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“Knowing Where I Am At” The Experience of Self-Monitoring Blood Glucose for People  
with Non-Insulin-Requiring Type 2 Diabetes

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A dissertation  
presented to  
the faculty of the Department of Nursing  
East Tennessee State University

In partial fulfillment  
of the requirements for the degree  
Doctor of Philosophy in Nursing

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by  
Dana Elisabeth Brackney  
August 2010

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Dr. Joellen Edwards  
Dr. Patricia Hayes  
Dr. Gary Kukulka

Keywords: Self-Monitoring Blood Glucose (SMBG), Type 2 Diabetes, Personal  
Knowledge, Interpretive Description, Numeracy, Illness Experience

## ABSTRACT

“Knowing Where I Am At” The Experience of Self-Monitoring Blood Glucose for People with Non-Insulin-Requiring Type 2 Diabetes

by

Dana Elisabeth Brackney

Eleven participants living with non-insulin-requiring Type 2 Diabetes (T2DM) discussed their self-monitoring blood glucose (SMBG) experience. All had been recently diagnosed (< 2 years) and treated for diabetes with a self-regulating SMBG guideline for primary care practice. Their digitally-recorded interviews and photographed logbooks were analyzed thematically and interpreted through the lens of numeracy literature to answer 2 questions: 1. What is the meaning of SMBG among people with non-insulin-requiring T2DM? 2. How do people with non-insulin-requiring T2DM perceive the function of SMBG in diabetes self-management? The meanings of SMBG were patient competence, “It is easy, just a little pin prick”; patient control, “I can control it. It doesn’t control me”; and patient security, “It is not that way anymore.” Three periods of lived time were observed: *Diagnosis* “The numbers say I have diabetes”; *Behavior change* “I just can’t figure out why it does that”; and *Routine* “I make my numbers.” Prominent numeracy functions emerged by time period. During *Diagnosis* primary numeracy functions included comparing SMBG results to target values. Participants expressed this experience as, “I am some kind of O.K.” During *Behavior change* applied numeracy functions included taking medication correctly. SMBG readings were experienced as a clue to the diabetes mystery, sometimes confusing the participants, “I just don’t know why it does what it does,” or answering questions, “Now there is no question marks.”

Numbers motivated some people for action “The numbers get me out a walking” or restraint “If I didn’t have the numbers, I would be tempted to cheat.” During *Routine* interpretive numeracy functioned to aid the evaluation of the efficacy of participant’s health behavior change. Numbers had taken on meaning helping a person to “know where I am at.” Clinical implications are suggested including adjustments to the self-regulating SMBG guideline for primary care practice. Findings are discussed in relation to personal knowledge processes (Sweeny, 1994) and related SMBG research. Participants concluded that routine SMBG is essential to maintaining and restraining health behavior. This study provides a model for use of SMBG in diabetes self-management and patient perspectives on SMBG during the 2 years following T2DM diagnosis.

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## DEDICATION

This work is dedicated to those who live day in and day out with Type 2 diabetes and to the nurses who strive to understand how best to help people live well with diabetes.

Because it is the listening that I want, I want you to hear and hear between the words and know, what is this happening and how do I fix it? Not how do you fix it; but, how do / fix it. Because it certainly is not another... don't push another pill at me. Explain to me how I can help myself (study participant).

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## CHAPTER 1

### INTRODUCTION

#### Statement of the Problem

Type 2 diabetes mellitus (T2DM) is frequently diagnosed in the primary care office. The absence of evidence based guidelines for the use of self-monitoring blood glucose (SMBG) and the context-dependent use of SMBG contribute to the lack of uniform implementation and prescription of SMBG for the treatment of T2DM (ADA, 2009). With this diversity it is not surprising that studies evaluating the relationship between SMBG in T2DM and glycosolated hemoglobin (HbA1c) have demonstrated mixed results (e.g. Davis, Bruce, & Davis., 2007; United Kingdom Prospective Diabetes Study [UKPDS] group, 1998). A systematic review (Clar, Barnard, Cummins, Royle, & Waugh, 2010) of the value of SMBG in terms of glycemic control, hypoglycemia, quality of life, and cost per quality adjusted life year leaned heavily on the findings from the Diabetes Glycaemic Education and Monitoring study (DiGEM). Researchers concluded that SMBG was *likely* not cost effective due to the absence of evidence that SMBG users had a clinically significant reduction ( $\geq 0.5\%$ ) of HbA1c, a measure of average estimated blood glucose (BG) over the most recent 3 months. This systematic review concluded that research is needed to determine the type of SMBG education and feedback that is most beneficial, characteristics of patients who benefit from SMBG, best practice for timing and frequency of SMBG, and the circumstances under which SMBG causes anxiety or depression (Clar et al., 2010). With so much unknown about SMBG in T2DM, I chose to use a qualitative approach to study the meaning and function of SMBG for the person with non-insulin-requiring T2DM.

Practice guidelines developed by the American Diabetes Association (ADA; 2009) recommend using SMBG in T2DM to achieve self-management goals. However, not enough is known about how SMBG functions in T2DM to guide efficient use of SMBG. For example, the International SMBG Working Group (2007) acknowledged a lack of consensus for use of SMBG in T2DM and stated that three factors influence the use of SMBG: country of residence, diabetes treatment, and cost. Within the United States the ADA guidelines (2009) specify that testing should be sufficient to achieve glucose targets (fasting blood glucose (FBG) < 100 mg/dl and 2 hour postprandial < 160 mg/dl). Standards have not been established for optimal SMBG frequency or timing in patients with non-insulin-requiring T2DM using oral agents or medical nutrition therapy alone. The ADA guidelines (2009) recommend that SMBG begin in T2DM once HbA1c is greater than 6.5%; however, to date the ADA has not provided specific recommendations regarding the frequency and timing of SMBG in T2DM.

In addition to an absence of specific recommendations for SMBG, researchers have debated the value of euglycemia. Normal HbA1c is less than 6.0%. However, several prominent studies (Veterans Administration Diabetes Trial [VADT], 2009; The Action to Control Cardiovascular Risk in Diabetes [ACCORD] study group, 2008) did not demonstrate short- or long-term cardiovascular benefits for attaining HbA1c in patients with levels less than 6.0% (Duckworth et al., 2009; Skyler et al., 2008). A possible explanation for the lack of benefit is that although considered long-term, neither of these large studies exceeded 5 years of data collection, whereas previous studies reported longitudinal data beyond 10 years.



Both the Diabetes Control and Complications Trial (DCCT) and UKPDS have > 10 years of longitudinal data and researchers concluded that euglycemia was beneficial (Diabetes Control and Complications Trial Research Group, 1993; UKPDS Group, 1998). In Type 1 Diabetes the DCCT study findings included a 76% reduction in eye disease, a 50% reduction in kidney disease, and a 60% reduction in nerve disease. In T2DM the UKPDS study demonstrated a 21% reduction of risk for diabetes complications for each 1% reduction in mean HbA1c. The findings of these newer studies (ACCORD, 2008; VADT, 2009) have challenged the vascular benefit of euglycemia. As a result, both the ADA and American College of Cardiology have called for individualization of glycemic targets because both organizations consider the long-term effects of hyperglycemia deleterious to cardiovascular and neurological body systems (Skyler et al., 2008). The 2009 ADA guidelines recommended a HbA1c goal of on or around 7%. This context-dependent guideline demands more skillful application of diabetes therapies by practitioners.

