus on developing her self-management. The photograph is of the hand-written calendars that she carried with her to remember where she needed to be and when.

Figure 6.4. Participant photograph: Schedule

The women's TGDs provided insights into the importance of time in developing self-management skills. In particular the TGDs, and TGD interviews, revealed that two

types of time, open and closed, had particular implications for the development of their DSM.

Closed time. Closed time, which each of the women maintained in their daily routines to some degree, was described as "spoken for," "non-negotiable," and "mandatory." The most common activities associated with closed time (a) comprised the morning routine (waking up, using the bathroom, and getting dressed), (b) were related to paid employment (working hours, travel to and from work), and (c) involved child and elder care. These activities were seen as essential to maintaining daily life; therefore, the DSM activities that the women integrated into closed-time intervals were also the ones they engaged in most consistently. This consistency was due in part to the fact that the relative sequencing of the women's activities within closed time intervals remained constant. For example, according to the women's TGDs, their activities during the first two hours after waking were the most consistently sequenced.

The second and third most consistently reported sequence of activities occurred, respectively, during working hours and the two hours before bedtime. The women who engaged in DSM activities during these closed-time intervals did so more regularly and reported feeling fewer barriers to engaging in these activities. The most common DSM activities that the women reported performing during closed-time intervals were 1) medication management, including blood glucose monitoring, 2) exercise, and 3) a healthy breakfast. Closed-time intervals tended to include relatively simple DSM tasks that were time-specific, required few tools and resources to complete, and that had already been habituated into the women's daily lives.

Open time. Open time referred to relatively unstructured time in the women's daily and weekly routines. Although the women generally made some tentative plans for open-time intervals, these intervals were much more flexible and accommodating about spontaneous or unforeseen events. In terms of DSM, the women most often used open time for preparatory activities and trying out new plans, particularly (a) couponing and looking at sales flyers, (b) recipe searching, (c) practicing new dishes, (e) trying novel exercise classes, and (d) spending quality time on themselves to "de-stress." This period of time use was predictable but still considered open because the relative timing and sequence of these activities could vary, as could the locations of the activities and who was present when they occurred. Yolanda conveyed that even though she had to perform her grocery shopping every Friday, she would sometimes visit her son and eat lunch with him, or visit with a church member before or after this errand. Open-time intervals tended to include more complicated DSM tasks that took more time and required more tools and resources than those performed in closed time. Open time was viewed as more hospitable to the kinds of inquiry and practice that enabled the women to develop their self-management abilities.

The benefits of open versus closed time. The women's TGDs did not indicate that having more open than closed time provided a qualitative advantage, but rather that both kinds of time could be helpful or not. The women described a general process of first engaging in new activities during open-time intervals, or trying out new potentials. Novel experiences tended to remain in an open-time interval until they had been refined enough to be added into a closed-time interval. DSM activities that occurred in closed-time intervals were seen as more "safe" than those in open-time intervals because open-

124

time intervals were more susceptible to spontaneous or unforeseen events that could change how the women used/intended to use them. For example, Cindy related how her plans to try out some new exercises during open time, with the intention of adding them to her closed-time exercise routine, had been thwarted by spontaneous invitations to engage in leisure pursuits with her friends.

> I had it all figured out you see… I mean I know what I want to do, but then this one come calling and that one come calling, and I said girl, ok, so I went here and there and next thing you know it's like—what work-out?

Because DSM activities that the women engaged in during open time were often preparatory or relatively new experiences, the women tended to be less invested in their completion in the face of competing daily demands. Conversely, the women reported feelings of stress when they failed to engage in activities during closed times, because these were more highly prioritized. The women mostly reported engaging in planning and preparation during open time. However, the women with the most successful DSM integration had merged the two types of time. By constructing their routines to include regular, protected intervals of open time, they had integrated the benefits of open time into the protected sequences of closed time. These stories indicate that having more open time may be beneficial, especially in the early stages of integration when it is particularly important for diabetes patients to practice and develop their skills. However, once these skills are refined, it seems that DSM activities are more likely to be completed consistently when placed within larger sequences of mandatory daily activities.

Experience Frame: Habits and Situations

The experience frame, which surrounds the process of DSM integration, includes the circumstances that promote integration from the diabetes diagnosis onward. The

women in the study did not perceive DSM as a blank slate; instead, their stories revealed how the habits they had derived from earlier life experiences shaped their present integration efforts. Therefore, the experience frame for these women represents what they brought with them when they entered the DSM process: a particular constellation of relevant habit elements that had been configured and reconfigured in conjunction with particular situational qualities. I derived the two primary components of the experience frame (i.e., habit elements and situational qualities) from the data. They represent the elements that exerted the most relevant influence on the women's DSM integration processes. The habit elements and situational qualities of the experience frame consciously and unconsciously drove the women's DSM integration.

Habit families. The women's narratives demonstrated patterns of thought, action, belief, and perception that influenced their integration efforts. I conceptualized these patterns as habits because they were largely unnoticed by the women yet shaped how they engaged in DSM integration. Figure 6.5 provides an example of a photograph that depicts habits associated with beliefs and perceptions.

Figure 6.5. Participant Photograph: Habits

Although their stories contained many different habit elements that I abstracted

for analysis, not all of the abstracted habit elements operated in equal importance in the

DSM integration process. Instead, the women configured and reconfigured them in

relation to particular situational qualities. The parameter that I used for creating the habit

families was their status as relevant habit elements that clustered around a particular

experience the women discussed with me. For example, a habit family labeled as "habits

of foodways" was relevant to the experience of planning for and preparing food. The

habit family of foodways incorporated not only the aesthetic habit elements of taste, but

also customary cooking habits including certain techniques and repertoires that included

the repeated use of particular ingredients. Relevant habit families abstracted from the data

in the study included (a) organizational skills, (b) coping methods, (c) temporal

preferences (i.e., early bird/night owl), (d) foodways, (e) physicality, (f) approach to tasks

(i.e., head-on or avoidance), (g) habits of caregiving, (h) habits of personal boundary-

setting, (i) approach to interpersonal challenges, (j) faith and its use, (k) financial habits,

and (l) habits of evaluation and inquiry. Table 6.1 includes a sample of some of the habit

families and corresponding habit elements derived from the data.

Table 6.1 *Habit Families*

Habit Family	Possible Subcomponents
Boundary-setting	The degree to which individuals plan, control, and monitor daily demands to ensure appropriate time for self. The degree to which the individual secures and protects time and resources to meet her own health needs. Evidenced by personal narratives and artifacts depicting the products of time and resource commitments.
Foodways	Aesthetic preferences for taste, preferred cooking methods and tools, ingredient and recipe repertoires, cultural associations with foods (e.g. Traditional family foods, or regional dishes). Evidenced by personal narratives regarding history of foodways from childhood to present, artifacts of foodways, and beliefs regarding qualities of food (e.g., harmful, beneficial).
Physicality	The degree to which individuals think about , plan for, value, and engage in physical activity for the purpose of health promotion. Evidenced by artifacts of physical activity (equipment and tools), narratives of past experiences with physical activity, and current beliefs and tendencies toward physical activity.
Organization	The degree to which individuals manage time, keep the home clean and orderly, manage finances, prioritize tasks, and plan for specified actions or goals. Evidenced by personal narratives and personal descriptions of tendencies, TGD routine and daily flow, artifacts and tools (e.g., calendars, reminders etc.).
Faith	Beliefs regarding nature of faith and religion in terms of effects on DSM (direct or indirect), including faith as an active or passive influence on DSM. Evidenced by personal narratives of roles and effects of faith on DSM and artifacts of faith (bibles, images of places of worship).

Situational qualities. The women used the term "situation" to depict their general

life circumstances in which their DSM integration took place. For example, in describing

her ability to engage in exercise, Cindy stated, "My situation may be different than other

people's situations, I mean with my situation, I can focus on me because my kids are

grown." Cindy was referring to the possibility that she may have more time than other

participants to focus on her DSM. Figure 6.6 is of a participant photograph that depicts

aspects of the participant's situation, having a secondary medical condition.

Figure 6.6. Participant Photograph: Medical Comorbidity

At times the women's situations supported existing habits, while at other times

situational aspects were seen as problematic and required them to take action. Their

situations and habits were linked so that a change in one often necessitated a change in

the other. The situational qualities that were the most relevant to the DSM integration

process and that were therefore abstracted from the data included (a) usable income, (b)

employment status, (c) health insurance, (d) housing type and location, (e) safety of

community, (f) family structure and caregiving responsibilities, (g) interpersonal stability,

(h) proximity and access to medical care, (i) education level, (j) medical comorbidities,

(k) recent major life transitions, (l) social supports, (m) special program eligibility, (n) self-reported roles (e.g., mother, employee, spouse), and (o) routine structure.

Habits, situations, and routines. The participants indicated that one of the most significant ways their habits and situations influenced their integration efforts was through the shaping of their daily routines. The women's stories and TGDs provided insights into this relationship, particularly how habits and situations influenced (a) their assessment of which daily activities they considered necessary and mandatory, (b) the resources (i.e., time, energy, and finances) at their disposal to complete those activities, and (c) their prioritization and rationalization of activities.

The women's routines reflected what they needed and wanted to do, where they did these things, and who they did them with. Which activities the women perceived as being mandatory or necessary depended on their habits and situations. For example, the women who had paid employment had to incorporate activities associated with their jobs (e.g., driving to work or making their home ready for children) into their daily routines. Similarly, participants who engaged in caregiving had to incorporate such activities as helping with homework, taking a parent to a medical appointment, or waiting for children at the bus stop.

The women's situations also influenced the resources (i.e., time, energy, and finances) at their disposal to complete activities. For Aleisha and Alyssa, having multiple medical comorbidities reduced their energy level. Their fatigue made it a struggle for them to engage in many activities. Aleisha related how the ladies at her church held a variety of social events for women over age 50 that she would have liked to attend: "I go to the potlucks, and some of the social tea stuff… you know when it's at someone's

130

house, but I can't do the stuff where they walk… like shopping or events, I just don't

have enough energy." Yolanda, who worked more than 40 hours per week while also

going to school, faced a different dynamic. Her busy work schedule allowed her to secure

sufficient funds to meet her daily needs, but she had little time left over to exercise or

"de-stress": "I thank the Lord I have a good job, I mean I got two good jobs and most

folks don't even have one, but man, I get so stressed, and what, there isn't any time to

even breathe."

During conversations with the women about their TGDs, they shared how habits

related to valuing family, hard work, and spirituality particularly influenced which

activities they prioritized in their routines. For example, Felinda, Yolanda, and Glenda

remarked how they prioritized spiritual and family activities over making time to engage

in preparing healthy meals or exercising. DSM was important to these women but they

valued other activities in their lives more highly. When Yolanda presented the

photograph in Figure 6.7 to me, she explained:

> I need church because I won't be able to manage my diabetes without the Lord,
> I've tried to do it in that past and I learned that I can't do it without him so now I
> pray when I want to do better and wait for wisdom.

Figure 6.7 Spirituality: A Valued Activity

Yolanda's faith was so important to her that she would pick up dinner at a fast food drive-thru so that she could arrive at her evening church service on time. Similarly, Glenda would prepare and serve healthy meals to her daughter, son-in-law, and grandchildren, but she often refrained from eating anything all day because she was consumed with attending to their needs: "That's just the way it's always been, even when I was married, I mean I don't know what I would be like if I didn't have someone to take care of." Glenda's family was aware of this habit; in fact, her daughter had told her that she needed to sit down and eat. Still, Glenda continually prioritized taking care of others over attending to her own needs.

During the TGD interviews, the women often reflected upon their situations and their habits of thought and belief that led them to prioritize certain activities. During her

TGD interview, Deidra expressed that completing the diary had made her think about her situation, particularly how it had gotten so "out of control." As she noted how her daily routine was dominated by long work hours and "picking up the slack" for others, she exclaimed, "You know what my problem is, I can't set any boundaries for myself, and seeing this [diary] it makes me mad because, no wonder I'm overwhelmed." Deidra felt frustrated when she realized that her habits had contributed to her chaotic life, as well as an inability to exert more control over her situation. Her comments are examples of how the women's habits and situations shaped their self-management efforts by influencing the construction of their daily routines.

Conclusion

The women's experiences revealed that DSM integration is a dynamic, ongoing process. The conditions through which the women engaged in DSM changed over time and were influenced by their habits and situations. Time and earlier life experiences were important influences on the women's integration trajectories. The experiential histories presented in chapter 5 illustrated how the women's initial approaches to their DSM could be seen as a manifestation of their previous life experiences, habits, and situations (e.g., initial approach to diet and exercise, or focusing primarily on medication). These approaches changed over time, as the women grew in knowledge and experience, their situations changed. The women's habits and situations were reflected in the construction of their daily routines. What they needed to do, and wanted to do, had an impact on the how daily activities were spread over time and space. These patterns posed particular challenges and opportunities for their integration efforts and also influenced the time available to them for engagement in becoming better self-managers. I have presented

these conditional influences to both preface and surround the model in order to illustrate

their continuous relevance to the integration process. The primary domains of the

integration process are discussed in Chapter Seven.

Chapter Seven: The Transactional Model of Diabetes Self-Management Integration

The purpose of the study was to explore the process that individuals with T2DM use to integrate diabetes self-management (DSM) into daily life, and the conditions under which DSM integration occurs. The discussion in Chapter Six explicated the conditions affecting DSM integration, including past life experiences and temporal dimensions, and introduced the experience frame. The end product of this dissertation, the transactional model of diabetes self-management integration (TMDSMI), is the focus of this chapter. This model reflects the participants' lengthy journey toward DSM integration and foregrounds the multitude of factors that must be continually coordinated and re-coordinated to make integration possible. This chapter details the five primary domains of the DSM integration process: (a) potential, (b) inquiry loop, (c) practice phase, (d) contingent integration, and (e) reconfiguration. Each of these primary domains is discussed below. The overall DSM integration process as it occurs through time is depicted again in Figure 7.1.

Figure 7.1. The Transactional Model of DSM

Figure 7.1. The Transactional Model of DSM

136
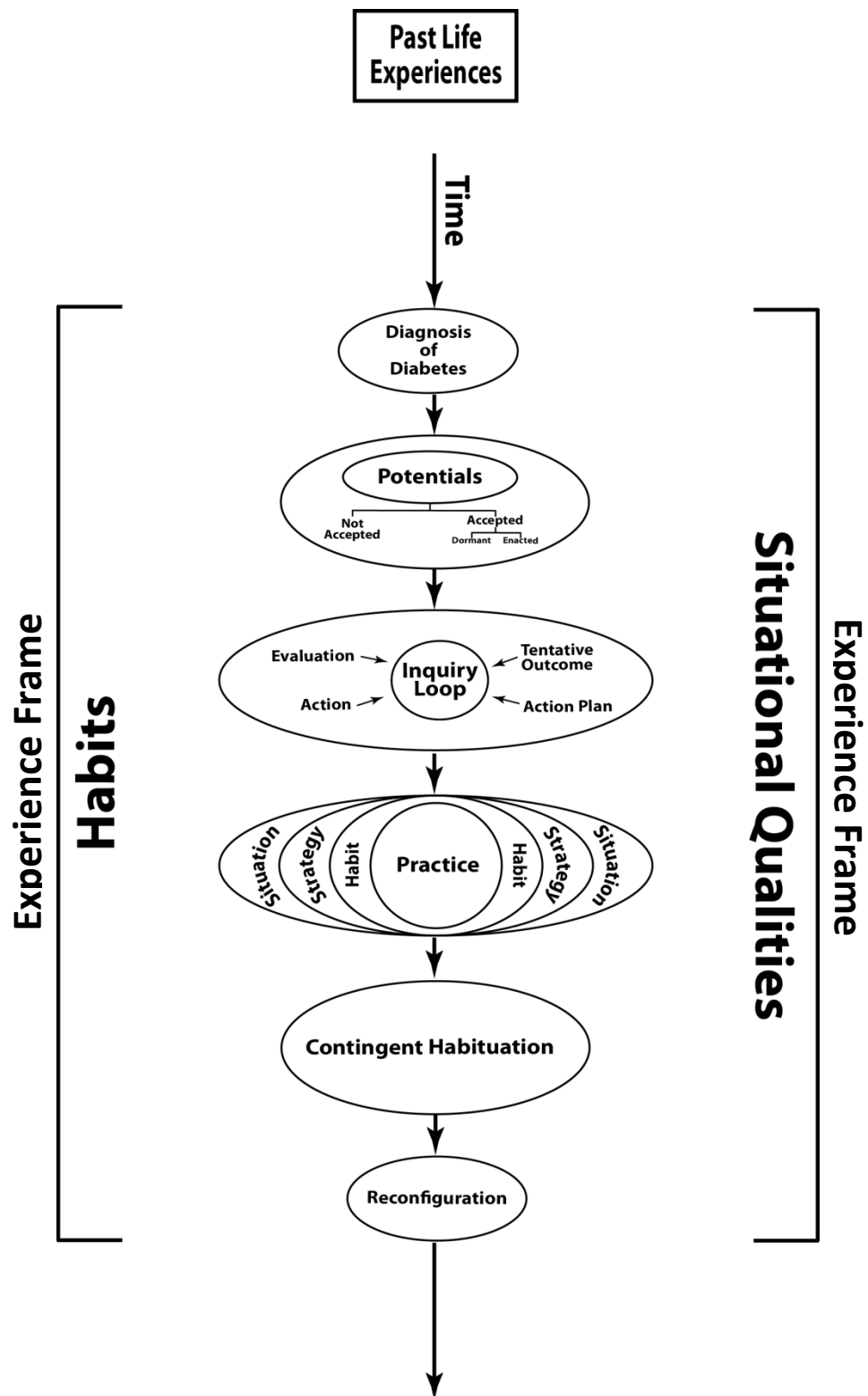
Potentials

        The information and guidance the women received after diagnosis, how they

received it, and what they did with it, was integral to understanding their DSM

integration processes. The second domain of the DSM integration model, potentials, is

depicted in Figure 7.2. I adopted the term "potentials" from the language that one

participant used to describe diabetes-related information and guidance. In the following

sections I will present the definition of potentials and describe how the women were

introduced to potentials, what influenced their uptake of potentials, and how they were

enacted in their integration processes.

Figure 7.2. Potentials
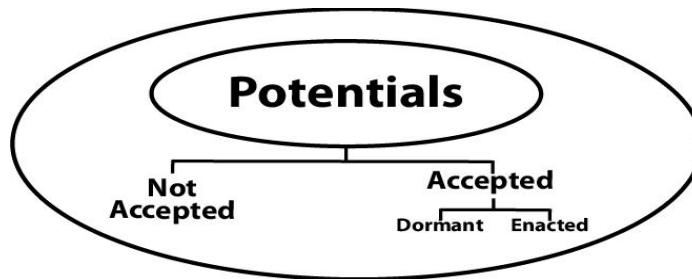
        Put simply, potentials are facts and recommendations that have relevance for

DSM and are therefore introduced into the experience frame. The delivery of a diabetes

diagnosis creates the need for action. Accordingly, the women needed to be exposed to

potentials because they did not possess a priori knowledge and skills with which to

manage a serious chronic condition such as T2DM. Many of the women did have basic

knowledge, skills, and abilities that they applied to DSM integration; however, these

customarily relied-upon ideas were often insufficient for the new needs, desires, and

goals of their DSM integration. Essentially, potentials served as the raw materials that the

137

women used to bring their pre-existing knowledge and skills into more effective

knowledge and skills needed for DSM.