In addition to therapeutic concerns, there is pressure to demonstrate the economic benefit of BG testing. The cost of most BG test strips exceeds 1 dollar per strip. Because many patients with diabetes qualify for Medicare, diabetes related costs consume 34% of the Medicare budget (Diabetes Report, 2008). Currently Medicare provides one BG test strip per day to beneficiaries with T2DM who are not using insulin. Therefore, prudent use of this resource is necessary. SMBG is likely to come under increased scrutiny as health care practices are reviewed within the current environment of health care reform, evidence-based practice, and cost containment. Researchers and

ultimately practitioners need to know more about the manner in which people use SMBG information to improve metabolic control.

Today physicians diagnose DM earlier in the disease process due in part to increased disease surveillance and changes in diagnostic criteria (ADA, 2007; National Institute of Diabetes and Digestive and Kidney Diseases, 2008). It is unclear to what extent those who are able to demonstrate metabolic control as evidenced by a HbA1c of less than 7.0% are benefiting from SMBG or other management efforts such as earlier initiation of medication. The increased number of people with T2DM who are testing their BG may not be related to the morbidity of diabetes. Instead, this increase may reflect changes in the availability of test materials (Center for Disease Control and Prevention, 2007). For example, many manufacturers provide glucometers to healthcare providers. These glucometers are given at no cost to patients who want to begin BG testing. Providing free glucometers to patients often benefits the glucometer manufacturer because patients must then purchase the test strips for the manufacturer's free glucometer. Therefore, the availability of free glucometers, combined with financial reimbursement for testing supplies may contribute to more frequent BG testing (Center for Disease Control and Prevention, 2007; Kelly, Ellison, Goldstein, Nomura, & Price, 2007; Li, Zhang, & Narayan, 2008). SMBG appears to be most effective when combined with intensive diabetes management (DCCT, 1993; UKPDS, 1998). In addition to the use of many classes of medication and more frequent dosing of medication, intensive diabetes management includes a team of professionals coordinating diabetes treatment (Bayless & Martin, 1998). Various diabetes professionals such as physicians, registered dietitians, exercise specialists, and

registered nurses monitor progress toward individualized goals, while supporting self-management skills and the personal efforts of people with diabetes (DCCT, 1993).

Although, SMBG shows clear benefits when used to adjust insulin dosages (common to Type 1 DM treatment), it is unclear that testing alone without the benefit of a diabetes health team or medication adjustment improves metabolic control.

In the Australian Fremantle Diabetes Study Davis, Bruce, and Davis (2006) found no association between glycemic benefit and SMBG testing or frequency for people with T2DM, regardless of medical treatment. The 5-year Fremantle study used a community based longitudinal and cross-sectional design ( $n = 1,286$ ). Kolb et al. (2007) concluded that this finding was flawed due to study design confounders with cross sectional designs not demonstrating the benefit of SMBG, but longitudinal studies supporting SMBG efficacy. This was attributed in part to the generally younger and higher HbA1c in those enrolled in the SMBG study compared to the control group. Davis et al. (2007) refuted this criticism and provided support for their original determination. However, the debate about the benefits of SMBG continues (e.g. Clar et al., 2010; McAndrew, Schneider, Burns, & Leventhal, 2007; McGeoch, Derry, & Moore, 2007; Welschen, Bloemendal, Nijpels, & Dekker, 2005).

The purpose of this study was to determine the perceived meaning and function of SMBG for people with non-insulin treated T2DM in primary care. In order to improve how DM health providers direct the use of this resource, diabetes health care providers need more information about how and why people use SMBG information. Knowing more about SMBG meaning and function for people with T2DM will likely strengthen the efficient use of SMBG. Specifically, this study addresses two research questions: 1.

What is the meaning of SMBG among people with non-insulin-requiring T2DM? 2. How do people with non-insulin-requiring T2DM perceive the function of SMBG in diabetes self-management?

In this study participants newly diagnosed with T2DM experienced a patient focused, self-regulating intervention using a self-regulating SMBG guideline for primary care practice (Appendix A). The participants were asked to discuss their experience with diabetes and SMBG. Their responses were analyzed to determine their perceived meaning and function of SMBG. Although HbA1c is an important measure of the metabolic health of participants, the focus of this study is the participants' experience of SMBG in the 2 years following diagnosis with T2DM.

#### Study Significance

DM is a chronic condition that often increases in severity over time and imposes significant personal and economic burden for those living with this disease. One diabetes health behavior is SMBG. The direct economic cost of SMBG is over \$350 US annually for a person with T2DM. Although the direct economic cost is easily measured, the personal burden of performing this behavior is variable. Approximately 18% of people with T2DM describe DM treatment as burdensome (Huang, Ewigman, Foley, & Meltzer, 2007). In addition to personal and financial costs, it is unclear how people with non-insulin-requiring T2DM can best use SMBG to improve DM outcomes (McAndrew et al., 2007). Broadly accepted as a cornerstone of personal self-care, some believe that SMBG was adopted without robust evidence of clinical efficacy (O'Kane & Pickup, 2009). People with DM need the most effective and least intrusive treatments. However, the efficacious use of SMBG in T2DM has yet to be determined.

## Assumptions

My decision to use a qualitative method to study people's experience with SMBG in the primary care office was influenced by both my experience working with people who live with DM and my experience reflecting on and analyzing the qualitative and quantitative studies surrounding DM self-management. Diabetes management may be more effective over the lifetime of the person with diabetes if behaviors associated with learning to live well with diabetes are initiated soon after a diabetes diagnosis. SMBG may provide the feedback that people with diabetes need in order to regulate their health behavior.

In every research endeavor there are both implicit and explicit assumptions. Beliefs about the nature of knowledge and the area of inquiry influence selection of research questions, study design, and methods. Assumptions in this and every study extend beyond those that are explicitly stated. Polanyi's (1966) essays on the tacit dimension and personal knowledge formed the philosophical context of this study and formed the basis for this study's assumptions. This study assumed that life-context is central to the meaning and function of SMBG and that personal knowledge influences the meaning and function of SMBG for the person with T2DM. Collectively, the assumption of this study was that people use SMBG by applying this information to their life-context in a way that is meaningful to them.

The first assumption was that life-context is central to the meaning of SMBG. Life-context is the sum of one's past, present, and anticipated future. Life-context likely influences the efficacy of BG testing strategies for people with non-insulin-requiring T2DM. Today people with T2DM may use SMBG to measure fasting BG, premeal BG,

and postmeal BG. People with T2DM have varied life-contexts. Often the only commonality evident between people with T2DM may be their diagnosis and treatment of DM. Diabetes health care providers advise people to rotate BG testing to different meals or times, resulting in broader testing contexts. Thus, people may test their BG at a variety of times but only once or twice each day. While some applications of SMBG such as preprandial and postprandial testing combined with fasting BG are considered more efficacious for metabolic control than fasting BG testing only, all of these strategies function to support the individual with diabetes. Diabetes health professionals provide BG targets that are dependent on life context. For example a BG of 135 mg/dl is considered elevated in a fasting state but is normal in a fed state.

The second assumption is that personal knowledge, conceptualized as experience, appraisal, and rational intuiting, influences the meaning and function of SMBG and results in a new pattern of behavior. This study explored Polanyi's (1966) philosophical understanding of individual experience alongside Sweeney's (1994) conceptualization of personal knowledge. Three attributes of Sweeney's definition of personal knowledge were considered: experience, appraisal, and rational intuiting.

Experience is considered in light of writings and research on illness experience (Keogh et al., 2007; Kleinman, 1988). Living well with diabetes requires attention to present health behaviors in order to prevent future health complications. People with T2DM describe self-management as a fluid experience (Rayman & Ellison, 2004). Together these works informed the assumption that the experience of living with diabetes influenced the meaning and function of SMBG.

Appraisal is considered in relation to self-efficacy and narrative. Self-efficacy is a forward looking appraisal, while narrative is a backward looking appraisal. Bandura's (1986) conceptualization of regulatory self-efficacy and the ensuing years of research on diabetes and self-efficacy inform this study's conceptualization of appraisal of future performance. Narrative is a retelling of one's experience (e.g., Broom, 2000; Frank, 1995). It is a meaning-making activity that communicates one's appraisal of his or her experience. Together these forward and backward looking appraisals inform this assumption that personal knowledge influenced the meaning and function of SMBG.

Finally, rationale intuiting, a third characteristic of personal knowledge, was considered in relation to a person's numeracy. Numeracy is the ability to comprehend meaning in numerical data. This study explored how people with T2DM interpreted and used SMBG information. A glucometer provides users with a BG reading in the form of a number. Therefore, numeracy was assumed to be one skill influencing personal knowledge of SMBG and the effective application of SMBG in diabetes self-management. For people with type 1 DM, SMBG informs daily medication adjustment and other self-care behaviors (DCCT, 1993). When daily medication adjustment is unlikely as in non-insulin-requiring T2DM the experience of SMBG needs further exploration to understand how numbers are used for self-management.

## CHAPTER 2

### REVIEW OF RELATED LITERATURE

The Diabetes Control and Complications Trial (DCCT Research Group, 1993) was a landmark study in the field of diabetes management. This longitudinal study established the causal relationship between hyperglycemia and diabetic complications. The study intervention included a multidisciplinary team of diabetes health professionals intensively managing patients with T1DM using SMBG. After researchers demonstrated the benefit of euglycemia, frequent SMBG became standard practice. This practice of SMBG was extended to those with T2DM as well. UKDPS (1998) was the first longitudinal study of people with T2DM. Researchers concluded that euglycemia benefitted health outcomes in T2DM and they supported the use of SMBG (UKDPS group, 1998). Today, with diabetes expenditures crippling health care budgets, the question of the cost effectiveness of SMBG, the value of euglycemia, and the function of SMBG have prompted researchers to revisit the benefit of SMBG. The following review of related literature explores the current health care context and what is known about the function of SMBG. In addition the philosophical, conceptual, and theoretical stance of this study is reported.

#### Health Care Context

Health professionals often identify the first symptom of DM, fasting hyperglycemia, in routine lab work. The majority of people with T2DM have insulin resistance combined with insulin deficiency (Fowler, 2010). Obesity is the primary cause of cellular insulin resistance. Insulin deficiency results when some pancreatic Beta cell function is lost due to age or pancreatic injury. Relative insulin deficiency occurs when



the demand for insulin is greater than the supply. Insulin deficiency and insulin resistance usually occur gradually during the 10-year period prior to a person meeting the diagnostic criteria for T2DM (Fowler, 2010).

### *Diabetes Diagnosis*

Prior to receiving test results both patients and providers may be unaware that BG levels are elevated. Rarely do patients attribute symptoms (e.g. fatigue, yeast infections, thirst) to underlying glucose intolerance or diabetes. In the primary care office patients respond to a diabetes diagnosis with disbelief, expressions of guilt, or a promise to do better. Receiving a diagnosis of T2DM initiates patients into the world of DM self-management. In a recent qualitative study women described feeling that they were not given enough information about DM when they were diagnosed (Matthews, Peden, & Rowles, 2009). To date no similar studies have been published for men diagnosed with DM.

Treatment for T2DM begins with lifestyle changes directed at weight loss and nutritional management (Fowler, 2010). Oral antidiabetic medications are added if glycemic values do not improve with lifestyle changes (Fowler, 2010). People with T2DM may see their diabetes symptoms disappear when they decrease their carbohydrate consumption, thereby lessening the need for insulin. They also may increase their activity in order to reduce weight and decrease insulin resistance. However, over time many people experience a decreased effectiveness in their initial lifestyle changes (Fowler, 2010). At this point medications in one or more classes of oral antidiabetic agents (e.g. biguanide, sulfonylurea, thiazolidinedione) are added to further improve metabolic control.

Diabetes self-management is comprised of daily activities including exercise, dietary modification, stress management, and monitoring. The demands of these activities may increase in complexity over time. Huang et al. (2007) reported that although the majority of the patients surveyed ( $n = 701$ ) indicated that diabetes management was not burdensome, up to 18% of people with T2DM would be willing to give up 8 out of 10 healthy years if they could avoid life with diabetes treatments. Many diabetes educators consider SMBG a foundation of diabetes self-management because prior to SMBG testing people with DM and diabetes educators did not have meaningful information about BG response to dietary intake, exercise, or medications. SMBG is a tool that people with DM and health care professionals use to evaluate the effectiveness of educational, behavioral, and medical therapies. Although SMBG is used extensively in both T1DM and T2DM, its use in non-insulin-requiring T2DM is not clear (McAndrew et al., 2007; McGeoch et al., 2007; Welschen et al., 2005). Living well with diabetes requires many health behaviors that are believed to improve metabolic control. Diabetes self-management is a collection of health behaviors adopted by people living with diabetes. Health professionals inform people with impaired fasting glucose or new onset T2DM that adopting diabetes health promoting behaviors improves metabolic control and contributes to overall health. Although the etiology of T2DM likely has a genetic component, many people with T2DM express feeling that their behavior (eating sugar, gaining weight) caused their diabetes, and thus their illness was their own fault (Broom & Whittaker, 2004).

The ADA (2007) recommends daily exercise and dietary restrictions for the initial treatment of T2DM. These lifestyle changes introduce patients to diabetes self-care,

also called diabetes self-management. Initially, depending on the person's dietary history, he or she is instructed to remove concentrated sweets and limit carbohydrate (45-60 grams per meal) and fat consumption (< 30% of total daily calories) (Fowler, 2010). In addition, depending on exercise and medical history, diabetes health professionals instruct the patient to increase activity (usually walking) to 30 minutes a day (Fowler, 2010).

### Diabetes Health Promoting Behavior

#### *American Association of Diabetes Educators-7 (AADE-7™)*

Over the past decade the American Association of Diabetes Educators (AADE) has defined diabetes health promoting behaviors. Peeples, Tomky, Mulcahy, Peyrot, and Siminerio (2007) reported in their historical account of the evolution of the AADE-7™ that the AADE reached consensus on the seven behaviors essential to diabetes health promotion in 1997. These behaviors were trademarked in 2006 as the AADE-7™. The AADE-7™ is healthful eating, being active, monitoring, taking medication, problem-solving, healthful coping, and reducing risks (Peeples et al., 2007). In 2006 the AADE chose the chronic care model as its practice model (Peeples, 2006). This selection further defined the organization's theoretical context for diabetes management.