The women provided numerous examples of potentials in many forms, including

formal medical information and advice, examples, ideas, suggestions, tools, strategies,

and inspiration. Table 7.1. illustrates some of these potentials.

Table 7.1. *Potentials*

Potential	Description
Example	Alyssa followed the example of a friend and took a small cooler with her when she traveled to keep her insulin accessible and at the proper temperature.
Suggestion	Aleisha ripped a diabetes-friendly recipe out of a magazine that she saw in her doctor's waiting room.
Tools	Glenda was given a portion plate during one of her diabetes classes to help her change portion size.
Inspiration	Yolanda took a photograph of people walking at an amusement park and reported that this had given her the idea to start walking for exercise.

The women acknowledged that potentials are introduced into the experience

frame in a variety of ways and that this happens throughout the integration experience.

They often stated that even if they considered themselves seasoned self-managers they

were open to new potentials. As Cindy put it: "Well I think I pretty much have a handle

on this [DSM integration] but you know, you can always learn something new and hey,

maybe it will be a better way of doing something you were already doing."

Exposure to potentials. How potentials were introduced to the women also

influenced whether or not the potential would be integrated. The women were exposed to

potentials most frequently through credible authorities and institutions, or through the

context of their social living conditions. Their narratives demonstrated the different circumstances under which they were exposed to potentials.

   Institutions. The women in the study reported that institutions varied in terms of how much and what type of information and assistance they offered to clients. The women who had been diagnosed with diabetes the longest reported the least satisfying exposures to diabetes information and support. As Glenda, who was initially diagnosed by her gynecologist almost 20 years ago, noted:

> I really didn't get what I needed back then; I mean he was a gynecologist… The only thing I remember is them touching on how to take my medicines but that's it, not the exercise and the food stuff like they do these days.

All of the participants who had lived with diabetes longer than 10 years echoed Glenda's statements, which reflect an unfortunate reality: standards of care cannot be updated unless medical science develops a greater understanding of a problem. Even so, the women's stories revealed that those who had been diagnosed with diabetes long ago were inconsistently updated or coached on new recommendations. Depending on their access to high-quality medical care providers, however, many of the women with recent diagnoses had also failed to receive appropriate coaching and information.

   Credible authorities. Many of the women had received potentials from healthcare providers. They expressed that when they perceived their healthcare providers as both knowledgeable and caring, they not only placed a higher value on the information these individuals gave them but also felt that the providers had already considered congruency with their lifestyles. The women all shared stories of poor patient/provider relationships they had had in the past. Currently, they were all receiving their diabetes care at a nonprofit clinic and felt that the providers there were "a cut above the rest." As Glenda

139

said: "She [her provider] knows my situation so she knows what I can do." Many of the women discussed how often they were able to talk about their life situations during their clinic visits. Because their providers made time to check in with these patients on a personal level, the participants believed the providers would not make recommendations that they were incapable of implementing given their situations. This trust privileged the potentials introduced by these healthcare providers as congruent with participants life circumstances.

The women's narratives also implied an unspoken hierarchy of patient education in terms of the order and type of potentials that supportive care providers, as well as their doctors, discussed. Almost unanimously, they said that their care providers focused the most on medication management, followed by diet, and, as Aleisha stated emphatically: *"Finally in the end they get on you about the exercise, especially if you're fat."*

Social exposure. The women related that they were often exposed to potentials through interactions within their circles of family, friends, church members, and other clients at the clinic. These stories revealed how ideas are socially transmitted as individuals try out DSM suggestions, evaluate the outcomes, and then pass them on to others. The women reported that the social vetting of potentials was important because others knew them and would have some idea about whether a suggestion would be congruent with their lifestyles.

Diane's example illustrates how her brother's experience resulted in her exposure to a new preparation method for healthy meals that involved one cooking pot and little oil. Diane described how her brother's experience evolved into a potential that she acted upon and eventually integrated into her daily life.

140

Well he tried it first, I mean he's actually been doing it for a while and he told me one day, "You need to try this," so he came over and showed me how to make the whole meal in one pan, and I thought well that makes sense you know, and hey I liked the way it tasted and so did my husband, and so you know I tried it again, and then I used it with pork, and then I tried some chicken and you know even like a meatloaf could work that way with the vegetable and all. So I still use that trick he showed me.

Diane adopted this particular technique because it was convenient, healthy, time-saving, and could be used for a variety of meals that her family enjoyed. In this example, the genesis of her integrated DSM component was her brother's experience and her social living conditions enabled the sharing of that experience. Diane's story was one of many in which one person's experiences were shared and thus became ideas to be embraced by another person. Cindy said that the most usable suggestions she acted on came from older diabetic women in her community. These women, who had engaged in so many potentials that they were able to refine the processes and outcomes, provided Cindy with recommendations that were already complete and congruent with her daily life.

The women reported that social sharing of potentials was important because doing so increased the types and varieties of ideas and suggestions to which they were exposed. Some reported that their busy lives did not afford them many opportunities to be exposed to new potentials.

Felinda: Well you pretty much get into a routine, and you do the same thing, and you keep busy, and you know there are new things out there but if you don't come across them in your daily goings you just miss them.

Felinda's comments illustrated that even in the age of computers and mobile devices, the women's routines could both facilitate and limit their exposure to new ideas.

The women's stories also illustrated the negative impact of sharing potentials. In particular, their narratives revealed moments when they perhaps placed too much trust in

the social vetting of suggestions. Yolanda described how she was influenced by a friend to try an all- liquid fruit juice diet to "help" her diabetes. Yolanda's friend did not have diabetes, and Yolanda did not have sufficient understanding of the disease to screen this suggestion as inappropriate. Only after acting on it did Yolanda realize the danger it posed to her blood glucose control:

> Man it was so bad, I mean I though you know, fruits, yeah that's like a vegetable it's good for you, and she [the friend] lost a lot of weight that way… now I got this juicer and everything and I don't even use it now.

Although the negative effects of Yolanda's experience were brief, her story draws attention to both the positive and negative effects of sharing potentials.

Potentials: usability and congruence. Not all potentials were equal in their perceived usability for the women in the study. Whether an idea would be utilized depended on a number of factors, including its usability and how congruent it was with the women's lifestyles.

Usability. The women described the usability of a potential in terms of the completeness and congruence of its content. They provided numerous examples of potentials that varied in their usability, relevance, and completeness. One potential that they criticized for limited utility was diabetes-related educational patient handouts. DSM scholarship suggests that DSME must go beyond simple didactic education (Funnell et al., 2011; Newman, Steed, & Mulligan, 2004); yet, the women said that the diabetes educators they had encountered did little more than provide them with mass-produced fact sheets. When I asked them to provide additional detail, the women said that they felt these materials were vague as well as incomplete; they wanted examples of what to do and what not to do. As the women reflected on the potentials they had utilized, they

142

expressed that vague ones (e.g., "eat better" and "exercise more") were difficult to

implement because they did not include intermediate-level directives for the women to

follow, and their lack of experience with the activities left them ill-equipped to construct

these intermediary steps. Lori described how she had acted on the potential of walking,

but at the time of her initial diagnosis she received little guidance about how fast, how

far, or for how long she needed to walk. The vague nature of the potential left Lori to

determine on her own what the end product should look like and how to get there.

> I knew I needed to work out back then, I thought , hey, I'm walking a lot at work, so that should be fine, I didn't know what I know now. Now I know it's not enough because your body gets used to it, but then I thought that, you know, well I'm walking at my job so I'm good.

Congruence. Participants often stated that any potential must be seen as

congruent with their lifestyle to be considered for adoption. According to Aleisha: "I

mean they tell you what to do, and you nod and say yeah that's good, but you know that

if it doesn't fit with what you're doing, so you're not going to really do it." The women's

habit elements, including past associations and preferences, influenced whether they

regarded a potential as possibly fitting into their lifestyles. The women judged

recommendations as acceptable (or not) depending on how closely they fit with their

values, beliefs, time constraints, and personal situations. One of the reasons the women

gave for placing so much importance on congruence was that it took more effort, both

cognitive and behavioral, to adopt behavioral recommendations that were perceived as

outside of how they saw their lives. Alyssa's comments illustrate this point.

> Well if you ask me, I think sometimes the doctor, well not the doctor I see now, but for the most part I don't think the doctors get it, I mean it's hard to just up and change things, especially when you have kids, I mean I'm still responsible for him [her son], I am not just having to think of myself. Look, if it's out there

143

somewhere in you know, left field or whatever they saying is, I am not going to do it, it's just too much work, and the doctors just need to understand that.

The importance of congruence was most often expressed when the women discussed dietary and physical activity recommendations. Regarding an article about the health benefits of a Mediterranean diet, Felinda said:

> Sure it sounds good, but that stuff is expensive, and I don't know how to cook a lot of it, I had to look up what a caper was, so just saying' it's good for you, I mean it looked like a good recipe, but I'd have to work it a little I think.

Felinda's statement reflects the many facets of congruence. Although information about a recipe may be beneficial, the price of ingredients and their novelty as well as the need to engage in possibly unfamiliar cooking techniques make it appear labor-intensive or unrealistic to integrate into daily life. Felinda's statement also foregrounds additional reasons why some suggestions at times appeared incongruent to some of the women. All of the women discussed the relatively higher prices of healthier foods, a difference that signals more than inconvenience for individuals in the lowest income brackets. When she presented the photograph in Figure 7.3. to me, Lori said that she was more likely to act upon and continue to use ideas and suggestions that saved her time, effort, and money.

Figure 7.3. Participant Photograph: Money is Necessary

Money makes the world go around you know. First I have to buy my meds, then I see what's left and I buy what I can on that… some weeks I eat better than others, but I have to get the meds and [testing] strips first, then look at the sales and then I try to figure out what I can do.

Enacted and dormant potentials. When the participants in the study decided to accept a potential they either acted on it quickly or let it lie dormant until they felt conditions were more conducive to acting on it. The women reported quickly acting on potentials when conditions already supported their engagement or when they were perceived as easy to implement. However, the women often mentioned ideas and suggestions that they had placed "on the back burner" and added that they would engage in them when conditions were right.

Dormant potentials have been accepted but not yet enacted. This state of inaction reflects a gap between actually planning for and considering action, and actual

145

engagement in the potential. The women most frequently cited their dormant potentials through their photographs, referring to them as the "going-tos, planning-tos, and working-ons." This language denoted their acceptance of various ideas and their intentions to act when circumstances became more conducive. In this way, the women acknowledged that a dormant potential was different than having passing thoughts about an idea.

The women provided several reasons why potentials might lie dormant for a time; for example, trying out a new recommendations often required additional time, resources, and effort, even when it was already congruent with their lives. When the women were asked to explain what circumstances would be necessary for them to act on a dormant potential, the most common answers included aspects of time, weather, caregiver responsibilities, money, transportation, and amenable work schedules.

Diane's example of a dormant potential was attending zumba dance classes as a way to increase her physical activity. Diane already had been engaging in regular physical activity but wanted to incorporate the zumba classes into her repertoire for more variety. Weather, however, acted as a deterrent:

> It is just so hot right now, there is a group of ladies doing Zumba at the church, and it looks fun, but to me it's just too hot for that since there is no air conditioning there [at the church]once the weather cools off I am going to start going though.

During her last interview with me, Diane said that she had indeed signed up for the class: "It's getting cool enough now that I can handle it."

At times the women knew that circumstances would eventually change, so they decided to wait to act on an idea (e.g., Diane and the zumba class). At other times, when able to do so, the women actively negotiated and attempted to coordinate their situations

so that they could activate dormant potentials. For example, Aleisha explained that in 2011 her doctor told her that it was safe to increase physical activity and suggested water aerobics because of her medical comorbidities. Accordingly, Aleisha joined a gym but could not continue to engage in this potential because she lost her job. At the time of the study, Aleisha had recently found a new job and was able to negotiate the work schedule with her boss so that she could work fewer hours one or two days per week and use that time to exercise. In other words, Aleisha actively negotiated competing daily demands to support her engagement in exercise.

Some of the women had difficulty enacting dormant potentials. At times this was because they were not successful in negotiating competing daily demands; at other times their life circumstances changed so drastically and so frequently that it became difficult to bring potentials out of dormancy. Unlike Aleisha, whose supervisor was willing to take her needs into account, Yolanda and Deidra found little support for their attempts to change their routines. This lack of support complicated their efforts to make enough time to act on suggestions. The lives of these women, in particular, were characterized by frequent and severe destabilizing events. Yolanda and Deidra were not unwilling to accept potentials, but the ones they accepted largely remained dormant because they were unable to plan for their eventual engagement.

Inquiry Loop

Whether or not potentials were acted upon quickly, or remained dormant for a time, the act of engaging in a suggestion or idea involved a phase of inquiry. The women in the study screened potentials for congruence with their lives and made decisions about which ones to enact. When they decided to act, they engaged in a process of inquiry. The

147

process by which the women tried out and further evaluated diabetes relevant

recommendations is called the *inquiry loop*. It begins with the uptake of a potential and

consists of three stages: creation of a tentative desired outcome, constructing and

pursuing an action plan, and evaluating the results (Figure 7.4.). Potentials represent the

relevant facts and recommendations that the women could act on to manage their

diabetes. Before acting on these ideas, the women screened them for congruence and

determined if they could fit into their lives. At this point, however, the potentials were

still just facts or ideas. It was through inquiry that the women placed these facts and ideas

into their own contexts and developed a greater sense of how a specific potential could fit

into their lives.

Figure 7.4. Inquiry Loop
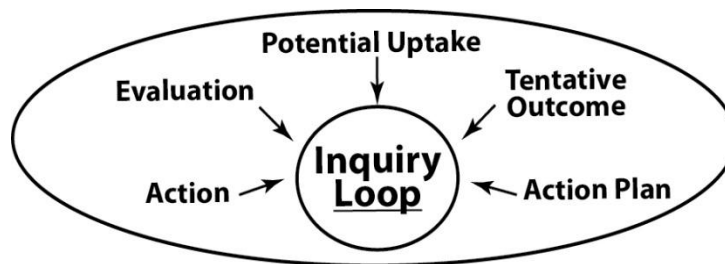
Inquiry: the influence of the experience frame. The women characterized

inquiry as a reflective process and acknowledged the novelty of their engagements.

According to Glenda: "Yeah I mean you think more about it, especially the first couple

times because it's like hey, I'm exercising [laughter]." Cindy made a similar observation:

"Well you know, it's new and fresh in the beginning, so you pay more mind to it I

guess." Despite the reflective nature of the inquiry loop, the women's stories revealed

that even their accounts of reflective thought and action were influenced by their habits.

The habits and situations that influenced how the women approached tasks in daily life

148

also influenced how they approached the inquiry loop. They were all active inquirers to some degree, but some were better at inquiry than others. At times, the women's situations and habits of thought and action interfered with their ability to determine appropriate outcomes, construct realistic action plans, and appraise their own efforts.

The women who had the most difficulty engaging in the inquiry loop were those who (a) had much less formal education, (b) were the least able to set personal boundaries, (c) had entrenched habits associated with disorganization, and (d) demonstrated less ability to reflect upon their DSM integration. For example, Lydia's DSM integration could be characterized as poor in that she continually struggled to control her BGL, exercise, and improve her diet. Lydia revealed that even after completing three different DSM educational and intervention programs she did not understand the process of DSM very well. When Lydia took up a potential, she approached it haphazardly, often curtailing the inquiry process and failing to reflect on or evaluate the outcomes.

Lydia's situation was often frustrating to her care providers as they struggled to find a way to facilitate consistency in her DSM regimen. Lydia's narrative revealed that both her daily life management and DSM were subject to the same effects of poor planning and execution of inquiry. She revealed a history of jumping from one task to another without seeing any to completion. Her home life emerged as highly disorganized as she narrated tale after tale of overdue bills, lost tax forms, and missed appointments. She also shared photographs that indicated clutter, including the presence of 11 cats. Lydia described the many potentials she had tried to enact, but when questioned about them she would most often reply, "I don't know, it just didn't work for me." Even during

follow-up questioning, Lydia appeared to have no real idea of why her attempts to act on recommendations were so unsuccessful.

> I just don't know what to do, I mean I should by now, but I don't. I go to the classes, I even sometimes write stuff down and carry it home with me… when I do try things I don't know, they just don't work, who knows.

Lydia's comments indicate that she struggled with evaluating her efforts and with understanding why they did or did not work.

Tentative outcomes. The term "tentative outcome" refers to goals that are loosely defined and open to modification. For example, the women in the study often had an end goal in mind when they acted on a potential. These goals were loosely defined in that the women would accept variations. For example, Lydia explained that she wanted to try jogging; the tentative outcome was her desire to run half a mile. As she relayed the story, Lydia noted that she did not quite run a half mile, but "it was very close." The women constructed their tentative outcomes while assessing their situational qualities, an appraisal process that included considering their existing knowledge, skills, resources, and abilities, along with habit elements and preferences. The latter two factors often applied not only to the woman engaging in the potential but to the rest of her family as well.

Felinda provided an example of how the women assessed their situational qualities when constructing tentative outcomes. She had been instructed to increase her physical activity in order to lose weight, which would in turn help to control her BGL. Felinda discussed how, through appraisal of her situational qualities, she came to own what she called the "stay-bike" (a small, stationary apparatus with one axle and two pedals that can be placed either on a floor or a table top).

150

I knew I needed to work out, but I am so busy if I was going to do it I needed it to be here [in her home]. I mean it's convenient, I can do it while I'm waiting for a load of laundry to finish, or while I'm waiting on the girls… I can move it out of the way… I can just fold it into my day. Plus, we can all do it, I mean my dad can do it and the girls, so it can be a family thing too.

Felinda assessed her situational qualities and noted that she had a busy schedule, which left little time to engage in long intervals of physical activity. Additionally, Felinda assessed that she would have to exercise at home to engage in caregiving responsibilities. Her selection of the "stay-bike" also reflected strong habits of caregiving and making all activities a family affair. Purchasing the "stay-bike" was Felinda's tentative outcome that she constructed after assessing her situational qualities. Felinda provided the photograph in Figure 7.5. to illustrate the importance of purchasing the "stay-bike."

Figure 7.5. Participant Photograph: The Stay-Bike

The action plan. When the women determined their tentative outcomes, they decided what courses of action to take in order to reach them. Similar to their construction of tentative outcomes, the women's habits and assessments of their situational qualities shaped their action plans. As they acted out their plans the women organized and compiled the tools and materials they anticipated would be needed (e.g., exercise equipment and cooking ingredients). They also negotiated time in their routines and secured the assistance of friends and family if necessary (e.g., arranging to work out with a fellow church member). The women made minor adjustments to their plans along the way as they enacted them. For example, Alyssa planned to use a salt substitute in a

new sauce recipe instead of regular salt; after tasting the sauce, she decided to reduce the amount of regular salt by half instead.

The women applied their existing knowledge, skills, and abilities to their action plans. They did not simply operate within their existing skill sets, but tried out and incorporated additional materials if they proved useful. In this way, engaging in their action plans also provided opportunities for the women to stretch their skills and try new things, which in turn contributed to their overall personal growth and development.

Alyssa an example of someone with an action plan. After losing her job in 2010, Alyssa continued to struggle with weight gain because of comorbidities. During Alyssa's involvement in the study she shared concern for her son, who also was clinically obese. Alyssa adopted an action plan to address her situational qualities because she wanted to eat healthier for the well-being of both herself and her son. One of her actions was to collect and organize coupons, which would allow her to both save money and purchase healthier food options. She also discovered a website that would produce a litany of recipes in response to the user's entry of a single ingredient. Finally, Alyssa identified that unhealthy snacks were a problem for her and made a plan to incorporate healthier snacks into her and her son's diet.

> I made me another snack. I found this recipe that you put peanut butter in… I put peanut butter in and a couple raisins. You can't put too many raisins because raisins have a lot of sugar in it. One of those little small boxes of raisins, I put a half a box of those because of the sugar. It called for a half, I think it was a half a cup or a cup of that cereal and a couple teaspoons of peanut butter and the raisins and you mix it up. Well, I ate it and it wasn't bad. Wasn't all that good either, but it's a starting point.

Alyssa's narrative represents how she utilized a potential that came from an Internet-derived recipe. The experience of creating the healthy snack took the skills that

153

Alyssa already had and extended them. In a later interview, Alyssa relayed that she was

still experimenting.

> I did some more healthy snacks. Me and my son got in there. OK. What we did, we cut the green off of the cucumber and then, well, some of them we did, not all of them. Next I sliced them into real thin pieces. Then we cut different designs you know stars and circles. Some of them we cut extra thin and then we took the long carrots sliced them thin and used them too. Then we cut them very thin and we took a piece of carrot and cucumber. That's the way we ate it like a little sandwich, but it was cute, you know without the bread. It was a new thing you know, but I liked it.

Alyssa continued to expand her snack-making skills and began to include her son in the

experience. Her example illustrates how, through inquiry, the women acted on facts (e.g.,

that healthy food is better for them) and recommendations (e.g., to eat healthy) in their

own contexts. The women evaluated experiences in terms of what they meant for them.

Alyssa's story also illustrates the meaning these experiences had for others in their

immediate social spheres. Alyssa's food preparation may lead to changing not only her

own long-term health, but that of her son as well.

Evaluation of inquiry. The evaluation phase of the inquiry loop is both the end

point of one plan of action and fodder for the next inquiry loop. When the women

evaluated the outcome of their inquiry loops, they appraised their whole experiences

rather than focusing on self-appraisal. It was not enough for the women to simply feel

that they had produced the desired outcomes; instead, they evaluated their experiences in

relation to their whole situations. The women reported asking themselves whether a

particular outcome had been worth the time involved, and even if it was, whether it

would have been feasible to spend the same amount of time on the experience on a

typical day; whether the process and outcome had been cost-effective; whether the

154

aesthetics of the outcome had been satisfactory to themselves and others; whether the resources used to achieve the outcome accessible; and whether the necessary resources could be repeatedly procured. These and additional considerations influenced the women's evaluation processes, which was key to their DSM integration. In general, outcomes that were perceived as good were acted on again. The study participant's habits, in conjunction with their situational qualities, influenced how they perceived the results of the inquiry loop. It is important to remember, however, that habits are tools and that some tools are more functional than others for the purposes of DSM integration. For example, Lydia expressed her love for Mexican food as she discussed her photo (Figure 7.6.) of peppers at the grocery store.

Figure 7.6. Participant Photograph: Peppers

Lydia stated that

> Those are green peppers, and yellow peppers, and red peppers, and stuff and avocados, because I like cooking a lot with those… like onions, jalapenos, the Mexican food, I just love the colors of the green and yellow together.

When asked about the nutritional value of certain Mexican dishes, however, Lydia discounted the fact most of her Mexican meals contained large amounts of refried beans, rice, and tortillas, which are high in carbohydrates. Lydia preferred to focus instead on the aesthetics of the colors and the fact that peppers are indeed vegetables—even if her Mexican meals contain relatively small amounts of them: "Well the beans are good, I mean they're like vegetables, and I have all the vegetables in the peppers, so it's not too bad." Lydia's statements reflect a simple truth: individuals enter into the DSM process with different habits and situational qualities along with varying degrees of knowledge, skills, and abilities, and all of these factors can affect how such individuals evaluate their efforts to practice DSM. At times what the women in the study perceived to be a good outcome was not necessarily good for their DSM. Thus the inquiry loop and the evaluative phase in particular, are fraught with possible pitfalls.

For these women, pitfalls arose from (a) the quality of their enacted potentials, (b) their ability to determine a tentative outcome, (c) their ability to construct a realistic action plan, and (d) the process they used to evaluate results. At times, the women's habits derailed their inquiry efforts. Yolanda, for example, had a tendency of creating reasonable action plans but foiling them half- way through because she was unable to tolerate the uncertainty and time associated with incremental change.

> I'm just all in, so I start out telling myself, ok, you need to just do a little at a time, but then I just go all in, and after a little while I can't keep it up and I go back to my bad habits.

156

Yolanda was referring to her many previous attempts to reduce her soda and coffee intake. She would start out with a plan to slowly and gradually reduce her intake, but would grow impatient and decide to just stop cold turkey. This approach would only work for a short time before she would start drinking soda again.

Study participants' inquiry skills varied. All of them had stories of successful inquiries that yielded outcomes they perceived as good and beneficial to their DSM integration efforts. Essentially, completion of an inquiry loop supplied them with a rough draft that could possibly be integrated into their daily lives over the long term. However, successful completion of an inquiry loop did not mean that integration had occurred, but simply that a potential had been acted upon and the outcome could possibly become part of daily life. As I consider the next essential domain in the DSM integration process, I will discuss how the women took the products of their inquiries and transformed them into the stuff of everyday life.

Practice

> Glenda: Practice, practice, practice, I mean it's like anything new really, you can't change if you don't practice… I look at my own situation when my kids were young and were at home, I mean I was working for the state then, had my kids, I was working all those hours, who has the time to practice all that stuff when you're like that?

> Lori: They say practice makes perfect right? Well in my case it really has taught me a lot about myself and how what I do affects my diabetes.

The inquiry loop represents the women's initial engagement with a potential. As previously noted, such engagement is only a rough draft: the women had to repeatedly engage with potentials over time and across situations before they became integrated into their lives. In essence, the women had to practice. The practice phase of the DSM

157

integration process links the women's initial experiences of engaging with potentials to their finished, integrated products. The women often made special accommodations when acting on their potentials, many of which could not be sustained long-term unless the women changed their habits and situations to become more supportive of their engagement. The women focused on this form of practice more than any other aspect of DSM integration because such practice was a precursor to integration. By characterizing their practice as reflective, the women noted that through engaging in repeated inquiry and evaluation, they became more skilled at both. Moreover, they reported that practice made them more aware of their own behavior and that this awareness allowed them to make changes to their habits and situations. The women also provided numerous examples of the strategies developed through practice that helped them to sustain and reduce the burden of their integration efforts. Figure 7.7. depicts the role of practice in shaping habits and situations along with developing strategies.

Figure 7.7. Practice
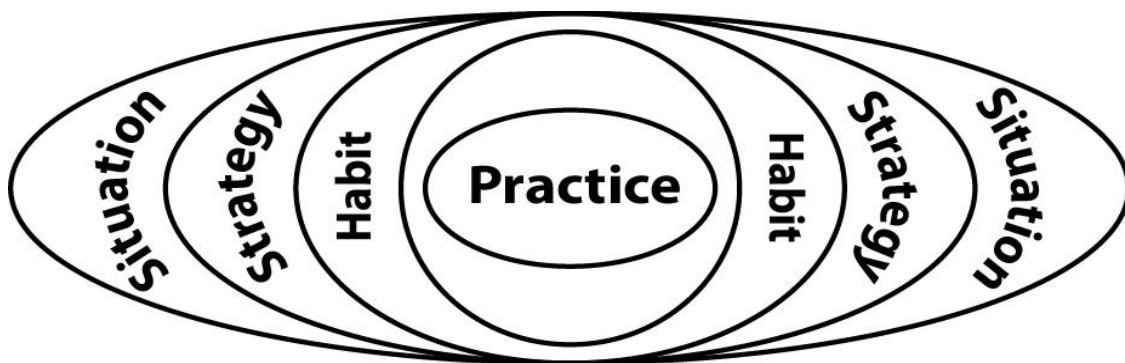
Improving inquiry skills. Some of the women reported that they had also improved certain skills as they practiced, and that this occurred because they became more adept at developing realistic action plans and evaluating their performance in

relation to their DSM. The women noted that it was not always clear exactly which changes would be necessary for them to integrate a DSM activity into their daily lives. They anticipated needing to negotiate aspects of time, transportation, childcare, mealtimes, or finances, although the exact reconfigurations of these aspects had to be determined through practice.

Glenda described how she had to refine her action plan several times while trying to integrate an exercise class into her daily schedule: "Well I thought, if I get up a little early I can get some of this other mess taken care of and I'll be able to get over there." She later added that this plan was more complicated than she had originally thought: "I mean yeah, it's free, but I'm not working and I didn't think about the gas to get over there… I found myself skipping breakfast too because of the time, which wasn't good." Glenda had difficulty constructing an appropriate action plan for participating in the class. Her comments illustrate the fact that the women had to practice reconfiguring their situations until they were able to integrate an activity.

The more frequently the women practiced, the better they became at anticipating necessary adjustments. For example, Aleisha shared that her past experiences with integrating physical activity into her schedule demonstrated that she would need to set up some form of accountability. This story reflected that she was aware of her habit of starting to exercise but then discontinuing this engagement when she felt tired, sad, or unmotivated. Anticipating this difficulty, Aleisha noted that she had established a network of people to whom she would be accountable, in order to ensure a sustained performance.

159

After a while, you get to know yourself… I mean I saw the pattern and so I thought when I started to do this [swim], OK let me go ahead and set this up ahead of time because you know how you are.

Changing habits and situations. Practice also allowed the women to see the possibilities in their situations and to change them to be more conducive to activity integration. Cindy provided an example of how, through practice, she incorporated aspects of her situation until her walking efforts were optimally supported.

So I got the idea, OK they say you're supposed to walk like 20 or 30 minutes or whatever a day, so yeah I started walking around the neighborhood because I always take the baby on a walk in the morning when it's cool anyway... Well after doing that for a while and feeling pretty good about it, then I said well I can do that hill, I mean it's a pretty big hill and that should really give me a good workout. So then I started with that hill… Well then I thought well I always check in on my girlfriend down the road so I got her to walk some with me some too, and that way I sort of stay with it, even when I don't feel like it. I know I need to take the baby out, and I need to check in on my girlfriend, so that gets me walking, the only exception to that is when it's raining.

Cindy's narrative illustrates how she accepted the recommended guidelines and tried to walk for 30 minutes daily. After Cindy became comfortable with this engagement she added the hill to her experience and finally incorporated a visit to a nearby girlfriend. By modifying her daily walk to incorporate the baby, the hill, and her girlfriend, over time she modified both her habits and situational qualities. She incorporated her situational qualities by extending the normal territory she would walk and incorporating a social visit. Cindy changed her habits as she began to place more value on exercise and prioritize it as an essential part of her day.

Similarly, Lori shared how she had transformed her pantry over the years by continuing to act on and practice with new potentials. Lori described her old food-related habits.

It has changed so much, I mean it [the pantry] is totally different, no sugar, no instant biscuit mix, not all that butter… now it's olive oil, salt substitutes, I use that artificial sweetener, and it's just been a good change.

By acting on new potentials and practicing with them, Lori incrementally changed her situation and habits of food preparation to be more supportive of her DSM.

Developing strategies. As they shared stories and photographs that represented the many strategies they had developed through practice, the women described strategies that included "helpers," "the glue that makes sure I stick to this," and things and people that "keep me on track." The women developed strategies that reflected their habits and situations to ensure they could consistently achieve their outcomes even in the face of mildly shifting circumstances. The more practice the women had, the more they developed numerous and varied strategies. The women reported that although they acquired some of their strategies from other individuals (e.g., family, friends, and healthcare providers), they had derived the majority through practice. They provided examples of strategies for specific tasks as well as strategies for daily life that also had repercussions for integration.

Alyssa spoke about strategies she described as more activity-specific. Alyssa was exposed to a potential in 2011, while in a hospital cardiac unit where she was served a heart- healthy diet; one of her entrees was a baked pork chop. Alyssa spoke with the dietary staff to obtain a better understanding of how to make this kind of pork chop. Once home, she practiced the method repeatedly and refined it to the point that she was able to use the same method with other proteins. Alyssa explained that she combined several strategies to ensure a consistent outcome.

Ok, so first I said OK, well I don't need to use butter so I substitute with olive oil, and if I don't have that I use just a touch of that Pam cooking spray, see I

161

substitute, that's a strategy I use a lot. I don't fry it neither, what I do is I bread it, but then I also started using the wheat breadcrumbs and then I bake it… and see, to get my family to eat the vegetables I layer them underneath so that they taste like the pork, so they taste better. […] I also cook ahead, that's another strategy I do, I just do a whole big thing of it and then portion it out into servings so it's quick and easy during the week. The last thing I do, another strategy I use is, I use these, my kids have you know those kids' plates with like Dora the Explorer or Spiderman and all that, well they're small, so what I do is I eat off of that plate, so that's a strategy I use to make sure I watch my portion size.

Alyssa went on to explain that she had started looking for coupons so that she could afford healthier options, and also going to the farmer's market to save money on fresh vegetables. Alyssa presented the photograph in Figure 7.8. as a way to illustrate the many strategies that facilitated her consistent completion of a breaded, non-fried, pork chop with butter beans (cooked with olive oil) that she had bought in bulk from the farmer's market. Alyssa further explained that she had photographed her laptop because she used it to look for coupons associated with this dish.

Figure 7.8. Participant Photograph: Pork chops and Strategies
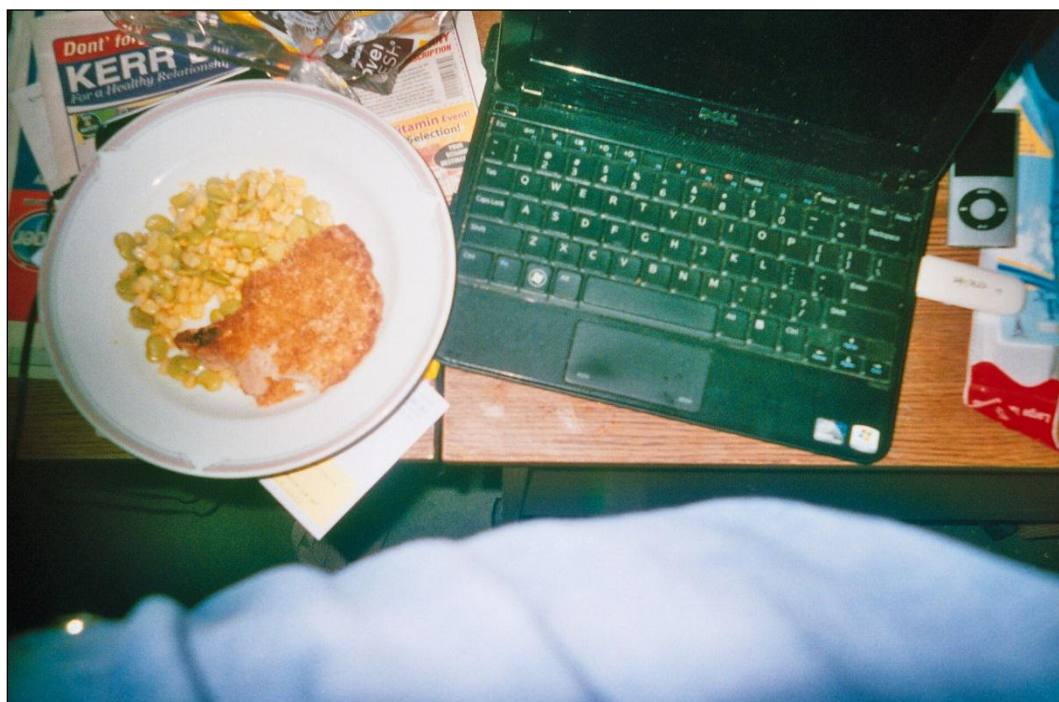
Alyssa associated all of the above-mentioned strategies with her desire to consistently plan, prepare, and consume a healthier diet. Other women in the group discussed how they often combined several different strategies, depending on the desired outcomes.

Felinda's case illustrated more general life-level strategies that could impact integration efforts, in particular how different strategies are used in response to different circumstances. Felinda lived with her elderly parents in her childhood home for many years, initially to care for her ailing mother (who had died only months before Felinda enrolled in the study); she is now the primary caretaker for her father and three grandchildren. She does not own a vehicle and lives on limited income, although her sister lives across town and occasionally offers assistance with caring for their father. Felinda uses a variety of strategies to manage her daily life while still making space to engage in DSM integration and to maintain as much stability as possible.

For example, although Felinda prefers to cook at home to ensure healthier meals, she feels it is more important to provide her grandchildren and father regularly scheduled meals as they cannot do so for themselves. However, to meet her goal of providing regularly scheduled meals, Felinda often utilizes a coordinative strategy in the form of substitution (i.e., obtaining fast food meals and serving them at home). She uses this strategy because of a situational quality (i.e., having to use a public bus service for transportation, which can extend a few simple errands over several hours). In order to maintain the stability of the family eating together at home at the usual time, on occasion she opts to substitute fast food for a home-cooked meal. With this strategy, she recovers the time she must spend running errands by bus.

It is important to note that as situational qualities change, so do strategies. At times Felinda uses delegation (i.e., assigning responsibilities to another), for example having her sister take care of her grandchildren so that she can attend a doctor's appointment, or having her son buy groceries once a month so that he shares the cost of caring for the grandchildren. Additionally, because of having to rely on the local transit system, Felinda often utilizes a strategy where she grouped activities that were in close geographical proximity, to facilitate efficient and timely running of errands, whether or not she is using the bus or being transported by a friend.

Task-level and life-level strategies both facilitated consistent engagement in activities and reflected the women's habits and situations. The women's strategies also had consequences, however, despite their utility. For example, Felinda had very strong habits of caregiving, placing others before self, and valuing hard work and self-sacrifice; her situation, which entailed caring for four other people besides herself, supported the function of these habits. Therefore, the strategy of turning to fast food to ensure that she could put her family's dinner on the table on time was acceptable, even if it was harmful to her blood glucose maintenance.

Lydia, also discussed two strategies (different from Felinda's) that she used to manage daily life. Lydia associated life management with maintaining her much-valued sense of calm. Lydia used a strategy of avoidance (i.e., disengaging from unpleasant tasks) to reduce the stress associated with daily life chores, such as cleaning and cooking. When Lydia experienced stress, she engaged in over consumption (e.g., food, experiences, and social events) which helped her restore her sense of contentment. Although Lydia avoided her daily responsibilities, she was able to maintain her

164

household because her adult daughter would inevitably perform them out of frustration. Although Lydia's avoidance and consumption could function unchallenged in her daily life context, she also applied the same strategies to her DSM, which resulted in adverse consequences for her blood glucose control.

When I asked the women about their strategies, most of them failed to acknowledge inadvertent negative consequences. Felinda's response was: "Well, I do what I need to do… I don't eat that way all the time… now I use the guide too, you know I get the stuff for me that's less than 400 calories or whatever." Initially she appeared bothered by being asked to acknowledge the potentially negative consequences of her strategies. Nonetheless, Felinda's response further highlighted the constant challenges the women faced in negotiating DSM within daily life, and the give and take associated with this process.