#### *Monitoring*

The AADE-7™ behavior termed monitoring includes daily SMBG, regular assessment of blood pressure, and assessment of weight. Although all three are important health measures, SMBG is the focus of this review. Glucometer manufacturers have worked to improve the ease of use and accuracy of BG testing. Two recent improvements in glucometers include devices that do not require manual

coding and those that use a smaller blood sample (< 3 microns). Laboratory regulators recommend the use of a control solution to determine the accuracy of the glucometer; however, this practice does not account for sample variations due to the person's own blood sample or testing technique (Arabadjief & Nichols, 2006).

User and environmental characteristics that may interfere with accurate testing include low hemoglobin, hematocrit, mean cell volume, and dialysis (Arabadjief & Nichols, 2006). Extreme temperatures interfere with the accurate functioning of glucometers and test strips. Obtaining a capillary sample may force cellular components to dilute the sample through maceration of the puncture site. Hand lotion and soap can interfere with results. Miscoding and improperly stored test strips also contribute to glucometer inaccuracy. Some people express doubts about the accuracy of their glucometers. When people retest within minutes of an earlier test and obtain a different result, conflicting findings weaken their trust in their glucometers' accuracy. The perceived trustworthiness of BG readings may influence people's self-management experience (Polonsky & Skinner, 2010).

### *Data Management*

Logbooks and electronic management of BG data have limitations due to the contextual meaning of BG readings. In my experience people often find it difficult to understand how to enter their readings into logbooks. Electronic data management systems need to be checked for accurate date and time stamps. When the date and time stamp is incorrect the data stored are much less meaningful. Practitioners are not usually paid for the evaluation of e-mailed logbooks or data. It is difficult for people to provide enough information about their life context in logbooks. For example a reading

at 1:00PM may be after or before lunch. If people do not code the relationship of their reading to their meal the reading is less meaningful to the practitioner. Understanding the BG context improves the usefulness of BG data.

### *The Function of SMBG in T2DM*

SMBG is a specific skill that is easy to perform. Young and old alike are physically capable of testing their BG. However, it is the cognitive response to numerical information that is challenging. Recently McAndrew et al. (2007) reviewed the efficacy of SMBG. Researchers concluded that “there is a need for studies that implement all the components of the process for self-regulation of SMBG to assess whether patient use of SMBG will improve HbA1c levels” (p. 992). The authors identified seven behaviors necessary for implementation of SMBG in diabetes management:

1. Know how to take a reading.
2. Understand when the reading is above or below target values.
3. See the connection between deviant readings and prior behavior.
4. Have and implement an action plan to control glucose levels.
5. Rely more heavily on SMBG readings and give less weight to subjective feelings of well-being and possibly false signs of hypoglycemic distress.
6. Create simple action plans that will allow the patient to integrate them into his or her ongoing life patterns, the use of SMBG, and the behaviors needed for effective blood glucose management.
7. Evaluate glucose reading in a nonjudgmental framework. (p. 1006)

These seven behaviors informed the content development of the interview guide (Appendix C) for the current study. This study explores the meaning and function of

SMBG among participants who experienced a self-regulatory approach to diabetes self-management.

### Metabolic Control

Diabetes is a disorder of carbohydrate metabolism. There are now four indicators of a diabetes diagnosis (ADA, 2010). The first is a random BG greater than 200 mg/dl with symptoms. The second is a fasting BG greater than 126 mg/dl measured on more than one occasion. The third is an oral glucose tolerance test with a 2-hour postload BG greater than 200 mg/dl. In January of 2010, the fourth indicator, HbA1c  $\geq$  6.5%, was approved by the ADA after an international committee assembled by the ADA, the International Diabetes Federation, and the European Association for the Study of Diabetes discussed diagnostic parameters for T2DM using HbA1c values (ADA, 2010; Saudek et al., 2008). Sandbaek, Lauritzen, Borch-Johnsen, Mai, and Christiansen (2005) determined that capillary whole BG and venous plasma glucose were equivalent in the identification of disease. Although these values are essential for diagnosis, it is impractical to measure BG continually in order to measure an average BG. Therefore, the HbA1c is a practical approximation of these values for ongoing measurement of metabolic control (Manley, 2008). Impaired fasting glucose, also called pre-diabetes, is defined as having a fasting BG greater than 100 mg/dl but less than or equal to 125 mg/dl (ADA, 2009). Type 2 diabetes mellitus is a metabolic disorder with a single diagnostic criterion, hyperglycemia, but a variety of etiologies (Fowler, 2010).

### *HbA1c*

HbA1c measures the overall glycemic control of diabetes. As an outcome measure it is diagnostic, evaluative, and predictive of future disease (DCCT Research

group, 1993). HbA1c approximates average BG values over the preceding 2 to 3 months (Fowler, 2010). Predictive of future health status, 50% of the HbA1c value represents the previous month's average BG, while 25% represents each of the distant 2<sup>nd</sup> and 3<sup>rd</sup> month's average BG (Rohlfing et al., 2000)

In their recent work, Monnier, Colette, Dunseath, and Owens (2007) described the progressive loss of glycemic control in T2DM. They used continuous glucose monitoring to examine BG patterns by time of day and created 4 HbA1c groups: ≤6.4%, 6.5%-6.9%, 7.0%-7.9%, 8.0%-9.0%. They observed stepwise BG changes between groups of people with T2DM classified by HbA1c values. The first significant difference was between people with HbA1c values less than 6.5% and those with HbA1c values between 6.5% and 6.9%. Those with the higher HbA1c (6.5%-6.9%) had deteriorated daytime postprandial BG control. The second significant difference occurred when fasting blood glucose (FBG) deteriorated. Those with better metabolic control (HbA1c 6.5% - 6.9%) had better FBG than those with HbA1c values between 7.0% and 7.9%. Finally, those with the highest HbA1c values (HbA1c 8.0%-9.0%) had significantly elevated nighttime BG. This observed progression supports the use of HbA1c to guide DM treatment plans. Specifically, treatment focused on postprandial BG values may benefit patients when HbA1c is above 6.5% despite near normal FBG levels. These findings provide a context for using HbA1c levels to guide the timing of SMBG. For example if a patient's HbA1c is 6.7%, one may assume that fasting BG is not as elevated as after meal BG readings. Therefore, focusing SMBG on postprandial testing may be more clinically efficacious in this context.

### *Influences on HbA1c*

Although widely accepted as reliable and valid, the use of HbA1c in research and practice does have some caveats. First, there are several chemical processes for obtaining an HbA1c reading. Different HbA1c analyzers may have results that may or may not be comparable across methods (Sacks et al., 2002). Second, the use of HbA1c to measure improved DM management may be a function of the time of year at measurement instead of a function of the experimental manipulation. Dasgupta et al. (2007) confirmed this observation and reported on two other studies and four letters to the editor that discussed a seasonal phenomenon in the Northern Hemisphere where elevations of HbA1c were observed during winter months and decreases in HbA1c were reported during summer months. Third, HbA1c results may vary due to patient factors such as hemoglobinopathies, hemolytic and iron deficient anemia, vitamin C and E consumption, and hypertriglyceridemia (Sacks et al., 2002). This seasonal variation is important because a change in HbA1c of 0.5% is considered significant (Clar et al., 2010). Researchers could falsely claim or disclaim the significance of their study findings due to seasonal variation.

### *Targets*

Despite analyzer and individual variation, it is generally accepted that a HbA1c greater than 7% places an individual at increased risk for diabetes related complications (DCCT Research group, 1993). According to Dhatt, Agarwal, and Bishawi (2005) a reading that is less than 6.3% is considered good BG control. The American College of Endocrinology and the ADA have identified different goals for HbA1c. The American



College of Endocrinology has set a target of less than or equal to 6.5%, while the ADA has set the target of less than 7.0% (Jellinger, Lebovitz, & Davidson, 2006).

In 2008 the ACCORD study researchers randomly assigned 10,000 people with T2DM to either an intensive glycemic control group or a standard care group in order to evaluate the heart disease imposed by diabetes. However, researchers stopped the ACCORD study when the intensively treated group (HbA1c goal < 6.0%, achieved median < 6.4%) had a significantly higher risk of mortality than the standard treatment group (HbA1c goal 7.0%-7.9%, achieved median < 7.5%). All participants had T2DM and two or more heart disease risk factors (The ACCORD Study Group, 2008). The cessation of the ACCORD study and the variable standards for the target HbA1c demonstrated the absence of clear evidence supporting a specific HbA1c target for people with diabetes.

In addition, the Veteran Administration Diabetes Trial (VADT) study of 1,791 veterans with suboptimal T2DM concluded that intensive glucose control had no significant effect on the rates of major cardiovascular events, death, or microvascular complications (Duckworth et al., 2009). The participants in the ACCORD study achieved lower HbA1c results than the most intensively controlled participants in the VADT study. In their position paper, endorsed by the American Heart Association, the American College of Cardiology, and the ADA, Skyler et al. (2008) supported the hypothesis that glycemic control early in the course of T2DM benefits coronary vascular disease outcomes. In addition, these organizations recommended HbA1c targets less than 7.0% and stressed the need for individualized care (Skyler et al., 2008).

### *HbA1c Knowledge*

In addition to the evidence that near-normal HbA1c may have a negative effect on mortality in some subsets of people with diabetes, knowledge of HbA1c values did not improve metabolic control. In 2005, the ADA launched a campaign to increase awareness of the HbA1c. Heisler, Piette, Spencer, Kieffer, and Vijan (2005) found that only 25% of the 686 people who had tested their HbA1c in the past 6 months accurately reported their HbA1c value. Heisler et al. determined that no association existed between knowledge of HbA1c and a respondent's diabetes related self-efficacy or reported self-management behaviors. Therefore, although there are many influences on metabolic control, Heisler et al. concluded that knowledge of HbA1c is useful, but it is not sufficient to improve diabetes self-management.

Many people with T2DM have difficulty understanding the meaning of their HbA1c (Heisler et al., 2005). For this reason HbA1c is a stronger outcome measure than a potential influence on metabolic control. The work of Heisler et al. (2005) champions a movement away from reporting of HbA1c values to patients. Manley (2008) suggested providing patients with an estimated average BG value. This value may be more easily integrated into patients' understanding of diabetes because it contains the same units as the BG reading they use every day. Manley (2008) anticipated that this estimated average BG derived from the HbA1c value will lead to better understanding of metabolic control by patients and better treatment by professionals. The International Federation of Clinical Chemistry and Laboratory Medicine regard this estimation as analogous to the estimated glomerular filtration rate (Manley, 2008). In addition recognizing that people do not easily interpret their HbA1c

values may be an important step towards improving communication of diabetes related to health numeracy.

### *Metabolic Indicators*

There are several other indicators of diabetes metabolic control including triglyceride levels, waist circumference, and daytime postprandial BG. Insulin resistance worsens metabolic control by decreasing the sensitivity of the action of insulin on peripheral tissues (Fowler, 2010). Two indirect measures of insulin resistance are triglyceride values greater than 150 (Nakamura et al., 2008) and waist circumferences greater than 102 cm in Caucasian men and greater than 88 cm in Caucasian women (Bari, Ostgren, Rastam, & Lindblad, 2006). The BG response to carbohydrate consumption varies throughout the day in people with and without diabetes. However, BG values greater than 140 mg/dl, 2 hours following a 60 gram carbohydrate meal, are believed to contribute to poor metabolic control. Although these measures of metabolic control (insulin resistance, glucose tolerance) are useful in the understanding and treatment of diabetes, at this time the best overall measure of glycemic control is HbA1c.

### *Medications*

Anti-diabetic medications are some of the most effective interventions for improving metabolic control. The effect of various anti-diabetic medications on HbA1c is well documented (Bolen et al., 2007). A single class of medications (e.g. sulfonylurea, biguanide) may lower HbA1c by as much as one percentage point (Bolen et al., 2007). For example Metformin (a biguanide) alone could lower a HbA1c from 7.5% to 6.5%. Although monotherapy is often desirable, combination therapies have additive effects

resulting in an additional one percentage point absolute reduction in HbA1c over monotherapy (Bolen et al., 2007).

The factors that influence metabolic control are many and varied. These factors include the person and his or her genetic and behavioral disposition, other medications such as steroids that elevate BG values, central obesity, smoking, stress, activity, and eating habits all of which influence carbohydrate metabolism. The beneficial effect of medication for diabetes metabolic control is not disputed. Rather than attempting to isolate each of these many influences on metabolic control, the current study seeks to examine SMBG holistically in the context of the person's experience of living with T2DM.

### Personal Knowledge

#### *Philosophical Foundation*

Polanyi (1966) in his book *The Tacit Dimension*, provided the philosophical foundation for this study. Polanyi defined tacit knowledge as knowing more than we can tell. Polanyi's epistemological beliefs define knowledge as containing a functional, phenomenal and semantic structure. He also defined an ontological structure of knowledge. This ontological structure described knowing as being embodied in the physical experience of living.

#### *Functional Structure*

People exhibit the functional structure of knowing by attending to the proximal (unaware) to avoid or in anticipation of the distal (aware) (Polanyi, 1966). People with T2DM exemplify this anticipatory functional structure in diabetes self-management when they fully integrate diabetes health promoting behaviors into their lives in anticipation of

improved health outcomes. Conversely a person who does not change his or her meal pattern in order to avoid conflict represents Polanyi's avoidant functional structure.

Some women maintain their family's dietary traditions in anticipation of their family's love and support (unaware). These women want to avoid the conflict that might come with change (distal aware). At times people who are not working on changing behavior are unconsciously living in a manner consistent with a perceived benefit like love and support in order to avoid a perceived loss such as the loss of affirmation.