Contingent Integration

Day in and day out, the women in the study accepted potentials in various forms and acted on them to produce outcomes. They evaluated these outcomes in terms of their unique situations, to determine if they were indeed good or bad. The women had to do more than successfully act upon one potential one time for DSM integration to occur. As previously noted, they characterized DSM integration as a state in which they were able to do almost everything that they needed to do, almost all of the time. Achieving this level of consistency meant being able to repeatedly generate the same or similar outcomes across the same or similar circumstances.

An integrated DSM component can be thought of as the most congruent, refined version of a potential that people are capable of constructing given their habits,

165

situational qualities, and developed strategies. (In the study, the participants associated integrated DSM components with a seamless process of execution that required little reflective thought.) The integration phase is marked by the possibility that a desired activity will cease to be a potential and will instead become an integrated DSM component. As the women moved from the practice to the integration phases, the quality of their engagement in the integrated DSM component changed. They expressed more reflective awareness of their engagements with, and modifications of, various potentials before the potential became habituated (e.g. during inquiry and practice) Notably, the content of almost all of the women's photographs focused on potentials, strategies, or aspects of their DSM that they were currently, or had recently, been practicing. It seemed that once the women integrated a DSM component into their daily lives, they had great difficulty recalling how they specifically engaged in it. Consider Diane's comment: "I don't know, I mean now I just do it, it's automatic… I don't really think about how I do it, because I have just been doing it that way for so long, it's just like clockwork."

As the women fleshed out their stories, it became apparent that once a potential became habituated, their engagement in it was relegated to habitual thought and action. In other words, the women no longer needed to expend the increased energy reflecting on the engagement process. As they discussed their habituated DSM components, they focused more on the strategies that they might use in a given situation because reflecting on this aspect of engagement was difficult. Just as the women found it difficult to explain why or how they engaged in some of their bad habits, they also found it difficult to discuss their positive, habituated activities.

166

The DSM integration model contains references to possible pitfalls on the path to integration. Integration, as a neutral state, signifies only that some potential has been refined enough to be considered a developed habits, incorporated into daily life; it makes no claims about the effectiveness of a given potential within DSM integration (i.e., inhibitory and facilitative potentials can be integrated through the same process). In addition, integration is always contingent. For example, the women often needed to reconfigure their DSM integration when they experienced destabilizing life events. This process involved more than simply waiting for the proverbial storm to pass; instead, significant events often changed situational qualities that rendered existing DSM integration ineffective and thereby necessitated a process of reconfiguration.

Reconfiguration

The women's narratives revealed that change was the only constant in their DSM integration journeys. Whether the changes took the form of minor daily disturbances (e.g., waking up late, catching a cold) or major life events (e.g., death of a loved one, acute illness), the women adjusted their self-management in response. The strategies that the women developed served to circumvent minor fluctuations in their daily lives, but major destabilizing life events often caused so much disruption that they had to find new ways to integrate previously habituated DSM components that were previously habits. The women characterized destabilizing life events as episodes that changed their circumstances so drastically that their usual ways of engaging in DSM were no longer functional. These events necessitated a process of reconfiguration, in which the women sought to successfully re-coordinate with their new situations in a way that promoted DSM integration. The magnitude of these reconfigurations depended on the degree of

167

mismatch between the women's prior ways of engaging in DSM and their new circumstances. The more frequent and severe the disruptions, the less likely the women were to be able to progress with integration, and the more likely they were to have to engage in reconfiguration. As Aleisha stated, when discussing her own experience with destabilizing life events, "you basically have to start over." The women's stories revealed variations in what they saw as destabilizing life events and in how they addressed reconfiguration.

Minor fluctuations or destabilizing events. The women's stories illustrated that the life events they perceived as destabilizing depended on their current circumstances and prior experiences. What was considered unbearable by one woman was merely an occasional annoyance to another. For example, Felinda was awarded custody of her third grandchild while participating in the study. Because this grandchild was close in age to the other two grandchildren who also lived with her the majority of the time, she did not consider accepting him into the home to be a major life transition.

> I've got six grandkids, I mean goddaughters, and one son so I'm just used
> to messing with all of them. I've always had somebody's child with me
> until I had my own. I didn't have my own until I was 35. My son is 28 and
> so, I'm just saying I have always had somebody's child with me at some
> point it's just the way I grew up around here.

Felinda's narrative revealed strong habits of caregiving that had been influenced by the neighborhood she grew up in as well as her moral upbringing in a close-knit, family-oriented church. Therefore, caring for another child was not a significant disruption for her. By contrast, her change in in employment status had a more significant impact. Felinda became unemployed in 2009, after working her whole life; her attempts to cobble together part-time jobs to make ends meet caused her a great deal of stress.

168

Felinda saw this life transition as the reason she was unable to manage her pre-diabetic

condition, which then "got pushed over" into diabetes.

> Not having a job and not knowing where to go for help when I did lose my job, I think that was really hard, that was really hard, that's what pushed me over. I mean, I was so active and organized when I was working, that's how, I mean that's how I managed. I was working and active and stuff.

When the option of early retirement became available, Felinda decided to pursue it in

order to provide some income stability and regular care for her elderly parents. Her

comments indicate that the emotional and psychological consequences of being

unemployed had a more drastic effect on her DSM management than accepting another

child into her home: "I mean not only do you lose your income, but your sense of

stability, and what you be doing during the day, you just have figure all that out again."

Lydia, by contrast, found caretaking to be a significantly disruptive life event.

During her second interview Lydia shared that her mother, who had just come home from

a rehabilitation center, expected her to assist with meals and some self-care. Lydia found

these demands exasperating: "I am completely wore out, I mean she just expects me to

run and run, I even forgot to take my insulin this morning [and that's the one thing that I

never forget!]. I don't think I can do this." Lydia and Felinda's comments illustrate that it

is difficult to predict exactly which life events will be seen as destabilizing, or which

aspects of DSM they will affect most.

The women's stories also revealed that destabilizing events do not necessarily

affect all integrated components equally; depending on the circumstances, they

prioritized reconfiguring some activities over others. In addition, reconfiguration may be

more successful for one activity than another. Yolanda, for example, was able to

reconfigure her dietary regimen yet did not maintain her exercise regimen. She explained

that she took the picture in Figure 7.9. because it represented that she had been exercising and walking regularly before going back to school, but had had to let go of this aspect of her DSM integration.

Figure 7.9. Participant Photograph: People Walking

When asked to elaborate about this change in her exercise routine, Yolanda answered:

> You know I thought well, when I'm done with this class in December then I'll get back on that, then I thought well if I wait that long it will be even harder to do it, so then I thought OK I'll walk, I'll just do that, but then I realized I just can't right now, no time, no time… but I will get to it in December.

Destabilizing events affected DSM components differently. These events could also change what potentials were now seen as congruent with the women's new life situations. For example, during her study involvement, Alyssa experienced a dramatic worsening of another chronic condition. As Alyssa became more limited by her illness, most of her previously integrated components needed to be reconfigured. In addition, her

170

intense fatigue, weakness, weight gain, and breathing problems made fewer and fewer

potentials seem congruent with her situation. As a result, she struggled to incorporate

new potentials.

> I mean I try, I do try, but I'm so tired, some days I spend 16 hours in the bed,
> yesterday I got a bath and then laid back down till 10 a.m. before I could get back
> up and just get dressed, how am I supposed to exercise when I can't breathe, how
> am I supposed to eat stuff when I can't hardly stand long enough to cook it some
> days?

Fortunately, by our last meeting Alyssa's condition had begun to improve and she

reported being able to go on a short walk. Still, her story reveals the frustration that

individuals feel when what they did previously no longer works, while at the same time

they struggle to find new ways to engage in DSM.

Understanding the effect of destabilizing events on DSM integration is essential

for helping people to integrate DSM into daily life. The women's stories indicate that at

times, they struggled to reconfigure their DSM components because they did not perceive

the potentials they were exposed to as congruent with their new situations. At other times,

their situations were simply hostile to their reconfiguration efforts. The longer the women

struggled with reconfiguration, the longer they engaged in sub-par DSM integration,

which in turn put them at further risk for diabetic related complications. The

reconfiguration domain of the DSM integration model is unique in that rather than

vaguely referring to the fact that individuals may need ongoing assistance with their

DSM integration efforts, it specifies that major life events create clear disruptions in

DSM integration patterns and that action must be taken to regain stability.

Chapter Summary

The processes of engaging in DSM and integrating it into daily life are lifelong and require the coordination of many factors. The model of DSM integration depicts how these low- income women with T2DM achieved their varying levels of DSM integration. The model illustrates that DSM integration can take a substantial amount of time and that significant life events can further complicate the process. It further illustrates how the women were exposed to potentials that could be transformed into integrated DSM components via inquiry and practice. Through these processes, the women refined their engagements while developing strategies and modifying their habits and situational qualities. They were able to produce outcomes from their engagements that were congruent with and could be integrated into their daily lives. However, their integration was contingent and vulnerable to the possibility of reconfiguration. For these reasons, the model of DSM integration can be thought of as relational and dynamic in that, over time, each component is influenced by and capable of influencing others.

Chapter Eight: Discussion

It is a logistical necessity that research projects have an ending, but concluding research never means that we have achieved the fullest possible understanding. In this study, I sought to better understand how women with T2DM integrate DSM into daily life. I did not begin the research as an expert in diabetes or in life integration. I had clinical experience as an occupational therapist with individuals trying to manage their diabetes, but that experience was insufficient for the task ahead. I began the project having done due diligence by reviewing the literature and talking with other scholars who had more experience with the subject. In the end, however, my relative ignorance about the challenges of DSM was at least as valuable as my knowledge. If the reader finds value in the study, much of that value is due to the 10 women who explained their DSM integration to me. Like them, I took up a potentiality that involved engaging in a process of inquiry, keeping a tentative outcome in mind, coming up with a plan, acting on that plan, evaluating the outcome, and drawing inferences about the subject matter. In the grand scheme of things or, more concisely, in the trajectory of an academic career, this study is the beginning of my inquiry loop. It is the sketching of a template for further research and practice.

The purpose of this research was to understand the process by which low-income women with T2DM integrate DSM into their daily lives and the conditions through which this integration occurs. I also intended to explore the roles of habit and occupation in the process. In the second and third chapters, I drew attention to limitations of DSM

interventions, in particular their ability to produce consistent, sustained engagement in DSM. I argued that the way DSM is conceptualized and theorized has contributed to those limitations. I also suggested alternative approaches for further development of the scholarship and overcoming these limitations. Those arguments provided the basis for the methods and analysis presented in the fourth through the seventh chapters. The purpose of this chapter is to discuss the relevance and implications of the study for the field of occupational science and for scholars in other fields who are interested in DSM integration.

Conditions of Integration

Through the grounded theory process, I developed a transactional model of DSM integration that depicts integration as a continuous process that begins at diagnosis and lasts through the lifespan. The experiences presented in chapter five reflect the women's current level of integration, along with illustrating how their life experiences, habits, and situations influenced their approach to DSM. The women's narratives provide insights into how their approach to DSM was further developed and refined over time, as they were exposed to new potentials, and had repeated experiences with inquiry and practice. These experiences indicate that the development of self-management abilities is a serial affair as experiences build upon each other. Integration is emergent and contingent because new experiences can always add to, and improve upon, existing integrated regimens, which are inevitably vulnerable to changes in life situations. DSM integration is also a very time-consuming and difficult process because it entails changing individuals' habits as well as their situations to become more supportive of future efforts. The findings from this study illuminate the difficulties of making necessary changes, particularly why becoming an effective self-manager takes so much time. The findings

also suggest avenues for better assisting individuals on their journeys as self-managers (e.g., improving the congruence of potentials, and facilitating individuals' inquiry and practice with them), thereby reducing the time and burden associated with developing self-managing abilities.

Temporal dimensions. DSM integration involves being able to perform health-promoting activities in the face of constantly shifting circumstances. Integration requires time and stability, not only for the actual engagement in DSM activities but also for preparation to engage. The women's stories illustrate that, along with the actual engagement in DSM activities, people also need ample time to think about, plan, prepare, and practice DSM activities. This dimension of time use, which remains underexplored in the DSM scholarship, has important implications for becoming a self-manager.

Some diabetes-related activities, such as exercise, are associated with guidelines that suggest a range of time in which to engage in them. For example, people with diabetes are encouraged to exercise 150 minutes per week (ADA, 2010). However, time guidelines for other activities such as healthy eating, symptom monitoring, and stress management are less clear. Even medication management can be more or less time-consuming, depending on how many medications one must take. The primary points are that temporal guidelines are incomplete and that the actual time needed for various components of DSM are both variable and interrelated.

The findings from this study also demonstrate that the time needed to plan and prepare for activities is just as important as the time one spends actually engaging in them. For example, in discussing how they developed their healthy eating skills, participants talked about the time they spent reading labels, looking for recipes, and trying out new cooking techniques. The model depicts the influence of time throughout

175

the integration process because the women consistently cited the influence of time as a phenomenon that both assisted and impeded their integration efforts. Furthermore, the women's stories illustrate that having the time to plan and prepare for DSM is especially important in the beginning of the integration trajectory. Perhaps they found this to be so because they had few DSM experiences to draw from in the beginning. At first, they needed to develop a foundation of experience that would then serve as a framework for future experiences. Then, as they gained more experience, they needed less time to prepare and think about DSM. Not only did participants need time in the beginning of their trajectories, in particular they needed open time (i.e., relatively unstructured time for inquiry and practice), which was particularly important in the early stages of integration and during reconfiguration. Open time was necessary for growth of self-management abilities because it was more conducive to practice and learning than other time use.

Stability and life situations. The findings also draw attention to how certain life situations further compound DSM. Particular aspects of the women's life situations could increase the time needed to engage in DSM activities; for example, these women had low incomes and were financially insecure. Therefore they had few resources to purchase healthy foods, which are often more expensive than foods that are laden with the fats, sugars, and carbohydrates that diabetics must restrict or avoid. In order to engage in healthy eating, poorer participants spent additional time looking for coupons and scanning grocery store sales flyers for bargains. Moreover, nearly all of the women engaged in responsibilities associated with gender roles (e.g., cooking, or caregiving). These activities often restricted the time, finances, and energy available to them for focusing on their DSM. Similarly, women who lived in unsafe or remote neighborhoods spent additional time planning where, when, and how to exercise.

Finally, DSM requires individuals to develop a regimen that fits into their lives and sustains it long-term. Developing the endurance needed to engage in DSM on a daily basis is challenging enough; sustaining it in the face of shifting circumstances is even more difficult. The findings suggest that instability affected these women's attempts to engage in DSM because significant changes in circumstances (i.e., intermittent instability) made it difficult for them to both develop and maintain their emergent DSM regimens. The model therefore depicts integration as contingent and includes the need for ongoing reconfiguration in the face of events that necessitate changes in DSM; it also supports the hypothesis that greater instability causes greater challenges. The more frequently participants needed to reconfigure their lives, the less ability they had to develop and learn the skills that are necessary to sustain DSM.

Integration conditions in context. DSM scholarship seldom addresses the temporal dimensions of DSM, or how life situations change self-management efforts. Those that do acknowledge time note how much time is needed for DSM activities (Shubrook & Schwartz, 2006), or how much time is associated with producing DSM outcomes (Norris, Lau, Smith, Schmid, & Engelgau, 2002). Scholars in occupational science, however, have previously discussed different types and arrangements of time and their effect on occupational engagement and health (Jonnson, 2008; Matsuka & Christiansen, 2008). Occupational scientists have subsequently developed a body of work dedicated to the many roles of time in human occupational engagement. Conceptions of time in occupational science have included occupations as ways to fill and organize time (Wilcock, 2006) and the optimum balance of time use (Reed & Sanderson, 1999). Scholars have also argued that there are different types of time for different types of activities (e.g., leisure vs. work; Christiansen & Baum, 1997). This study supports

existing occupational science scholarship on time while contributing to a new understanding of temporality in DSM.

The findings from this study are innovative in that they draw attention to DSM as a temporally contiguous process whereby past experiences become an essential framework for present and future actions. The findings also uncovered two different types of time within participants' routines (i.e., open and closed time), each of which influenced DSM in different ways. Furthermore, the women's experiences explicate why they needed different types of time at different points in their DSM trajectories, and how life situations affected their time. For low-income women, their socio-economic status (SES) further complicated their DSM efforts and made them more vulnerable to destabilizing life events. Health sciences scholarship acknowledges a host of SES-related barriers to self-management and also demonstrates that women are particularly at risk to being affected by low SES status (www.APA.org; McCollum, Hansen, Lu, & Sullivan, 2005). Moreover, scholars in occupational science have explored some of the consequences of disruptive effects of destabilizing live events on daily occupations (Crepeau, 2007; Koome, Hocking, & Sutton, 2012; Molyneaux-Smith, Townsend, & Guernsey, 2003). But scholars have rarely, if ever, discussed the effects of these types of events on health behavior management, or how individuals reconfigure their management approaches after such disruptive events.

More specific to the issue at hand, this study sheds light on why conditions associated with low SES, such as less formal education and low-paying jobs, impair integration efforts. Most evident was the fact that participants' low SES status perpetuated resource restrictions (e.g., time, money, energy). Although the women in this study developed and utilized a multitude of strategies to manage their lives in the face of

these limitations, unfortunately those strategies often conflicted with their integration efforts. For example, low wages often prompted participants to work longer hours to secure more financial resources. The extra time spent at work reduced their time to engage in DSM. In addition to their long work hours, many of the women experienced fatigue and stress associated with also caring for spouses, children, or grandchildren, once off work. Long work hours, multiple competing daily demands, and numerous role related responsibilities often led participants to rely on time- and labor-saving strategies. For example, in response to these demands, some of the women consumed (quicker and easier) fast food instead of home-cooked meals, or they skipped exercise because they needed to sleep. DSM scholarship has increased our understanding of barriers to DSM, but this study's findings extend this discourse by drawing the connection between barriers, strategies that can be developed as negotiated responses to those barriers, and the consequences of these strategies for DSM.

Integration: Changing Habits and Situations

The process of integration is complex because it involves more than the conditions that help to influence it. It is also an active dynamic that invokes habits and their modification.

The challenge of changing habits. DSM is both difficult and time-consuming because it requires individuals to change their habits, which in turn requires changing aspects of their situations. Scholars have long understood that DSM involves adopting health-promoting habits. They also have attempted to facilitate this change with only marginal long-term success. One possible reason for this limited success is the set of theories that are commonly used to frame the problem. A common example is to consider behavior change by viewing humans as fully agentic beings whose actions are

purposeful, reflective, and goal-driven (Bandura, 1998; Callagan, 2006, Cox & Taylor, 2005). Although individuals are capable of a great deal of reflective thought and action, emerging literature suggests that the majority of human thought and action is actually the product of habitual rather than deliberate or reflective processes (Lindbladh & Lyttkens, 2002; Neal, Wood, Wu, & Kurlander, 2011; Orbell & Verplanken, 2010; Wood & Neal, 2007). The failure of theories to account for the impact of habitual action on health behavior (i.e., how habits develop and function) has led to significant limitations in DSM research and scholarship. The findings from this study contribute to our understanding of how habits develop and function in DSM, and why they are so difficult to change.