### *Phenomenal Structure*

Polanyi's (1966) second knowledge structure, the phenomenal structure of knowing, interprets life events as understanding beyond the naming of the event. It is this phenomenal structure that gives meaning. This structure is exhibited by an awareness of that from which we are attending to another thing in the appearance of that thing (Polanyi, 1966). In diabetes-management people exemplify this phenomenal structure of knowing when feelings are given meaning. For example when people see an elevated BG reading, they may interpret this as a personal failure. Or people may believe that they will become an amputee because of a DM diagnosis. The interpretive effort creates meaning from the physical experience of living with diabetes.

### *Semantic Structure*

The semantic structure of knowing is exhibited through attending to the meaning of its impact on us in terms of its effect on distal objects (Polanyi, 1966). SMBG results exemplify a semantically structured knowledge. In diabetes self-management people use SMBG results (as a distal object) that have been given meaning by diabetes professionals. A person with diabetes defines a BG as elevated if it is greater than 180

mg/dl. He or she may not experience a bad feeling with an elevated reading. In fact, many people say they feel better when their BG is elevated. The elevated BG result (distal object) imparts a semantically structured meaning of poor future health (elevated BG = poor metabolic control = poor future health).

### *Ontological Structure*

Finally, the ontological structure of knowledge occurs when bodily experiences translate into meaning. Bodily experiences may be innate and internal actions that we are incapable of controlling or even feeling. The ontological structure of knowledge occurs when we become aware of subliminal processes inside our body in order to perceive outside objects. “By elucidating the way our bodily processes participate in our perceptions, we will throw light on the bodily roots of all thought” (Polanyi, 1966, p.15).

Personal knowledge is expressed in diabetes management when a person says, “I’m diabetic.” This expression is an ontological knowledge of the diseased body defining the way that people think about life and therefore the way he or she will live. Not all people with diabetes come to know themselves in this way. Indeed, people may define themselves in other bodily ways, such as equating large size with strength and vigor. This ontological knowledge may explain why each person with a diabetes diagnosis cannot integrate similar educational or behavioral interventions into his or her life in the same manner.

Polanyi (1966) also discussed the role of pattern understanding. He stated that we may lose sight of a pattern by dwelling on the particulars too much. However, “. . . the detailing of particulars, which by itself would destroy meaning, serves as a guide to their subsequent integration and thus establishes a more secure and more accurate

meaning of them” (p. 19). This observation is congruent with the finding that adults use estimation in much of their everyday application of mathematical information, as reported in the numeracy literature (Ancker & Kaufman, 2007). It follows that an estimate may be more meaningful than an exact figure.

In my diabetes practice I use estimation of patient data to make medication adjustments. A patient testing more frequently at times of hypoglycemia or conversely following BG closely on a day that hyperglycemia is present easily skews mean BG values. The adjustment of medication based on numerical data alone without an understanding of context could be devastating to metabolic control. This example supports Polanyi’s statement, “Speaking more generally, the belief that, since particulars are more tangible, their knowledge offers a true conception of things is fundamentally mistaken” (1966, p. 19). It is with this philosophical stance of looking at particulars embedded within their context that this study bases its understanding of truth.

### *Concept Analysis*

Sweeney’s (1994) derived definition of personal knowledge provided a conceptual definition for this phenomenon. Sweeney defined personal knowledge as:

Recognition of a new pattern through processing by the human being. The processing may consist of any combination of human and environmental interaction (experience), rational intuiting, appraisal, active comprehension, and personal judgment, all in a setting of departure from the current conceptual framework. The personal knowledge may be new

only to the individual or to all of humanity. It is the individual's perception of the personal knowledge which denotes its presence. (p. 919)

### *Pattern Recognition*

Accepting Sweeney's (1994) definition, pattern recognition is the outcome of personal knowledge. Pattern recognition is a clinical skill used by diabetes health professionals for adjustment of medications, meals, and activity (Linekin, 2002). Some people living with diabetes also recognize patterns in their diabetes management. SMBG provides information that informs the appraisal of control over one's metabolic experience.

Linekin (2002) assisted DM professionals in pattern recognition by providing a table that displayed the interpretation of BG results by time of day. This table included possible causes of and possible solutions for high and low BG readings. I have observed that people with diabetes appraise these values differently than diabetes professionals. For example people will say that their BG is doing well. With further investigation they report fasting readings greater than 140 mg/dl, a value most DM professionals would define as too elevated. Understanding the process of pattern identification and interpretation may be central to understanding the impact that SMBG has on metabolic control.

### *Personal Knowledge Processes*

Experience, appraisal, and rational intuiting are three of the five processes that Sweeney (1994) suggested could be combined to reach a new pattern of personal knowledge. Although the other two processes of personal knowledge, active comprehension and personal judgment, are not included here as primary processes



they will likely be evident within the process of appraisal. It is the interpretation of these processes that may influence metabolic control.

The following review of the literature explores diabetes research in relation to these processes. Experience is examined in light of illness experience literature. Appraisal of past performance is examined with research on making meaning with personal narratives (story). Appraisal of future performance is considered in light of research on diabetes and self-efficacy. And finally rational intuition is examined with emerging literature on numeracy.

### *Illness Experience*

Frank (1995) proposed four body problems that people work to resolve over the course of their life. These four general problems are control, desire, body-relatedness, and other-relatedness. Each of these four problems has an associated continuum of possible responses that in turn create a matrix of ideal body types. For example in the general problem of control the continuum of body responses are predictability at the highest level of control and contingency when forces that cannot be controlled are at work. Recognizing that no one individual would exemplify a single ideal type, Frank's disciplined body or dominating body were two possible ideal types in response to the problem of control. Broom and Whittaker (2004) examined the narratives of 119 people living with diabetes. They concluded that meanings of control are at the core of the moral discourse surrounding life with diabetes. According to Frank (1995) a desire for control is central to the disciplined body. However, Broom and Whittaker identified chaos narratives as central in their participants' experience. In Frank's conceptualization of chaos narratives people are unable to act to communicate their overwhelming needs.

This combination of the body's need for control with the inability to express its need and take action towards control likely creates a barrier to self-management.

Recently researchers have begun exploring illness narratives as an avenue for increased understanding of behavior and in order to identify models that explain illness experiences (Broom, 2000). In my practice as a Board Certified-Advanced Diabetes Manager many people master the physical skill of SMBG testing. However, individual application and interpretation of SMBG is variable. Some people dread SMBG. Others perform the skill routinely. Some find the BG information helpful. Some only test when they believe they will obtain a "good" reading. Others test only when they do not feel well. SMBG provides people with their BG value for a moment in time. The individual must interpret whether that value is on its way up or down, whether it is high or low, and whether he or she needs to take action based on the reading. In sum the understanding of the reading is much more complex than the skill performance required to obtain the reading.

Individuals develop personal knowledge of diabetes through SMBG. Kleinman (1988) discussed the meaning of illness for people with chronic diseases. He stated that meanings ". . . communicated by illness can amplify or dampen symptoms, exaggerate or lessen disability, impede or facilitate treatment" (p. 9). For example people living with diabetes may realize that eating certain foods elevates their BG. They may observe that physical activity decreases BG. However, others may not experience clarity in interpreting their readings. They may find no patterns and no explanatory models for their BG response. In turn they may feel defeated in their efforts at self-management.

Personal knowledge differs from general knowledge. One may know theoretically that eating cake elevates BG; however, one may not see this response personally. Personal knowledge is a different way of knowing about diabetes. Personal knowledge comes from the experience of living with the disease. McAndrew et al. (2007) described this knowledge as subjective and stated that it is a less desirable guide than the objective BG readings. In contrast the current study examined the person's creation of meaning for symptoms with SMBG. The subjective symptoms that people experience are not invalid; however, SMBG should be used to confirm that the interpretation matches the BG reading. The wife of a man with DM told me that, "Every time he says, 'I feel funny', I get the juice ready because he is having an insulin reaction." This feeling was confirmed with a continuous glucose monitor that clearly demonstrated his rapid decline in BG. I am comfortable with this person's, "I feel funny" as a measure of impending hypoglycemia (phenomenological structured knowing). To disregard the confirmed human experience to the deference of numerical data seems incomplete as both subjective and objective knowledge provide information necessary for self-management.

Self-management literature describes three ways in which people integrate their experience with illness and their self-identity: integrating, separating, and vacillating. Aujoulat, Marcolongo, Bonadiman, and Deccache (2007) observed that handing over control is as important to empowerment as the process of gaining control. They described how both 'letting go' and 'hanging on' were important self-processes influencing self-management. In their case study, Tilden, Charman, Sharples, and Fosbury (2005) described one woman's experience living with diabetes. This woman

separated her identity from her diabetes and became motivated to self-manage. In contrast people who accepted asthma, another chronic disease, as part of their identity demonstrated better self-management (Jones, Pill, & Adams, 2000). In these examples either holding disease out as separate or integrating disease supported self-management.

Rayman and Ellison (2004) studied diabetes self-management among women. In their study women “engaged and adjusting” to diabetes management “expressed a degree of success in management and spoke of a life goal and having diabetes in the context of their life” (p. 908). These women were able to navigate the rules of diabetes by approaching management with flexibility and appraising diabetes management as “doable”. They succeeded in preserving their self-identities by holding loosely to management ideals. These women vacillated between the demands of self-management and their life context. The women neither embraced fully nor separated diabetes from the self. In this way the literature demonstrated three effective models (integrating, separating, and vacillating) of self-management and provided insight into the personal knowledge and fluid processes of successful managers of chronic disease.

#### *Appraisal of Past Experience: Narrative Knowing*

In addition to the specific relationship between SMBG and interpretation of readings, the person’s life likely influences health in ways that may be less overt. Story is one means of developing personal knowledge. Many people express their appraisal of experience through personal narratives. Over a 10-year period Broom (2000) identified 347 patients with both physical symptoms and an apparently relevant story that he categorized as: “(1) Physical disorder with onset apparently associated with

significant emotional material or life events; (2) Physical disorder with apparent metaphorical or symbolic meaning; (3) Physical disorder with apparent meaning which is neither metaphorical nor symbolic” (p. 166). Skillful health care providers listen to life events and the meaning people find in their stories. These interpretations of the self and health may provide an ontological structured knowledge that contributes to people’s success as self-managers.

Frank (1995) identified narratives common to illness experience. His writing was congruent with Polanyi’s (1966) understanding of the body’s need for a voice. Frank stated that a common bodily response to illness is story; however, story may not reveal all personal knowledge. As Polanyi defined, tacit knowledge knows more than can be told; therefore, personal knowledge may be unaware and unexpressed. Frank has identified four common narrative forms that people use to express their illness experiences. These forms included the restitution narrative, the chaos narrative, the quest narrative, and the testimony. According to Frank restitution narratives dominate our society and tell an illness story with a time sequence such as, “I found out I have diabetes, I still have elevated blood sugar; but, I am losing weight and will be healthy soon.” The chaos narrative is the opposite of the restitution narrative (Frank, 1995). It tells a story of being overwhelmed and lacks a coherent beginning, middle, and end. Frank defined the quest narrative as a story that takes the form of accepting illness and using it to transform the person’s life. In the quest narrative people own and express their illness experience as a journey. Finally, the testimony differs from the previous three narrative forms. In a testimony people are not reporting on what they saw; they report on who they are through their living bodies (Frank, 1995). Frank concluded that

being a witness to a person's illness narrative is an important means of supporting the person experiencing an illness. Researchers identified chaos narratives as central to their participants' experience of T2DM (Broom & Whitaker, 2004). Being a witness to a chaos narrative is the most difficulty in our social context (Frank, 1995); however, these narratives are common to the T2DM experience. Learning to recognize and listen to the chaos narrative is likely important for practitioners working with people who have T2DM.

#### *Appraisal of Future Behavior: Self-Efficacy*

Self-efficacy can be considered an appraisal of future behavior. Hurley and Shea, (1992) reported that the earliest conceptual work with self-efficacy and diabetes was Crabtree's 1986 dissertation. Hurley and Shea (1992) demonstrated the role of self-efficacy and diabetes self-management among individuals with complex insulin regimes. Prior to 1986 the role of self-efficacy and health behavior had been studied in relation to smoking cessation, weight loss, and rheumatoid arthritis pain management. Since 1986 researchers have published thousands of studies examining the relationship between self-efficacy and diabetes self-management.

*Self-efficacy's attributes.* Self-efficacy contributes to the process of personal knowledge development. Belief not action is the central characteristic of self-efficacy (Bandura, 1997). Self-efficacy is a cognitive event that is distinct from action. Thus, people can perform health behaviors yet believe that they were not able to accomplish these tasks. Self-efficacy is a belief about oneself and one's world that has many influences on future behavior while also being influenced by the environment, past experience, and other people. Efficacy beliefs are variable across several dimensions

(Bandura, 1997). According to Bandura (1997) these beliefs differ in level, generality, and strength.

The first self-efficacy dimension, level, is defined as ranging from simple to complex (Bandura, 1997). Although researchers have defined health behaviors or interventions as simple or complex, no studies were identified that defined self-efficacy itself on a continuum from simple to complex (Clark, Hampson, Avery, & Simpson, 2004; Sturt, Whitlock, & Hearnshaw, 2006). Perhaps it is assumed that simple behaviors require simple self-efficacy. Although it appears that the level of self-efficacy is closely related to the behavior's complexity, this was not discussed in any of the theoretical or experimental research.

The second self-efficacy dimension, generality, can be expressed as general or task specific (Bandura, 1997). This dimension was broadly discussed in some of the DM research (Rapley & Fruin, 1999; Senecal, Nouwen, & White, 2000; Skelly, Marshall, Haughey, Davis, & Dunford, 1995). Rapley and Fruin (1999) examined the relationship between general and task specific efficacy to discuss conceptual issues related to self-efficacy. Experimental studies examined for this review reported task specific self-efficacy measures (Clark et al., 2004; Gerber et al., 2005; Lorig, Ritter, Laurent, & Plant, 2006; Siebolds, Gaedeke, & Schwedes, 2006). Bandura (1997) conceptualized a bidirectional relationship between general self-efficacy and task specific self-efficacy. He theorized that as the strength of general self-efficacy increased, the strength of task specific self-efficacy would also likely increase. However, Sousa, Zauszniewski, Musil, McDonald, and Milligan (2004) reported that general self-efficacy was a poor predictor of behavior.