Habit change is difficult and time-consuming. The cases presented in chapter five provide insights into the fact that people are generally unaware of their habits and of their influence on DSM. Participating in this research prompted some of the women to reflect upon and gain new insights into their habits, some of which had subconsciously influenced their DSM for many years. Participants' narratives demonstrated how habits developed from their past experiences, entered into their DSM trajectories, and continued unchallenged as long as situations supported their use. The women approached DSM in much the same way they had approached other life challenges, which meant that they applied the habits developed through their previous life experiences to DSM. Until problems arose, participants seldom perceived that habits from other domains of life were ineffective for DSM. The women became aware of their habits when they experienced a mismatch between habit and situation (most often in the form of a critical episode). Only then did they appear to reflect on habit changes. These findings suggest that simply educating individuals about habit change is probably not sufficient to assist in DSM.

Habit modification through inquiry. The findings also draw attention to the fact that the phenomenon referred to as "habit change" may in fact be habit modification through inquiry and practice, which is different than outright dismissal of one habit and its replacement with another. This process might also be called "habit refinement." The process of habit change can be likened to the way an ice cube changes from a solid into a liquid because of temperature change. The solid and liquid forms are both comprised of H_2O, and one habit is different from another only in form of action. Of course, modifying habits is more complicated than melting ice, yet the metaphor illustrates that the habits participants in this study developed for DSM were not completely distinct phenomena; their new habits were only modifications of previous ones.

In other words, newly developed habits of DSM were an extension of existing habits, modified to function within the corresponding changes in the life situation. For instance, when Alyssa was making her breaded pork chop with butter beans, she was not changing the foods that she customarily cooked. Instead, she was changing how she prepared these foods. Moreover, Alyssa made changes in a stepwise fashion by first addressing fat, then salt, then carbohydrates, and so forth. She practiced these changes continually by placing different facts into context (e.g., using less salt), evaluating each experience, and conceiving of how to modify her efforts the next time. Practice and inquiry are helpful concepts with which to understand people in the midst of DSM integration and how they might change their health behaviors to benefit the process.

Reflective thought and cognitive habits. The findings of this study also indicate that reflective awareness alone was insufficient to change the participants' habits. The women's experiences demonstrated that they were often unable to determine how to change their habits and situations. Their individual data demonstrated that they had

developed habits of thought (i.e., cognitive habits) as well as habits of action. These cognitive habits influenced how they engaged in reflective thought processes, including those involved in inquiry and practice. For example, Yolanda's experience (discussed in chapter 5) revealed that she approached most life tasks in an all-or-nothing style, often rushing through and under developing the necessary intermediate steps of her action plan. She carried this same approach over to her DSM. Although she reflectively considered that she needed to change her health habits, she was much less reflective about how to approach to changing her habits. Because cognitive habits influence reflection, and because habits and situations are co-constitutive, the women often failed to identify both their own habits and aspects of their situations that caused problems with their DSM. The model draws attention to the fact that because the inquiry process relies on reflective thought and is influenced by habits, it can be faulty.

Changing situations. Changing behavior also required participants to change their situations. This process was complicated because participants' habits were influenced by the habits of others and also exerted influence upon the habits of others. The insight into how social networks influence habit change adds a novel dimension to our understanding of habits, DSM, and occupation. My analysis of participants' routines revealed how their DSM efforts were distributed through time, space, and social spheres. The people and places they encountered during their daily lives influenced how easy or difficult it was to change habits and situations. In this way the women's habits were linked to their situations, which in turn were linked to larger networks, including the habits and situations of contiguous familial and social contacts. The distribution of activity, which reflected both wants (e.g., spending time with loved ones) and needs (e.g., receiving assistance from others), added further complications. Participants often spoke

about this dynamic in the context of their pursuit of healthy eating. For example, they remarked that changing their habits was difficult because they lived with, cared for, or "hung out with" others who had different dietary expectations. The circumstances of their social contact communal living supported the women's efforts at times and hindered them at others.

Integration of habits and situations in context. DSM requires individuals to adopt health-promoting habits. Habit development or change is difficult, and DSM interventions have been only marginally successful in producing long-term habit change. This study's findings are valuable because they provide examples of how these women sustained behavior change by changing their habits and situations together—dynamics that are under theorized in DSM scholarship. Researchers have suggested that health habits can be changed via addressing other psychological determinants, such as through developing decision-making skills or self-efficacy (Jeffery, 2004). Researchers have likewise used ecological theories to suggest that contextual factors are associated with behavior change (Fisher, Brownson, O'Tool, Shetty, Anwuri, & Glasgow, 2005; Naar-King, Podolski, Ellis, Frey, & Templin, 2006). The transactional model of DSM integration, however, illustrates that every aspect of integration is influenced by both habits and situational qualities; therefore, it offers scholars a more representative framework for thinking about habit change. In particular, the findings and corresponding theorization propose that DSM integration includes identifying problematic habits along with the corresponding elements of the environment, and changing them in combination. The findings illustrate the need to consider human beings not as persons or collections of actions but rather as part of a functional whole; as such they provide a new view of habit

183

change that focuses on the interconnectedness of person and situation (material and social) as a factor that may affect habit change.

With regard to integration as a core process of DSM, the findings raise questions about how we think of teaching skills (e.g., problem solving or decision making) as ways to facilitate habit change. We may be able to teach people how to make plans, set goals, and self-monitor their performance; however, DSM integration is not a purely reflective process that is separate from their usual ways of thinking and doing. Therefore, individuals may know (i.e., have been educated about) how to set goals and develop action plans, yet they may default to their usual ways of approaching and solving problems because they have not changed their cognitive habits. Through the recognition and foregrounding of habits and situational qualities, the transactional model of DSM integration prompts scholars to consider the mutual influence of these two forces on integration efforts.

Inquiry and Practice

Scholars have derived lists of skills that individuals must master in order to become effective self-managers (Ryan & Sawin, 2009), but how individuals with diabetes go about developing such skills, and how such individuals become more skilled over time, have not been clarified. Taken together, inquiry and practice represent the fundamental sub processes within the larger process through which individuals become more adept at DSM. Inquiry and practice are different than doing. During inquiry, people reflect on their situation to determine which tools are available to them. They then engage in a process of determining an outcome, acting toward the outcome, and evaluating their efforts. Inquiry and practice, therefore, require reflective thought and action. This process

184

includes considering potentials (e.g., facts, suggestions, and recommendations), understanding what they mean in one's own life, and acting on them to change habits and situations. The processes of inquiry and practice are important in that they account for the ongoing functional relationship among reflective and habitual thought and action. Inquiry and practice explain how persons with diabetes develop self-management skills. These processes are valuable because they demonstrate why individuals who must change habits and situations need to reflect on and practice DSM within their own contexts.

Placing facts into context. Inquiry and practice are particularly important in the initial stages of integration. The findings of this study demonstrate that the women who participated did not change their habits simply because they had been educated about what they could or should do. Participants were frequently exposed to potentials (i.e., recommendations) such as "eat less carbohydrates" or "exercise to reduce diabetes complications." Such facts and recommendations, however, are no more than abstract references until they acquire meaning by being acted upon in real-life situations. In other words, it was only as the women repeatedly engaged with (i.e., practiced) potentials in their contexts that they came to understand what the potentials meant for them. With that meaning in mind, participants began to generate ideas about how they could change specific contexts to accommodate sustained engagement. Thus, the model proposes that practice is the means of increasing reflective awareness and that this increased awareness can lead to changing habits and situations.

Skill development. During the inquiry phase, participants acted on potentials and evaluated whether and how the outcomes could fit into their lives. Because persons engage in repeated inquiry during practice, practice can be thought of as a form of meta-inquiry that helps individuals to improve skills (e.g., assessing situations, constructing

possible outcomes, planning) and thereby to improve their ability at future inquiry. This continuum is important because people may know they need to change their behavior, yet have relatively little idea about how to do so. Participants' stories illustrated that DSM integration required them to continually assess their situations and determine how they could be modified. Not all participants had efficient DSM integration skills, however—at least not at first. Glenda's example in Chapter Six illustrates how she initially struggled to construct an action plan for engaging in exercise; however, with repeated practice Glenda was better able to construct a plan and evaluate its effectiveness. Like many of the other women in the study, Glenda developed and refined her skills through practice. Through continual meta-inquiry, participants learned to place their potentials in context, act on them, and evaluate their outcomes. This outcome evaluation allowed them to better understand the meaning of these experiences and how to make them better. As the women accumulated more experiences, they spent less time in pure trial-and-error learning because their efforts were more directed and effective. The findings suggest that practice developed reflective awareness, skills, and abilities that allowed the women to better integrate DSM into their daily lives.

Inquiry and practice in context. Practice is important for DSM integration because it helps people develop the skills, abilities, strategies, and reflective awareness needed to grow as self-managers. With the exception of recent work in occupational science (Cutchin, 2013; Cutchin & Dickie, 2013a), the concepts of inquiry and practice (as I have used these terms) are absent from the DSM and occupational science literature. Furthermore, although scholars and researchers acknowledge that individuals require time and experience to become better self-managers, the DSM literature contains little

186

guidance. Therefore, this study offers two new concepts for theorizing DSM integration: *practice* and *inquiry*.

Occupation as Central to Integration

This study revealed that occupation is central to the DSM integration process. The following discussion focuses on the role of occupation in the DSM process and, in doing so, problematizes the relationship between occupation and health. Namely, the findings suggest that the power of occupation to affect health may come from its role in larger life processes.

Contributions to occupational science theory. The transactional perspective was introduced to the occupational science community in 2006, by Dickie, Cutchin, and Humphry. Since 2006, occupational science scholars have largely used the perspective as a meta-theory. The transactional perspective influenced my thinking about the problem of DSM integration, while also offering an alternative way, at the broadest level of theory, to consider occupation as a process central to person-situation relationships. Put another way, this perspective proposes a general ontology of occupation as the means by which individuals coordinate themselves with their worlds.

Since the introduction of the transactional perspective, scholars have used it to explore many facets of occupation (e.g., Cutchin & Dickie, 2013a; Frank, 2011; Fritz, 2012; Heatwole Shank & Cutchin, 2010). Authors of those studies indicated that they used the transactional perspective as a guiding theory because of its holistic, relational orientation. Few, if any, have generated problem-specific middle range theory from this meta-theoretical basis, however, and no studies to date have utilized the transactional perspective for understanding health behavior change processes such as those involved in DSM.

How an individual engages in self-management, and how self-management changes over time, are very complex phenomena that require theory to address their complexity. As this study's findings indicate, people's involvement in DSM can be represented as a complex coordination and re-coordination of the person-in-world relationship; in turn, this ongoing coordination is central to the transactional perspective. The findings indicate that the transactional perspective is relevant to DSM and can be applied to the study of health behavior change processes. Beyond that, the theorization represented by the transactional model of DSM integration stands as one of the very few examples of middle-range theory influenced by a transactional perspective viewpoint. This new, middle-range theorization of DSM opens up new avenues of inquiry even as it provides ways to think more carefully about the role of occupation in health and personal growth.

Occupation and health. There is no shortage of claims regarding the link between occupation and health, despite the fact there is little evidence to support such claims (Law, 1998; Wilcock, 2006). Scholars have provided reasons why finding more evidence of a link has been difficult. One of the most fundamental problems is that the discipline of occupational science continues to debate the definition of both occupation and health (Creek & Hughes, 2008) and has therefore not been able to pin down the concepts for more definitive research. Nonetheless, researchers continue to produce accounts of occupation and the role it plays in people's lives.

In designing this study, I consulted occupational science and therapy research to assess how scholars had understood the role of occupation in DSM. Some had focused on occupational therapy interventions aimed at ameliorating diabetic complications such as vision loss (Sokol-McKay, 2010), whereas others had investigated the needs of

188

individuals with diabetes and their quality of life (Jengliang, Truax, Claire, & Caytap, 2009; Schukar Cordova, Poole, Sibbitt, & Skipper, 2010). Other descriptions of multidisciplinary outpatient diabetes education programs have been produced, along with studies that have demonstrated the impact of individuals' daily occupational choices on DSM (Pyatak, 2011; Raztan, Futeran, & Isakov, 2010). These studies, which have provided a foundation for occupational scientists and therapists to think about diabetes and DSM, show that DSM is viewed typically as either a clinical problem that requires remediation through therapy, or as a separate phenomenon that affects other realms of occupational engagement. While investigating whether DSM affects other occupations, scholars have overlooked the role of occupation in DSM.

My research participants' accounts provided insight into DSM integration as an occupational process and also suggested specific qualities of their engagements that led to the growth and development of their DSM skills. The role of occupation in the integration process was multifactorial. The primary factor includes engaging in occupation-generated potentials that are often socially transmitted, usually during social occupational engagement. For these women, the inquiry loop and practice phases of integration were synonymous with occupational engagement; as such, they served as vehicles for growth and development that ultimately helped the women become more skilled self-managers. These insights indicate that the link between occupation and health is indeed important, but that the nature of that link may be indirect.

More specifically, participants' experiences reveal that occupation impacts health via its functional role in larger complex life processes. Inquiry and practice are processes situated within occupational engagement. Through inquiry and practice, while engaged in occupations, people develop skills that help them negotiate and coordinate with their

worlds. More numerous and varied occupational engagements lead to more diverse and robust skills. In the case of diabetes, individuals must engage in DSM to remain healthy. DSM, however, takes place as part of larger life processes. These processes are inextricably linked: people cannot engage in DSM without addressing the daily life circumstances through which it takes place. Instead, people use the skills they develop during occupational engagement to bring the two components (DSM and life) together as an integrated whole that supports their DSM integration. Therefore, occupation leads to health because it serves as the vehicle by which individuals practice, inquire, and ultimately experience growth.

Occupation in context. Occupational scientists believe that engaging in occupation is a powerful force for shaping human lives, especially in regard to health and well-being (Reilly, 1962, in Dunn & Hocking, 2001). Since the early 2000s, occupational scientists have cited John Dewey's work and the transactional perspective as a theoretical basis for this claim. For example, growth is theorized to be the result of repeated occupational engagement through time (Aldrich & Cutchin, 2013). With this study, I have gathered empirical support for the theorization of growth by providing more precise detail about how occupational engagement can contribute to growth. Growth, in and of itself, is value- neutral. Growth in relation to DSM, however, was labeled by the women as positive or negative based on the value they placed on particular outcomes. Moreover, not all types of occupational engagement resulted in growth in the positive sense; some participants grew and developed skills that were not useful for DSM. Nonetheless, the study findings suggest that facilitating reflective occupational engagement may be a powerful tool for influencing DSM, and that coaching may be one way to facilitate reflective occupational engagement.

Study participants used the term "coach" to represent their desire for longer-term contact and support throughout their DSM integration trajectory. Ideally, coaching would involve more than simply explaining how to perform DSM activities; instead, it would involve facilitating clients' optimum engagement in DSM while also facilitating their thinking about this engagement. More specifically, occupational therapy practitioners could use this understanding of occupation to help people with diabetes act on congruent potentials and develop better action plans, given their unique situations. Additionally, some women in this study struggled to evaluate the outcomes of their inquiry in relation to their DSM. That struggle suggests that people may need to be coached through the evaluation phase of inquiry. Finally, practitioners could serve as resources, intermittently coaching their clients as they practice their DSM over time and especially during more challenging periods.

Conclusion and Future Directions

This study's findings have implications for our understanding of individuals' engagement in DSM and of their integration of self-management into daily life. In particular, this study's findings contribute to how we understand behavior change as influenced by habits, inquiry, and practice. Moreover, the findings demonstrate that integration is an occupational endeavor and provide insights into the role of occupation as it affects health and fosters growth.

Limitations. This study's readily identifiable limitations are its relatively small sample and geographically limited urban context. All of the participants were recruited from the same clinic, and all had received some level of DSM education before enrollment. Moreover, they all were participating in additional DSM education as part of

another research project while enrolled in this study. Therefore, the sample may not be representative of typical middle-aged, low-income urban women faced with DSM. It is likely that this group of women may have been better able to reflect on certain aspects of their DSM because of their additional experiences with DSM education. Further, I had additional contact with the participants and also provided educational materials to them through my role in another research project. This dual role may have further influenced the women's responses during our interviews, because both they and I were aware of the information they were learning in their DSM classes. Therefore, it is possible that the women's perceptions of my expectations shaped their stories influenced what aspects of their experiences I attended to.

In addition, the sample was predominantly lower-income and African American. Because of the small sample size and specific context, the study's findings may not be generalizable. The study also included women only; whether aspects of the model would be as relevant to men remains uncertain. For example, the amount of time and effort these women dedicated to practicing diet-related DSM activities may be an artifact of gender-associated roles. It is possible that, for example, a similar cohort of men would dedicate more time to exercise. Because habits and situations affect the prioritization of DSM activities, it would be realistic to expect that habits associated with the enactment of gender roles could very much influence the DSM integration process.

The study faced some limitations due to methodological choices. The women reported that it was difficult to commit to completing the TGD and suggested that future studies could simply involve a modified TGD interview during which the researcher documented the sequence of activities. Additionally, using disposable cameras resulted in poorer-quality photographs. Originally I was uncertain if all participants would have the

ability to, or be willing to, use their mobile devices to take and send photographs. The women shared that they would have preferred this method and recommended that I use it in future studies. Unfortunately, some of the women's photographs could not be included in the text because of their poor quality.

Strengths. This study has several strengths. The in-depth, multi methods approach facilitated a fuller understanding of the DSM integration process than would have been possible with a larger sample. A qualitative approach that included spending extensive time with each participant was necessary to develop insights into the complexity of and changes undergone by persons and situations. Each aspect of data collection offered some marginal overlap with other methods while also contributing new information. For example, habits and situations through time were derived more from the first SSIs, whereas a more thorough understanding of potentials and the role of practice came from the photographs. Additionally, combining interviews with participant photography and TGDs led to additional lines of inquiry as the women elaborated on aspects of their experiences they had documented with these methods. Although the socio-economic similarities of the women in the study can be viewed as a limitation, it also served as a strength. For example, the women in this study were low-income and many lived in a state of near-personal or -financial crisis. Had the study included a different group of individuals it is quite possible that their stories would not have revealed the contingent nature of integration or the necessity for reconfigurations.

Future directions. Several possible lines of future inquiry arose from the completion of this study. One is additional research on the utility of the transactional perspective to develop more middle-range theory for occupation-based interventions. Because this theory provided guidance for the design and implementation of this study, it

is not surprising that some aspects of the model align well with the transactional perspective's relational orientation. Further research that applies the transactional perspective to health problems could help refine the way we conceptualize, develop, and implement interventions. This type of theoretical development would be useful for scholars who have an occupational science orientation, and could also assist others who are engaged in public health interventions such as DSM.

Another line of future research that makes sense in light of this study would involve further explication of the role of habits in DSM. The findings from this study present a very rudimentary understanding of how constellations of habits may be relevant to DSM. Further research is needed to more clearly understand how different habit-situation configurations manifest and influence processes similar to DSM. It would be particularly fruitful to know whether particular constellations of habits and situations are associated with a particular DSM approach. This knowledge could assist researchers in identifying individuals at risk for poor integration and allow them to better tailor their interventions.

In a similar vein, further research is needed to understand how habits and situations shape the distributions of daily activities, and the effects of these distributions on health behavior change. This study offers a very general understanding of this relationship, based on these specific participants; additional research could further explicate this. Understanding the dynamic of this relationship could also assist researchers in identifying aspects of social and spatial distributions that are problematic in DSM and allow them to better tailor their interventions.

This study's findings indicate that occupational engagement provides opportunities for practice and inquiry that are essential to developing self-management

skills. However at this point, it offers only an exploratory understanding of this process. Future studies might focus on understanding the key dimensions of occupational engagement that contribute to developing certain skills that are relevant to DSM.

Finally, future avenues for research should include the development of occupation-based DSM integration programs. The transactional model of DSM integration suggests some key concepts and dynamics to use in future studies that could eventually lead to intervention development. The model presents the first steps in research that could examine the concepts and dynamics more carefully, across more varied populations, in order to inform the development of better interventions. Such interventions would focus on people in their complex situations and how occupational inquiry and practice can lead to the outcome that is elusive for many people with diabetes: ongoing success at integrating DSM into their lives in the face of personal and situational changes.

Final thoughts

Previous research has demonstrated that individuals need to engage in DSM to reduce their risks of diabetes associated morbidity and mortality. In addition, studies suggest that optimal DSM includes healthy eating, being active, self-monitoring, taking medication, problem solving, healthy coping, and reducing risks (Mulcahy et al., 2003). The stories of the women who participated in this study illustrate that integrating these behaviors into their daily lives required them to change their habits. Existing scholarship has suggested that psychological and cognitive approaches are useful in changing health behaviors, although the success of these approaches has been short-lived. In light of this

195

less-than-optimal utility, the scientific community has sought to further explicate the unique dynamics of sustaining health behavior changes long-term.

The process of DSM integration theorized in this study contributes to our understanding of long-term behavior change because it suggests some key dynamics that have importance for DSM integration. The women's experiences revealed that changing habits included changing their own habits and situations as well as the habits of others in their social milieu. They also provided insights into the role of inquiry and practice as the means by which individuals can develop and grow in their self-management abilities. This study offers a view of the larger conditions that affect integration efforts across the DSM trajectory.

When I think about the participants in this study, and about my late grandmother, I think about what is at stake. Individuals must integrate health-promoting behaviors in order to ameliorate the negative effects of diabetes. Practitioners expect their clients to quickly become effective self-managers despite the fact that we do not fully understand what this process entails. Nonetheless, clients accept this responsibility and try their best to engage in these activities despite often lacking the necessary skills. This dynamic creates a sense of urgency and serves as a call to action for scholars to continue to understand the key dynamics involved in long-term behavior change, so that we can assist people who have type II diabetes with integrating their diabetes self-management into daily life. This study represents one step in that process.

Picture Managing Your Type II Diabetes

You can help us better understand how individuals with type II diabetes manage their disease through the use of pictures.

I am looking for Caucasian and African American females ages 40 through 64 with type II diabetes who might be eligible for a study about how individuals with type II diabetes complete their diabetes self- management tasks. The purpose is to understand how individuals complete their diabetes self-management tasks in relation to their other daily activities.

This study is being conducted by a researcher at UNC, and your participation, if you are eligible, will take about 2 months. Eligible participants will be interviewed 3 times, and be given a disposable digital camera and asked to take pictures of situation, places, people, or items that they use in managing their type II diabetes or that make their diabetes management easier or harder. Eligible participants will also be asked to complete a diary of their daily activities for two days. All activities will take place at your convenience. The study will not cost you anything.

If you are interested, please contact me at the number below to talk about the study further. Thank you!

Principal Investigator: Heather Fritz, PhD Candidate
Project phone: 919-370-1928   Project email: Heather_ Fritz @med.unc.edu

Recruitment Script

University of North Carolina-Chapel Hill
Recruitment script
IRB Study #<u>12-1030</u>

Hello, my name is Heather Fritz. I am a doctoral student from the University of North Carolina at Chapel Hill conducting research about how individuals with type II diabetes integrate all activities associated with managing type II diabetes into daily life. Your participation in this research is completely voluntary. This means that you do not have to participate in this research unless you want to.

Would you be willing to answer some questions to help me determine if you are eligible for this study? (If yes, proceed; if no thank them for their time and end the call).

Good. I will read off a list of questions. If you answer to any of them is no, wait until I am all done and tell me that when I am finished. I do not want you to answer each question, individually.

> Are you between the ages of 40-64?
>
> Are you African American?
>
> Are you a Female?
>
> Have you ever been diagnosed with type II diabetes?

Would your response to any of these questions be "yes?" (If person says yes, thank them for their time and that they are not eligible for the study. If they answer no, proceed)

The purpose of this research study is to look at how individuals with type II diabetes manage their illness in the context of their everyday lives. We estimate that approximately 10 individuals will enroll in this study. You will be asked to complete three interviews about how you manage your type II diabetes. This should take about 90 minutes for each interview. There is a small chance that some of the questions may make you feel uncomfortable. You don't have to answer those questions if you don't want to. In fact you don't have to answer any question that you choose not to answer. And that is fine. We will just skip that question and go on to the next one. Additionally, you will be given a disposable digital camera and asked to take pictures of situations, places, persons,

or items that represent how you manage your type II diabetes, or that make management easier or harder for you. Finally, you will be asked to keep a diary for two days (one weekend day and one weekday) where you record the activities you did during the day, where they occurred, who was with you, if there was anything else you were doing at the same time, and any additional thoughts or feelings you have about the activity.

All the information I receive from you by phone, including your name and any other identifying information, will be strictly confidential and will be kept under lock and key. I will not identify you or use any information that would make it possible for anyone to identify you in any presentation or written reports about this study. If it is okay with you, I might want to use direct quotes from you, but these would only be quoted as coming from "a person" or a person of a certain label or title, like "one woman said."   When I finish with all the interviews from everyone who has agreed to participate, I will group all the answers together in any report or presentation. There will be no way to identify individual participants.

The only risk to you might be if your identity were ever revealed. I will keep all of your answers confidential so this cannot occur. There are no other expected risks to you for helping me with this study. There are also no expected benefits for you either. As a participant you would be eligible for a visa gift card of up to $100.00 if you complete all three phases of the study to compensate you for your time.

This study is being paid for by a fellowship through the University of North Carolina at Chapel Hill School of Nursing.

Do you have any questions?

You can call Heather Fritz at 919-370-1928with questions about the research study. All research on human volunteers is reviewed by a committee that works to protect your rights and welfare. If you have questions or concerns about your rights as a research subject you may contact, anonymously if you wish, the Institutional Review Board at 919-966-3113 or by email to IRB_subjects@unc.edu.

Do you agree to be in this study?

Consent Form

University of North Carolina-Chapel Hill
Consent to Participate in a Research Study
Adult Participants
Social Behavioral Form

_____

IRB Study #12-1030_____
Consent Form Version Date: __June 21,2012___

Diabetes Self-Management Study into Daily Life: Exploring Process, Habit, and Occupation

Principal Investigator: Heather Fritz, MS OTR/L
UNC-Chapel Hill Department: Allied Health Sciences
UNC-Chapel Hill Phone number: (919) 843-4465
Faculty Advisor: Brian Boyd PhD

Study Contact telephone number: (919) 370-1928
Study Contact email: Heather_fritz@med.unc.edu

_____

What are some general things you should know about research studies?
You are being asked to take part in a research study. To join the study is voluntary. You may refuse to join, or you may withdraw your consent to be in the study, for any reason, without penalty.

Research studies are designed to obtain new knowledge. This new information may help people in the future. You may not receive any direct benefit from being in the research study. There also may be risks to being in research studies.

Details about this study are discussed below. It is important that you understand this information so that you can make an informed choice about being in this research study. You will be given a copy of this consent form. You should ask the researchers named above, or staff members who may assist them, any questions you have about this study at any time.

What is the purpose of this study?
The purpose of this study is to learn about how individuals who have been diagnosed with type II diabetes integrate all of the multiple activities associated with managing their diabetes into daily life. Research suggests that many individuals struggle to manage their diabetes because of the complexity of the disease and the fact that individuals have to

commit to lifelong regimens that include a mix of medical and lifestyle recommendations while trying to manage their other everyday activities and responsibilities. Though research demonstrates many activities that are important to managing diabetes, we still do not know much about how people with diabetes manage their illness within their everyday contexts. In general understanding more about what works and doesn't work for people managing their diabetes on a day to day basis, will lead to improving programs aimed at helping persons with diabetes obtains the information, skills, and supports necessary to better manage their disease and live healthier lives.

This research study will contribute to building a better diabetes self-management.

How many people will take part in this study?
If you decide to be in this study, you will be one of approximately 11 people enrolled.

How long will your part in this study last?
This primary data collection will last for approximately two months. The total time commitment will be 10-12 hours.

What will happen if you take part in the study?
1. Your participation in the study will begin with an interview, which will be conducted by the PI at the Alliance Medical Ministry Clinic. This interview contains questions about your experience being diagnosed with type II diabetes, how you manage your diabetes, your daily activities, supports, any challenges to managing your diabetes, and your thoughts about diabetes self-management in general. If given permission, you will be audio recorded during the interviews to ensure accuracy of the information you have provided.
2. Following the first interview you will be given a disposable digital camera to use for 7 to 14 days. You will be asked to take pictures of situations, places, and tools that affect your diabetes management. You will be specifically asked to not take photographs of other's faces or your own to protect the privacy or others. You will also be asked to not take pictures of markings that may identify yourself or other individuals such as tattoos, or names legible on paperwork. You may take pictures of any other subject that you feel relates to how you manage your diabetes. You will be asked to return the camera to a secured drop box at the Alliance Medical Ministry clinic when you have finished taking your selected photographs. The photographs will be developed at a commercial photo lab.
3. After the collection and development of the photographs you will be asked to participate in a second interview. During this interview the researcher will review the photographs you have taken and discuss them further with you to better understand their significance in your diabetes management. If given permission, you will be audio recorded during the interview to ensure accuracy of the information you have provided.
4. Following the interview, you will be given a time geographic diary in which you will be requested to record aspects of your daily routine over the course of two days such as: the timing and location of your activities, who is with you while you perform them, and how you feel while performing them. The researcher will provide you with a diary, instructions, and writing instruments. You will be asked

201

to complete the diary for two days-one weekday, and one weekend day only. Upon completing the diary you will be asked to deposit the diary at the Alliance Medical ministry clinic in a secured drop box.

5. You will be sent a text message daily to remind you to complete the diary. Text messages will be sent by the PI from the telephone associated with the study. The text message will read "diary reminder." The PI will delete the text thread after sending the text message to you to protect you from any risk of accidentally disclosing your cellular number. In the event that you do not own a cellular phone with a data plan, or would have to incur costs to receive a text reminder, the PI will issue you a pre-paid cellular phone with restricted minutes for you to use to receive text messages from the PI during the two week time diary phase of the study. If you are issued a phone to use during the two week collection period you will be instructed to return it to the clinics secured drop box along with the time diary.

6. A final interview will allow both you and the researcher to reflect on the information you provided in the diary, and will focus on understanding the patterns, places, supports, and activities that make up your daily life and how diabetes self-management fits into these patterns. Again, if given permission, you will be audio recorded during the interview to ensure accuracy of the information you have provided.

What are the possible benefits from being in this study?
Research is designed to benefit society by gaining new knowledge. You may not benefit personally from being in this research study. However, many people find that the opportunity to talk about their experiences and life situation is a positive experience, and the reflection may result in an awareness of how certain activities or dynamics affect how you manage your diabetes.

What are the possible risks or discomforts involved from being in this study?
There are no known risks to being in this research study. You should report any problems to the researcher.
The study is being conducted in cooperation with the Alliance Medical Ministries facility. However, the PI and this research study are not connected to your diabetes care. Furthermore your decision to participate or not participate in this study will not affect your relationship to the Alliance Medical Ministry clinic or your medical care in any way.

How will your privacy be protected?
Your privacy is very important. All of the data gathered during this study will be de-identified by the PI, and she alone will have access to a master list of information such as names and telephone numbers of participants. Pseudonyms will be created and used in all transcriptions, field notes, and mapping exercises. Audiotapes, along with electronic and printed records will be stored in a locked office or on password protected computers, and will not be shared with anyone not directly involved in the research.

Participants will not be identified in any report or publication about this study. Although every effort will be made to keep research records private, there may be times when federal or state law requires the disclosure of such records, including personal information. This is very unlikely, but if disclosure is ever required, UNC-Chapel Hill will take steps allowable by law to protect the privacy of personal information. In some cases, your information in this research study could be reviewed by representatives of the University, research sponsors, or government agencies for purposes such as quality control or safety.

During interviews, the researcher may wish to make a digital audio recording. Recordings will help the researcher more accurately recall and transcribe the interview, and will not be shared with anyone not directly involved with this research. The digital recording will be saved on a secure server and only analyzed on a computer that is password protected. All digital recordings will be destroyed at the end of the study. If you consent to audio recording, you may still request that the recording be turned off at any point in time.

Check the line that best matches your choice:
　　　　_____ OK to record me during the study
　　　　_____ Not OK to record me during the study

What if you want to stop before your part in the study is complete?
You can withdraw from this study at any time, without penalty. The investigators also have the right to stop your participation at any time.

Will you receive anything for being in this study?
You will receive a participant incentive of $100.00. You will receive 25.00 after completing phase one, 25.00 after completing phase two, and 50.00 after completing the final phase.

Will it cost you anything to be in this study?
There will be no costs for being in the study.

What if you have questions about this study?
You have the right to ask, and have answered, any questions you may have about this research. If you have questions, complaints, concerns, or if a research-related injury occurs, you should contact the researchers listed on the first page of this form.

What if you have questions about your rights as a research participant?
All research on human volunteers is reviewed by a committee that works to protect your rights and welfare. If you have questions or concerns about your rights as a research subject, or if you would like to obtain information or offer input, you may contact the Institutional Review Board at 919-966-3113 or by email to IRB_subjects@unc.edu.

- -

Title of Study: Integrating diabetes self-management into daily life: Exploring process, habit, and occupation

Principal Investigator: Heather Fritz

Participant's Agreement:

I have read the information provided above. I have asked all the questions I have at this time. I voluntarily agree to participate in this research study.

_____   _____
Signature of Research Participant   Date

_____
Printed Name of Research Participant

_____   _____
Signature of Research Team Member Obtaining Consent   Date

_____
Printed Name of Research Team Member Obtaining Consent

Appendix D

Diabetes Care Profile (DCP)

Section I - Demographics

Please answer each of the following questions by filling in the blanks with the correct answers or by choosing the single best answer.

Note: For this survey, a <u>Health Care Provider</u> refers to a doctor, nurse practitioner, or physician assistant.

Q1.   Age: __ __ years old

Q2.   Zip Code: __ __ __ __ __

Q3.   Sex: ☐₁ Male   ☐₂ Female

Q4.   What year were you first told you had diabetes? (Please enter the year) __ __ __ __

Q5.   What is your marital status? (check one box)

☐₁   Never married

☐₂   Married

☐₃   Separated/Divorced

☐₄   Widowed

Q6.   What is your ethnic origin/race? (check one box)

☐1   White

☐2   Black

☐3   Hispanic

☐4   Native American

☐5   Asian or Pacific Islander

☐6   Arabic

☐7   Other _____

Q7.   Where do you live most of the year? (check one box)

☐1   Your home, apartment or condo

☐2   Senior citizen apartment/condo

☐3   Home of a relative/friend

☐4   Retirement home

☐5   Adult foster care

☐6   Nursing home

☐7   Other _____

Q8.   How many people live with you? (check one box)

☐0   I live alone

☐1   1 person

$\square_2$ 2 people

$\square_3$ 3 people

$\square_4$ 4 people

$\square_5$ 5 or more

Q9.   How much schooling have you had? (Years of formal schooling completed) (check one box)

$\square_1$ 8 grades or less

$\square_2$ Some high school

$\square_3$ High school graduate or GED

$\square_4$ Some college or technical school

$\square_5$ College graduate (bachelor's degree)

$\square_6$ Graduate degree

Q10.   Which of the following best describes your current employment status? (check one box)

$\square_1$ Working full-time, 35 hours or more a week

$\square_2$ Working part-time, less than 35 hours a week

$\square_3$ Unemployed or laid off and looking for work

$\square_4$ Unemployed and not looking for work

$\square_5$ Homemaker

$\square_6$ In school

$\square_7$ Retired

$\square_8$ Disabled, not able to work

$\square_9$ Something else? (Please specify): _____

Q11.　How would you describe the insurance plan(s) you have had <u>in the past 12 months</u>? (check all that apply)

　$\square_1$　An individual plan – the member pays for the plan premium

　$\square_2$　A group plan through an employer, union, etc. – the employer pays all or part of the plan premium

　$\square_3$　U.S. Governmental Health Plan (e.g., Military, CHAMPUS, VA)

　$\square_4$　Medicaid

　$\square_5$　Medicare

　$\square_6$　I have not had an insurance plan in the past 12 months

Q12.　What type(s) of insurance plans have you had <u>in the past 12 months</u>? (check all that apply)

　$\square_1$　<u>Indemnity</u> or <u>fee-for-service</u> plan (i.e., you choose which health care provider you see for care without financial penalty)

　$\square_2$　<u>Health Maintenance Organization</u> (HMO) (i.e., you must have a primary care provider who must refer you to specialty care if needed)

　$\square_3$　<u>Preferred Provider Organization</u> (PPO) (i.e., you have lower co-payments when you see a preferred provider within the network, but you can see a provider out-of-network for a higher co-payment)

　$\square_4$　<u>Point of Service</u> (POS) (i.e., you must have a primary care provider; you have the option to self-refer to an in-network specialist, or you can see an out-of-network

　　specialist with a higher co-payment)

　$\square_5$　Other (please specify): _____

☐6   I have not had an insurance plan in the past 12 months.

Q13.   Do you test your blood sugar? (check one box)

☐1 No ☐2 Yes   Q13a. How many days a week do you test your blood

                            sugar?

                                              _____ (days / week)

                     Q13b. On days that you test, how many times do you test
                            your blood sugar?

                                              _____ (times / day)

                     Q13c. Do you keep a record of your blood sugar test
                            results? (check one box)

                     ☐1 No   ☐2 Yes   ☐Only Unusual Values

Section II – Health Status

Q1. In general, would you say your health is: (check one box)

☐₁	☐	☐₃	☐	☐₅
Excellent	Very Good	Good	Fair	Poor

Q2. These questions ask about how you feel and how things have been with you **during the past 4 weeks**. For each question, please give the one answer that comes closest to the way you have been feeling.

How much of the time **during the past 4 weeks**: (circle one answer for each line)

		All of the Time	Most of the Time	A Good Bit of the Time	Some of the Time	A Little of the Time	None of the Time
A.	Have you felt **calm and peaceful**?	1	2	3	4	5	6
B.	Did you have a **lot of energy**?	1	2	3	4	5	6
C.	Have you felt **downhearted or blue**	1	2	3	4	5	6

Section III – Education / Advice Received

Q1.   Has your health care provider or nurse ever told you to take special care of your feet? (check one box)

☐₁ No ☐₂ Yes   ☐₃ Not Sure

Q2.   Has your health care provider or nurse ever told you to follow an exercise program?(check one box)

☐₁ No ☐₂ Yes   ☐₃ Not Sure

Q3.   Has your health care provider or nurse ever told you to follow a meal plan or diet?
(check one box)

☐₁ No ☐₂ Yes   ☐₃ Not Sure

Q4.   Have you ever received diabetes education? (for example: attended a series of classes or series of meetings with a diabetes educator) (check one box)

☐₁ No ☐₂ Yes   ☐₃ Not Sure

Section IV - Understanding

Q1.	How do you rate your understanding of:(circle one answer for each line)	Poor		Good		Excellent
	a) overall diabetes care	1	2	3	4	5
	b) coping with stress	1	2	3	4	5
	c) diet for blood sugar control	1	2	3	4	5
	d)the role of exercise in diabetes care	1	2	3	4	5
	e) medications you are taking	1	2	3	4	5
	f)how to use the results of blood sugar monitoring	1	2	3	4	5
	g) how diet, exercise, and medicines affect blood sugar levels	1	2	3	4	5
	h) prevention and treatment of high blood sugar	1	2	3	4	5
	g) prevention and treatment of low blood sugar	1	2	3	4	5

Section VI - Control Problems Scale

For the following questions, please <u>check</u> the appropriate response.

Q1. How many **times** in the last **month** have you had a **low blood sugar** (glucose) reaction with symptoms such as sweating, weakness, anxiety, trembling, hunger or headache?

☐₁ 0 times

☐₂ 1-3 times

☐₃ 4-6 times

☐₄ 7-12 times

☐₅ More than 12 times

☐₆ Don't know

Q2. How many **times** in the last **year** have you had **severe low blood sugar** reactions such as passing out or needing help to treat the reaction?

☐₁ 0 times

☐₂ 1-3 times

☐₃ 4-6 times

☐₄ 7-12 times

☐₅ More than 12 times

☐₆ Don't know

Q3. How many **days** in the last **month** have you had **high blood sugar** with symptoms such as thirst, dry mouth and skin, increased sugar in the urine, less appetite, nausea, or fatigue?

☐₁ 0 days

☐₂ 1-3 days

☐₃ 4-6 days

☐₄ 7-12 days

☐₅ More than 12 days

☐₆ Don't know

Q4.How many **days** in the last **month** have you had **ketones** in your urine?

☐₁ 0 days

☐₂ 1-3 days

☐₃ 4-6 days

☐₄ 7-12 days

☐₅ More than 12 days

☐₆ Don't test

Q5.	During the past year, how often did your blood sugar become **too high** because: (circle one answer for each line)	**Never**		**Sometimes**		**Often**	**Don't Know**
	a) you were sick or had an infection?	1	2	3	4	5	DK
	b) you were upset or angry?	1	2	3	4	5	DK
	c) you took the wrong amount of medicine?	1	2	3	4	5	DK
	d) you ate the wrong types of food?	1	2	3	4	5	DK
	e) you ate too much food?	1	2	3	4	5	DK
	f) you had less physical activity than usual?	1	2	3	4	5	DK
	g) you were feeling stressed?	1	2	3	4	5	DK

Q6.	During the past year, how often did your blood sugar become **too low** because: (circle one answer for each line)	**Never**		**Sometimes**		**Often**	**Don't Know**
	a) you were sick or had an infection?	1	2	3	4	5	DK
	b) you were upset or angry?	1	2	3	4	5	DK
	c) you took the wrong amount of medicine?	1	2	3	4	5	DK
	d) you ate the wrong types of food?	1	2	3	4	5	DK
	e) you ate too little food?	1	2	3	4	5	DK
	f) you had more physical activity than usual?	1	2	3	4	5	DK
	g) you waited too long to eat or skipped a meal?	1	2	3	4	5	DK
	h) you were feeling stressed?	1	2	3	4	5	DK

Addition to Section I (Demographics) - Income Question

Q15. Which of the categories best describes your total annual <u>combined</u> household income from <u>all</u> sources? (check one box)

☐ 01   Less than $5,000

☐ 02 $5,000 to $9,999

☐ 03 $10,000 to $14,999

☐ 04 $15,000 to $19,999

☐ 05 $20,000 to $29,999

☐ 06 $30,000 to $39,999

☐ 07 $40,000 to $49,999

☐ 08 $50,000 to $59,999

☐ 09 $60,000 to $69,999

☐ 10 $70,000 and over

Addition to Section I (Demographics) - Occupation Question (from NHANES III)

Q15/Q16. During the past 2 weeks, did you work at any time at a job or business,

not counting work around the house?

☐₁ No   ☐₂ Yes   ⌐→

Q15a/Q16a. What kind of work were you doing?
(For example: electrical engineer, stock clerk, typist, farmer.)

☐₀₁ Executive, administrators, and managers	☐₂₁ Miscellaneous food preparation and service occupations
☐₀₂ Management related occupations	☐₂₂ Health service occupations
☐₀₃ Engineers and scientists	☐₂₃ Cleaning and building service occupations
☐₀₄ Health diagnosing, assessment, and treating occupations	☐₂₄ Personal service occupations
☐₀₅ Teachers	☐₂₅ Farm operators, managers, and supervisors
☐₀₆ Writers, artists, entertainers, and athletes	☐₂₆ Farm and nursery workers
☐₀₇ Other professional specialty occupations	☐₂₇ Related agricultural, forestry, and fishing occupations
☐₀₈ Technicians and related support occupations	☐₂₈ Vehicle and mobile equipment mechanics and repairers
☐₀₉ Supervisors and proprietors, sales occupations	☐₂₉ Other mechanics and repairers

☐10 Sales representatives, finance, business, and commodities except retail	☐30 Construction trades
☐11 Sales workers, retail and personal business	☐31 Extractive and precision production occupations
☐12 Secretaries, stenographers, and typists	☐32 Textile, apparel, and furnishings machine operators
☐13 Information clerks	☐33 Machine operators, assorted materials
☐14 Records processing occupations	☐34 Fabricators, assemblers, inspectors, and samplers
☐15 Material recording, scheduling, and distributing clerks	☐35 Motor vehicle operators
☐16 Miscellaneous administrative support occupations	☐36 Other transportation and material moving occupations
☐17 Private household occupations	☐37 Construction laborers
☐18 Protective service occupations	☐38 Laborers, except construction
☐19 Waiters and waitresses	☐39 Freight, stock, and material movers
☐20 Cooks	☐40 Other handlers, equipment cleaners, and handlers
	☐41 Don't Know

Diabetes Self-Management Study: Exploring Process, Habit, and Occupation

Semi-Structured Interview Guide

Tell me about when you were first diagnosed with type two diabetes.

- Was it unexpected/expected?
- What was your life like at that time?
- What did the diagnosis mean to those persons close to you?
- What were your initial thoughts, feelings or perceptions?
- How much information/knowledge did you have about T2DM in the beginning?
- Did you/do you know anyone else who has diabetes?

What has it been like living with the disease?

- Did you notice any immediate changes to your life situation
- What education and services have you or others close to you received or sought out?
- Did you notice any changes physically or emotionally since your diagnosis?
- Have there been any particular effects on those close to you (friend, family)?

How do you manage your T2DM?

- Describe medicine regimen, exercise and dietary activities, and any other related management activities such as checking ones feet and blood glucose monitoring.
- What changes have you experienced due to time, situation, persons, places, etc…?
- Are there/what kind of adaptations have you had to make to accommodate managing your T2DM?
- Has/How has your approach changed over time?
- Has managing your T2DM interfered with other things you have wanted to do?
- Has managing your T2DM interfered with your relationships with other people?
- Are there other people that help or effect how you manage your T2DM

How do you feel you're doing regarding managing your diabetes?

- Is anything particularly difficult?
- Are there things that are easy for you?
- Are there things you have learned that make it easier for you?
- Are there things you would like more help with?
- Do you feel you have everything necessary to appropriately manage your T2DM or is there anything lacking?

Overall how has having to manage T2DM affected your life?

What do you see in your future regarding your diabetes?

- Do you feel your ability to manage your diabetes will get better/worse?
- What challenges do you foresee?
- Is the reality of living with T2DM what you anticipated when first diagnosed?
- Is there anything you would do differently?
- How do you think managing your T2DM will change/effect your future?

Time Geographic Diary Sample

Diabetes Self-Management Study:
Exploring Process, Habit, and Occupation
Participant Time Diary

An important part of our research is to find out how you spend your time during a typical week, what types of activities you do, where you do them and who you do them with. The Time Diary is for you to list your activities during one weekday and during one weekend day.

During the next 2 weeks please do the following.

- Please fill out the Time Diary for one weekday (Monday-Friday)
- Please fill out the Time Diary for one weekend day (Saturday or Sunday)
- Please use one line for each activity and write in what you were doing.
- Please indicate who was doing the activity with you.
- Please indicate if you were doing any other activity at the same time.
- Please indicate where you were when doing the activity (home, car, store etc…)
- Please fill out the diary from the time you wake up in the morning until you go to sleep at night on the day that you select to record your activities.
- List the activities in the order they occurred.

On the following page, you will find an example of these activities and how they would be filled out for this time diary. The following scenario is only an example of how to fill out a time diary. It may not be at all reflective of your typical day. Your interviewer will be glad to help you with any questions or problems you may have in completing the diary. When finished with completing the diary, please contact Heather Fritz (919)-370-1928, and I will come and pick up the diary from you.You may also deposit the diary at the Alliance medical ministry clinic.

Figure 1.

Time	Activity	Secondary Activity	Location	Persons Present	Forfeited Activities	Miscellaneous
7:00-7:15	Breakfast	Child care	home	Child	Morning exercise	Felt rushed
7:15-7:30	Dressing	Child care	Home	Child	Morning exercise	Spouse not home yet to help

Activity: In your own words, write what activity you completed during the time interval

Secondary Activity: Write down any additional activities that may be occurring at the same time as the main activity you were performing.

Location: Fill in the location of the activity completed for the given time interval (e.g. home, work, school, grocery store, etc).

Persons Present: Fill in who was present when you were doing the activity.

Forfeited Activities: Fill in any activities that you had intended or wanted to do, but were unable to do because of the other activities you were performing. For example, if you missed lunch because you had to take a child to school.

Miscellaneous: This is an open column in which you can write in any thoughts about the particular activity you were doing.

Time	Activity	Secondary activity	Location	Person Present	Forfeited Activities	Additional Comments
A.M.						
0:00-0:15						
0:15-0:30						
0:30-0:45						
0:45-1:00						
1:00-1:15						
1:15-1:30						
1:30-1:45						
1:45-2:00						
2:00-2:15						
2:15-2:30						
2:30-2:45						
2:45-3:00						
3:00-3:15						
3:15-3:30						
3:30-3:45						
3:45-4:00						

4:00-4:15					
4:15-4:30					
4:30-4:45					
4:45-5:00					
5:00-5:15					
5:15-5:30					
5:30-5:45					
5:45-6:00					
6:00-6:15					
6:15-6:30					
6:30-6:45					
6:45-7:00					
7:00-7:15					
7:15-7:30					
7:30-7:45					
7:45-8:00					
8:00-8:15					
8:00-8:15					

8:15-8:30					
8:30-8:45					
8:45-9:00					
9:00-9:15					
9:15-9:30					
9:30-9:45					
9:45-10:00					
10:00-10:15					
10:00-10:15					
10:15-10:30					
10:30-10:45					
10:45-11:00					
11:00-11:15					
11:00-11:15					
11:15-11:30					
11:30-11:45					
11:45-12:00					

References

Agency for Healthcare Research and Quality (AHRQ) (2004). National healthcare quality report. Retrieved from http://www.innovations.ahrq.gov/content.aspx?id=736. Accessed June 2nd, 2012.

Ajzen, I., & Fishbein, M. (1980). *Understanding attitudes and predicting social behavior*. Englewood Cliffs, NJ: Prentice Hall.

Audulv, A., Asplund, K., & Gustaff-Norbergh, K. (2012). The integration of chronic illness self-management. Qualitative Health Research, 22(3), 332-345. doi:10.1177/1049732311430497

American Association of Clinical Endocrinologists (2004). State of diabetes complications in America AACE report. (n.d.). Retrieved from http://www.stateofdiabetes.com. Accessed November, 4th,2013.

Aldrich, R. M., & Cutchin, M. P. (2013). Dewey's concepts of embodiment, growth, and occupation: Extended bases for a transactional perspective. In M. P. Cutchin, & V. A. Dickie (Eds.), *Transactional perspectives on occupation* (pp. 13-23). New York: Springer.

American Psychological Association. (n.d.). Fact sheet: Women and socioeconomic status. Retrieved from http://www.apa.org/pi/ses/resources/publications/factsheet-women.aspx

Atwal, A., Morley, M., & Spiliotopoulou, G. (2011). Has occupational science taken away the occupational therapy evidence base? A debate. *British Journal of Occupational Therapy, 74*, 494-497.

Asbring, P. (2001). Chronic illness-a disruption in life: Identity-transformation among women with chronic fatigue syndrome and fibromyalgia. *Journal of Advanced Nursing, 34*(3), 312-319. doi: 10.1046/j.1365-2648.2001.01767.x

Bandura, A. (1977). Self-efficacy: Toward a unifying theory of behavioral change. *Psychological Review, 84* (2), 191-215.

Bandura, A. (1997). *Self-efficacy: The exercise of control.* New York: W. H. Freeman.

Bandura, A. (1998). Health promotion from the perspective of social cognitive theory. *Psychology & Health*, *13*(4), 623-649.

Barker, L. E., Kirtland, K. A., Gregg, E. W., Geiss, L. S., & Thompson, T. J. (2011). Geographic distribution of diagnosed diabetes in the U.S.: A diabetes belt. *American Journal of Preventive Medicine, 40*(4), 434-439. doi: 10.1016/j.amepre.2010.12.019

Baum, C. M. (1985). Growth, renewal, and challenge: An important era for occupational therapy. *The American Journal of Occupational Therapy, 39*(12), 778-784. doi: 10.5014/ajot.39.12.778

Bowen, G. (2006). Grounded theory and sensitizing concepts. *International Journal of Qualitative Methods, 5*(3), 2-9.

Britten, N. (1995). Qualitative interviews in medical research. *British Medical Journal, 311*(6999), 251-253.

Blumer, H. (1954). What is wrong with social theory? *American Sociological Review, 18,* 3-10.

Burrows-Hudson, S., Curtin, R. B., Mapes, D., & Schatell, D. (2005). Self-management in patients with end stage renal disease: Exploring domains and dimensions. *Nephrology Nursing Journal, 32*(4), 389-395.

Catalani, C., & Minkler, M. (2010). Photovoice: A review of the literature in health and public health. *Health Education & Behavior, 37*(3), 424-451. doi: 10.1177/1090198109342084

Callaghan, D. (2006). The influence of basic conditioning factors on healthy behaviors, self-efficacy, and self-care in adults. *Journal of Holistic Nursing*, *24*(3), 178-185.

Campbell, J. (1995). *Understanding John Dewey: Nature and cooperative intelligence*. La Salle, IL: Open Court.

Centers for Disease Control and Prevention. (2011). National diabetes fact sheet: National estimates and general information on diabetes and prediabetes in the United States 2011. Atlanta, GA: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention.

Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis.* Thousand Oaks, CA: Sage.

Christiansen, C., & Baum, C. (1997). *Occupational therapy: Enabling function and well-being.* Thorofare, NJ: Slack.

Christiansen, C. H., & Matuska, K. M. (2006). Lifestyle balance: A review of concepts and research. *Journal of Occupational Science*, *13*(1), 49-61.

Clark, N. M., & Dodge, J. A. (1999). Exploring self-efficacy as a predictor of disease management. *Health Education & Behavior, 26*, 72-89. doi:10.1177/109019819902600107

Clark, F. (1997). Reflections on the human as an occupational being: Biological need, tempo and temporality. *Journal of Occupational Science, 4*(3), 86-92. doi: 10.1080/14427591.1997.9686424

Clair, V. W. (2003). Storymaking and storytelling: Making sense of living with multiple sclerosis. *Journal of Occupational Science, 10*(1), 46-51. doi: 10.1080/14427591.2003.9686510

Clark, F., Sanders, K., Carlson, M., Blanche, E., & Jackson, J. (2007). Synthesis of habit theory. *OTJR: Occupation Participation and Health, 27*, 7S-23S.

Clark-Ibáñez, M. (2004). Framing the social world with photo-elicitation interviews. *American Behavioral Scientist, 47*(12), 1507-1527. doi: 10.1177/0002764204266236

Cramer, J. A. (2004). A systematic review of adherence with medications for diabetes. *Diabetes Care, 27*(5), 1218-1224. doi: 10.2337/diacare.27.5.1218

Creek, J., & Hughes, A. (2008). Occupational and health: A review of selected literature. *BJOT, 71,* 456-468.

Crepeau, E. (2007). Introduction. *OTJR: Occupation, Participation & Health, 27*, 3S-5S.

Creswell, J. W. (2011). *Designing and conducting mixed methods research* (2nd ed.). Los Angeles: Sage Publications.

Cox, K. R., & Taylor, S. G. (2005). Orem's self-care deficit nursing theory: Pediatric asthma as exemplar. *Nursing Science Quarterly, 18*(3), 249-257. doi: 10.1177/0894318405277528

Crosby, R. A., Kegler, M. C., & DiClemente, R. J. (2002). Understanding and applying theory in health promotion practice and research. In R. J. DiClemente, R. A. Crosby, & M. C. Kegler (Eds.), *Emerging theories in health promotion practice and research: Strategies for improving the public health* (pp. 1-15). San Francisco, CA: Jossey-Bass.

Crosby, R., & Noar, S. M. (2010). Theory development in public health promotion: Are we there yet? *Journal of Behavioral Medicine, 33*(4), 259-263.

Cutchin, M. P. (2004). Using Deweyan philosophy to rename and reframe adaptation-to environment. *American Journal of Occupational Therapy, 58*, 303-312.

Cutchin, M. P. (2007). From society to self (and back) through place: Habit in transactional context. *OTJR: Occupation, Participation, and Health, 27*, 50S-59S.

Cutchin, M. P., & Dickie, V. A. (2013a). *Transactional perspectives on occupation.* New York: Springer.

Cutchin, M. P., & Dickie, V. A. (2013b). Transactional perspectives on occupation: An introduction and rationale. In M. P. Cutchin & V. A. Dickie (Eds.), *Transactional perspectives on occupation* (pp. 1-10). New York: Springer.

Cutchin, M. P. (2013). The art and science of occupation: Nature, inquiry, and the aesthetics of living. *Journal of Occupational Science.* 1-12. doi. 10.1080/14427591.2012.744290

Dewey, J. (1941). Propositions, warranted assertibility, and truth. *The Journal of Philosophy, 38(*7), 169-186.

Dewey, J. (1957). *Human nature and conduct*. New York: Modern Library. (Original work published in 1922)

Dewey, J. (1960). *Logic: The theory of inquiry.* New York: Holt, Rinehart and Winston. (Original work published in 1938)

Diabetes Control and Complications Trial Research Group. (1993). The effect of intensive treatment of diabetes on the development and progression of long-term complications in insulin-dependent diabetes mellitus. *New England Journal of Medicine, 329,* 977-986.

Dickie, V., Cutchin, M. P., & Humphry, R. (2006). Occupation as transactional experience: A critique of individualism in occupational science. *Journal of Occupational Science, 13*, 83–93.

Dickie, V. & Cutchin, M. P. (2013). Transactional perspectives on occupation: Main points of contributions in this volume. In M. P. Cutchin, & V. A. Dickie (Eds.), *Transactional perspectives on occupation* (pp. 257-261). New York: Springer.

Dungan, J. M. (1997). Dungan model of dynamic integration. *Nursing Diagnosis 8*, 17-28.

Dunn, T., & Hocking, C. (2001). Occupational terminology. *Journal of Occupational Science*, *8*(2), 38-41.

Fesmire, S. (2003). *John Dewey and moral imagination: Pragmatism in ethics. Bloomington:* Indiana University Press.

Fisher, E., Brownson, C., O'Tool, M., Shetty, G., Anwuri, V., & Glasgow, R. (2005). Ecological approaches to self-management: The case of Diabetes. *American Journal of Public Health, 95*(9), 1523-1535.

Fritz, H. A. (2012). Improvisational theater and insights into the function of habit in occupation. *Journal of Occupational Science,* 1-12. doi:10.1080/14427591.2012.724352

Frank, G. (2011). The transactional relationship between occupation and place: Indigenous cultures in the American Southwest. *Journal of Occupational Science, 18*, 3-20.

Funnell, M., Anderson, R., Arnold, M., Barr, P., Donnelly, M., & Johnson, P. (1991). Empowerment: An idea whose time has come in diabetes education. *Diabetes Educator, 17,* 37-41.

Funnell, M., Brown, T., Childs, B., Haas, L., Jensen, B., Maryniuk, M., Peyrot, M., Piette, J., Reader, D., Siminerio, L., Weinger, K., & Weiss, M. (2011). National standards for diabetes self -management education. *Diabetes Care, 34* (1), S89-S96.

Futeran, R. (2001). The role of occupational therapy in patients with diabetic neuropathy. *Israel Journal of Occupational Therapy, 10,* 27-33.

Garrison, J. (2001). An introduction to Dewey's theory of functional "trans-action": An alternative paradigm for activity theory. *Mind, Culture, and Activity, 8*, 275-296.

Garrison, J. (2002). Habits as social tools in context. *Occupational Therapy Journal of Research, 22*, 11S–17S.

Gary, T. L., Genkinger, J. M., Guallar, E., Peyrot, M., & Brancati, F. L. (2003). Meta-analysis of randomized educational and behavioral interventions in type 2 diabetes. *The Diabetes Educator, 29*(3), 488-501. doi: 10.1177/014572170302900313

Glasgow, R., & Anderson, R., (1999). In diabetes care moving from compliance to adherence is not enough: Something entirely different is needed. *Diabetes Care, 22,* 2090-2091.

Glasgow, R. E., Goldstein, M. G., Ockene, J. K., & Pronk, N. P. (2004). Translating what we have learned into practice: Principles and hypotheses for interventions addressing multiple behaviors in primary care. *American Journal of Preventive Medicine, 27(*2Suppl*),* 88-101.

Glanz, K., Lewis, F. M., & Rimer, B. K. (2002). Linking theory, research and practice. In K. Glanz, F. M. Lewis, & B. K. Rimer (Eds.), *Health behavior and health education: Theory, research and practice*, *2ⁿᵈ edition* (pp.19–35). San Francisco, CA: Jossey-Bass.

Gomersall, T., Madill, A., & Summers, L. K. M. (2012). Getting one's thoughts straight: A dialogical analysis of women's accounts of poorly controlled type 2

diabetes. *Psychology & Health, 27*(3), 378-393. doi: 10.1080/08870446.2011.583649

Haltiwanger, E. P. (2012). Effect of a group adherence intervention for Mexican-American older adults with type 2 diabetes. *American Journal of Occupational Therapy, 66*, 447.

Hammell, K. W. (2009). Self-care, productivity, and leisure, or dimension of occupational experience? Rethinking occupational "categories". *Canadian Journal of Occupational Therapy, 76,* 107-114.

Harvey, A. S. (1993). Guidelines for time use data collection. *Social Indicators Research, 30*(2/3), 197-228.

Heatwole Shank, K., & Cutchin, M. P. (2010). Transactional occupations of older women aging in place: Negotiating change and meaning. *Journal of Occupational Science, 17*, 4-13.

Hernandez, C. A. (1995). The development and testing of an instrument to measure integration in adults with diabetes mellitus. *Canadian Journal of Diabetes Care 19*, 18-26.

Hernandez, C. A. (1996). Integration: the experience of living with insulin (type 1) diabetes mellitus. *The Canadian Journal of Nursing Research, 28,* 37-56.

Hickman, L. (1998). Dewey's theory of inquiry. In L. Hickman (Ed.), *Reading Dewey: Interpretations for a postmodern generation (pp. 166-186).* Bloomington, IN: Indiana University Press.

Hill-Briggs, F., & Gemmell, L. (2007). Problem solving in diabetes self-management and control: A systematic review of the literature. *The Diabetes Educator, 33*(6), 1032-1050. doi: 10.1177/0145721707308412

Hibbard, J. H., Mahoney, E., Stock, R., & Tusler, M. (2005). Does increasing patient activation result in improved self-management behaviors? A further validation of the patient activation measure (PAM). *Health Services Research, 40*(6), 1918-30.

Hocking, C. (2000). Occupational science: A stock tale of accumulated insights. *Journal of Occupational Science, 7*(2), 58-67.

Hocking, C. (2009). The challenge of occupation: Describing the things people do. *Journal of Occupational Science, 16 (3),* 140-150.

Hocking, C., & Wright-St. Clair, V. (2011). Occupational science: Adding value to occupational therapy. *New Zealand Journal of Occupational Therapy, 58*, 29-35.

Horne, R., (2006). Compliance, adherence, and concordance: Implications for asthma. *Chest, 30*(1), 65S-72S.

Horsten, A., Jutterstrom, L., Audulv, A., & Lundman, B. (2010). A model of integration of illness and self-management in type two diabetes. *Journal of Nursing and Healthcare of Chronic Illness, 3*(1), 41-51. doi: 10.1111/j.1752-9824.2010.01078.x

Humphry, R. (2005). Model of Processes Transforming Occupations: Exploring societal and social influences. *Journal of Occupational Science, 12*, 36-41.

Ismail, K., Winkley, K., & Rabe-Hesketh, S. (2004). Systematic review and meta-analysis of randomised controlled trials of psychological interventions to improve glycaemic control in patients with type 2 diabetes. *The Lancet, 363*(9421), 1589-1597. doi: 10.1016/S0140-6736(04)16202-8

Janz, N. K., & Becker, M. H. (1984). The health belief model: A decade later. *Health Education & Behavior, 1*(1), 1-47.

Jeffery, R. (2004). How can health behavior theory be made more useful for interventions research? *International Journal of Behavioral Nutrition and Physical Activity, 1(1)*, 10-15.

Jengliang Eric, H., Truax, C., Claire, M., & Caytap, A. (2009). Occupational therapy in diabetic care: Areas of need perceived by older adults with diabetes. *Occupational Therapy in Health Care*, *23*(3), 173-188.

Jonsson, H. (2008). A new direction in the conceptualization and categorization of occupation. *Journal of Occupational Science, 15*(1), 3-8.

Kantartzis, S., & Molineuz, M. (2010). The influence of western society's construction of a healthy daily life on the conceptualization of occupation. *Journal of Occupational Science, 18*(1), 62-80. doi:10.1080/14427591.2011.566917

Kerr, A., & Ballinger, C. (2010). Living with chronic lung disease: An occupational perspective. *Journal of Occupational Science, 17*(1), 34-39. doi: 10.1080/14427591.2010.9686670

Kestenbaum, V. (1977). *The phenomenological sense of John Dewey: Habit and meaning*. Atlantic Highlands, NJ: Humanities Press.

King, D. K., Glasgow, R. E., Toobert, D. J., Strycker, L. A., Estabrooks, P. A., Osuna, D., & Faber, A. J. (2010). Self-efficacy, problem solving, and social-environmental support are associated with diabetes self-management behaviors. *Diabetes* Care, *33*(4), 751-753.

Koome, F., Hocking, C., & Sutton, D. (2012). Why routines matter: The nature and meaning of family routines in the context of adolescent mental illness. *Journal of Occupational Science, 19*(4), 312-325. doi: 10.1080/14427591.2012.718245

Kroksmark, U., Nordell, K., Bendixen, H.J., Magnus, E., Jakobsen, K., & Alsaker, S. (2006). Time geographic method: Application to studying patterns of occupation in different contexts. *Journal of Occupational Science, 13,*11-16.

Law, M., Steinwender, S., & Leclair, L. (1998). Occupation, health and well-being. *Canadian Journal of Occupational Therapy*, *65*(2), 81-91.

Leeman, J. (2006). Interventions to improve diabetes self-management: Utility and relevance for practice. *The Diabetes Educator, 32*(4), 571-583. doi: 10.1177/0145721706290833

Lindbladh, E., & Lyttkens, C. H. (2002). Habit versus choice: The process of decision-making in health-related behavior. *Social Science & Medicine, 55*(3), 451-465. doi:10.1016/S0277-9536(01)00180-0

Lorig, K. R., Sobel, D. S., Stewart, A. L., Brown, B. R., Bandura, A., Ritter, P., & Holman, H. R. (1999). Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization. *Medical Care, 37*(1), 5-14.

Lorig, K. (2002). Partnerships between expert patients and physicians. *Lancet*, *359*(9309), 814.

Lorig, K., & Holman, H. (2003). Self-Management education: History, definition, outcomes, and mechanisms. *The Society of Behavioral Medicine, 26*(1), 1-7.

Matuska, K. M., & Erickson, B. (2008). Lifestyle balance: How it is described and experienced by women with multiple sclerosis. *Journal of Occupational Science, 15*(1), 20-26. doi: 10.1080/14427591.2008.9686603

Matsuka, K., & Christiansen, C. (2008). A proposed model of lifestyle balance. *Journal of Occupational Science, 15*(1), 9-19.

Mannay, D. (2010). Making the familiar strange: Can visual research methods render the familiar setting more perceptible? *Qualitative Research, 10,* 91-111.

McCollum, M., Hansen, L. S., & Sullivan, P. W. (2005). Gender differences in diabetes mellitus and effects on self-care activity. *Gender Medicine, 2*(4), 246-54.

J.T. Fitzgerald, J. Y., Davis, W. K., Connell, C. M., Hess, G. E., Funnell, M. M. & Hiss, R. G. (1996). Diabetes Care Profile [Survey Instrument]. Retrieved from http://www.med.umich.edu/mdrtc/profs/survey.html#dcp

Miles, M., & Huberman, M. (1994). *Qualitative analysis. An expanded sourcebook*, Thousand Oaks, CA: Sage.

Molyneaux-Smith, L., Townsend, E., & Guernsey, J. R. (2003). Occupation disrupted: Impacts, challenges, and coping strategies for farmers with disabilities. *Journal of Occupational Science, 10*(1), 14-20. doi: 10.1080/14427591.2003.9686506

Mulcahy, K., Maryniuk, M., Peeples, M., Peyrot, M., Tomky, D., Weaver, T., & Yarborough, P. (2003). Diabetes self-management education core outcomes measures. *Diabetes Educator, 29(5),* 768-770. doi:10.1177/014572170302900509

Naar-King, S., Podolski, C., Ellis, D. A., Frey, M. A., & Templin, T. (2006). Social Ecological model of illness management in high-risk youths with Type 1 Diabetes. *Journal of Consulting & Clinical Psychology*, *74*(4), 785-789.

Nagle, S., Valiant-Cook, J., & Polatajiko, H. (2002). I'm doing as much as I can: Occupational choices of persons with a severe and persistent mental illness. *Journal of Occupational Science, 9*(2), 71-81.

 Narayan, K., Boyle, J. P. Thompson, T. J., Sorensen, S. W., & Williamson, D., F. (2003). Lifetime risk for diabetes mellitus in the United States. JAMA, 290(14), 1884-190. doi: 10.1001/jama.290.14.1884

National Diabetes Information Clearinghouse. (2008). Diabetes prevention program (DPP). Retrieved from http://www.diabetes.niddk.nih.gov.

Newman, S., Steed, L., & Mulligan, K. (2004). Self-management interventions for chronic illness. *The Lancet, 364*(9444), 1523-1537. doi: 10.1016/S0140-6736(04)17277-2

Neal, D. T., Wood, W., Wu, M., & Kurlander, D. (2011). The pull of the past: When do habits persist despite conflict with motives? *Personality and Social Psychology Bulletin, 37*(11), 1428-1437.

Nilsen, W., Haverkos, L., Nebeling, L., & Taylor, V. (2010). Maintenance of long term behavior change. *American Journal of Health Behavior, 34*(6), 643-646.

Noar, S., & Zimmerman, R. (2005). Health Behavior Theory and cumulative knowledge regarding health behaviors: Are we moving in the right direction? *Health Education Research, 20*(3), 275-290.

Norris, S. L., Lau, J., Smith, S. J., Schmid, C. H., & Engelgau, M. M. (2002). Self-management education for adults with type 2 diabetes: A meta-analysis of the

effect on glycemic control. *Diabetes Care, 25*(7), 1159-1171. doi: 10.2337/diacare.25.7.1159

Orbell, S., & Verplanken, B. (2010). The automatic component of habit in health behavior: Habit as cue-contingent automaticity. *Health Psychology, 29*(4), 374-383. doi:10.1037/a0019596

Shook, J. R. (n.d.). Pragmatism's history. Retrieved from http://www.pragmatism.org/research/history.htm

Painter, J. E., Borba, C. P., Hynes, M., Mays, D., & Glanz, K. (2008). The use of theory in health behavior research from 2000 to 2005: A systematic review. *Annals of Behavioral Medicine, 35*(3), 358-362.

Peeples, M., Tomky, D., Mulcahy, K., Peyrot, M., & Siminerio, L. (2007). Evolution of the American Association of Diabetes Educators' Diabetes Education Outcomes Project. *The Diabetes Educator, 33*(5), 794-817.

Pentland, W**.,** & Harvey, A. S. (1999). Future directions. In W. Pentland, M. P. Lawton, A. S. Harvey, & M. A. McColl (Eds.), *Time use research in the social sciences* (pp. 259-261). New York: Plenum Publishing.

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

Pyatak, E. A. (2011). Participation in occupational and diabetes self-management in emerging adulthood. *American Journal Occupational Therapy, 65*, 462-469.

Raztan, N., Futeran, R., & Isakov, E. (2010). Indetifying predictors of function in people with diabetes living in the community. *British Journal of Occupational Therapy, 73*(6), 277-284.

Reed, K., & Sanderson, S. (1999). *Concepts of occupational therapy. 4th ed*. Baltimore: Lippincott Williams and Wilkins.

Reichard, P., Nilsson, B., & Rosenqvist, U. (1993). The effect of long-term intensified insulin treatment on the development of microvascular complications of diabetes mellitus. *New England Journal of Medicine, 329*(5), 304-309. doi: 10.1056/NEJM199307293290502

Reynolds, F. (2004). Textile art promoting well-being in long-term illness: Some general and specific influences. *Journal of Occupational Science, 11*(2), 58-67. doi:10.1080/14427591.2004.9686532

Riley, L. (2005). The sandwich generation: Challenges and coping strategies of multigenerational families. *The Family Journal, 13*(1), 52-58.

Riley, M. A. (1998). The effects of medical conditions on aging and hand function. *OT Practice, 3,* 24-27.

Rudman, D. L, Dennhardt, S., Fok, D., Huot, S., Molke, D., Park, A., & Zur, B. (2008). A vision for occupational science: Reflecting on our disciplinary culture. *Journal of Occupational Science*, *15*(3), 136-146.

Russell, L., Dong-Churl, S., & Safford, M. (2005). Time requirements for diabetes self-management: Too much for many? *Journal of Family Practice, 54*(1), 52-56.

Ryan, P., & Sawin, K. J. (2009). The individual and family self-management theory: Background and perspectives on context, process, and outcomes. *Nursing Outlook*, *57*(4), 217-225.

Scaffa, M. E., Van Slyke, N., & Brownson, C. A. (2008). Occupational therapy in the promotion of health and prevention of disease and disability statement. *American Journal of Occupational Therapy, 62*(6), 694-703.

Shubrook, J., & Schwartz, F. (2006). Time demands for diabetes self-care. *Diabetes, 55*(1), A199.

Cordova, J. S., Poole, J. L., Sibbitt, W. L., & Skipper, B. (2010). Quality of life in American Indian women with arthritis or diabetes. *American Journal of Occupational Therapy, 64*(3)*, 496-505.

Schulman-Green, D., Jaser, S., Martin, F., Alonzo, A., Grey, M., McCorkle, R., & Whittemore, R. (2012). Processes of self-management in chronic illness. *Journal of Nursing Scholarship, 44*(2), 136-144. doi: 10.1111/j.1547-5069.2012.01444.x

Sokol-McKay, D. (2011). *Occupational therapy's role in diabetes self-management* (Fact Sheet). Retrieved from American Occupational Therapy Association website: http://www.aota.org/Consumers/Professionals/WhatIsOT/HW/Facts/Diabetes.aspx?FT=.pdf

Sokol-McKay, D. A. (2010). Vision rehabilitation and the person with diabetes. *Topics in Geriatric Rehabilitation, 26*(3), 241-249.

Steed, L., Cooke, D., & Newman, S. (2003). A systematic review of psychosocial outcomes following education, self-management and psychological interventions in diabetes mellitus. *Patient Education and Counseling, 51*(1), 5-15. doi: 10.1016/S0738-3991(02)00213-6

Strauss, A. (1987). *Qualitative analysis for social scientists.* New York: Cambridge University Press.

Strauss, A. L., Corbin, J., Fagerhaugh, S., Glaser, B. G., Maines, D., Suczek, B., & Wiener, C. L. (1984). *Chronic illness and the quality of life*. St Louis, MO: The CV Mosby Company.

U.S. Department of Health and Human Services. (2012). 2012 HHS poverty guidelines. Retrieved from http://aspe.hhs.gov/poverty/12poverty.shtml

Vég, A., Rosenqvist, U., & Sarkadi, A. (2007). Variation of patients' views on Type 2 diabetes management over time. *Diabetic Medicine, 24*(4), 408-414. doi: 10.1111/j.1464-5491.2006.02064.x

Wagner, E. H., Austin, B. T., Davis, C., Hindmarsh, M., Schaefer, J., & Bonomi, A. (2001). Improving chronic illness care: translating evidence into action. *Health Affairs, 20*, 64-72.

Wang, C., & Burris, M.A. (1997). Photovoice: Concept, methodology, and use for participatory needs assessment. *Health Education and Behavior, 24*(3), 369-87.

Westley, L. J. (1991). Level I fieldwork is important to students' growth as professionals. *The American Journal of Occupational Therapy, 45*(2), 183-184. doi: 10.5014/ajot.45.2.183d

Whittemore, R., & Dixon, J. (2008). Chronic illness: The process of integration. *Journal of Clinical Nursing, 17*(7), 177.

Wilcock, A. (2006). *An Occupational Perspective of Health* (2nd ed.). Thorofare, NJ: Slack.

Wood, W., & Neal, D. T. (2007). A new look at habits and the habit-goal interface. *Psychological Review, 114*(4), 843-863.

Yerxa, E., Clark, F., Frank, G., Jackson, J., Parham, D., & Peirce, D., Stein, C., & Zemke, R., (1990). An introduction to occupational science, a foundation for occupational therapy in the 21st century. In Johnson, J., & Yerxa, E. (Eds.), *Occupational science: The foundation for new models of practice (pp.1-17).* New York, NY: The Haworth Press.