The third self-efficacy dimension, strength, is characterized by the degree of tenacity with which one holds to self-efficacy beliefs and results in perseverance (Bandura, 1997). Schlenk and Boehm (1998) attempted to strengthen self-efficacy beliefs through the use of contingency contracts. Contingency contracts make an individual aware of potential barriers to behavior performance while planning to overcome these performance barriers. DM health professionals often use contingency contracts as an intervention during motivational interviewing. Theoretically, the action of planning to overcome barriers increases the strength of self-efficacy beliefs (Schlenk & Boehm, 1998). Van der Bijl, van Poelgeest-Eeltink, and Shortridge-Baggett (1999) structured the Self-Efficacy type 2 tool to measure the strength dimension of self-efficacy. Of the three self-efficacy dimensions (level, generality, strength), they concluded that strength is a more powerful predictor of self-efficacy than complexity or specificity (van der Bijl, van Poelgeest-Eeltink, & Shortridge-Baggett, 1999). This means that the perseverance of an individual is more predictive of health behavior than the complexity of the task.

*Self-regulating efficacy.* In addition to these three dimensions characteristic of self-efficacy, Bandura (1997) identified several broad types of self-regulating efficacy including initiating efficacy, recovery efficacy, and maintenance efficacy. These descriptors of self-efficacy are abstract enough to apply to any use of the concept of self-efficacy, but they are especially applicable when permanent behavior change is desired. Initiating efficacy is the belief that one can begin to perform a behavior. Recovery efficacy is the belief that one can return to the desired behavior if one has



stopped performing the behavior. Maintenance self-efficacy is the belief that one can continue a desired behavior indefinitely.

Self regulating-efficacy, with its emphasis on perseverance, appears to have a good fit with the demands of a chronic disease such as DM. However, with the exception of Determination Theory little has been written about the role of regulatory efficacy in health behavior models or experimental studies. Although thousands of studies employ the concept of self-efficacy, a 2007 Pub Med search for the related concept, regulatory self-efficacy, identified only 106 studies. Only one study of DM and the self-regulatory model of illness was identified (Keogh et al., 2007). This family-based intervention study is believed to be the first to incorporate evidence from illness perceptions research with poorly controlled diabetes (Keogh et al., 2007). Most quantitative studies of DM and self-efficacy do not measure the regulatory functions of initiating, recovery, and maintenance efficacy. However, qualitative studies have described people's DM self-management as fluid (Rayman & Ellison, 2004). This finding that people with T2DM move in and out of performing DM self-management behaviors is consistent with the theoretical descriptions of self-regulating efficacy. The concept of regulatory self-efficacy is important to the theoretical perspective of the current study as it is an appraisal of future behavior, a process of personal knowledge development.

#### *Quantitative Knowing: Rational Intuition*

Unlike the ambiguity of self-perception, there is some agreement among diabetes health professionals as to the meaning of BG values. Meanings health professionals ascribe to BG values are consistent with Polanyi's (1966) semantic structure of knowledge. Diabetes health professionals provide patients with individualized target BG

values based on time of day and in relation to eating and activity. Although the targets are somewhat static, the BG number is not static or formulaic. Instead, the quantitative information provided by SMBG must be interpreted in the context of a person's life. In this way and over time a rational activity becomes intuitive (Sweeney, 1994). The patient's capacity to understand and integrate these values into health behavior requires rational intuition.

### *Numeracy*

Rational intuition is one process of personal knowledge development as defined by Sweeny (1994). Numeracy is the ability to understand numerical information. Numeracy informs diabetes self-management. Evans (2000) defined health numeracy as the "degree to which individuals have the capacity to access, process, interpret, communicate, and act on numerical, quantitative, graphical, biostatistical, and probabilistic health information needed to make effective health decisions" (cited in Golbeck, Ahlers-Schmidt, Paschal, & Dismuke, 2005, p. 375). Golbeck et al. (2005) provided clarification of the numeracy literature by proposing a definition of numeracy that encompassed four broad categories: basic, computational, analytical, and statistical. Each numeracy category is conceptualized as building upon the other; therefore, they are not exclusive. Most numeracy skills used in SMBG are contained in the first three categories (basic, computational, analytical). However, even the fourth category, statistical numeracy, may be asked of people with diabetes. For example people with diabetes may be asked to discuss the percentage of time their fasting BG is at their target. Statistical numeracy may be helpful to patients as they predict and interpret their pattern of BG in relation to their diabetes self-management behaviors. In

this way numeracy influences people's ability to use SMBG information for self-management.

A 2008 Pub Med search for the concept "health numeracy" identified 61 articles. Twenty-three of the articles focused on the evaluation of risk (probability). Eleven articles remained when the search was limited by 'English language', 'age > 19,' and excluded those studies associated with 'risk or probability.' The earliest article was published in 1995. The results included an article on the development of numeracy measures (Baker, Williams, Parker, Gazmararian, & Nurss, 1999). The only disease-specific numeracy studies focused on anticoagulation (Estrada, Martin-Hryniewicz, Peek, Collins, & Byrd, 2004) and asthma (Apter et al., 2006). With the exception of these examples, the remaining numeracy research has focused on helping people understand their risk for disease and their risk for cancer recurrence or survival based on treatment options.

Ancker and Kaufman (2007) evaluated the numeracy literature in the context of the entire system of health communication, not "solely (a product) of the individual patient's skills" (p. 714). Their review considered the verbal communication skills of the information provider and the design of information systems (e.g. documents). Altogether they identified eight factors of a health communication system that contribute to the beneficial use of quantitative information in health management. They recognized that numerical ability was distinct from its application for health decision making. For example someone with math ability alone would not be able to interpret BG values without also understanding the function of diabetes health behaviors on the BG value.

DM self-management involves responding to a wide variety of personal health information as well as understanding how to translate what is observed into health behavior. Estimation and graphical literacy are two skills important to SMBG. Estimation is a quantitative skill useful in real-world problem solving. Adults use estimation in many day-to-day mathematical calculations such as when they estimate the size of a serving of food. Graphical literacy is helpful for use of SMBG logbooks. The ability to place data in rows and columns helps patients visualize their data by time of day. Some glucometers provide graphs of BG data. Visualizing data with a graph and recognizing patterns may assist patients in diabetes self-management.

In addition Ancker and Kaufman (2007) reported that unlike readability level assessments of documents, there are no tools to assess the quantitative demands of written communication. Numeracy instruments are available (e.g. Baker et al., 1999). However, there are no tools to evaluate the ability of providers to communicate information about numbers. Finally, Ancker and Kaufman concluded:

Our framework suggests that the divide can be narrowed by educating not only patients but also information providers. Furthermore, by enhancing the design of health-related systems and documents, the informatics community can help improve the fit between task demands and individual competencies, helping consumers use quantitative information to make genuinely informed decisions about health. (p. 719)

Schapira et al. (2008) developed a framework for health numeracy after analyzing audio and videotaped participants (n=50) in focus groups. Their framework was conceptualized as a triangle divided into three sections. The base of the triangle

contained primary numeracy skills such as counting and adding. The middle section contained applied numeracy skills such as taking medication correctly. And the highest level contained interpretive numeracy. Although similar to Golbeck et al.'s (2005) definition of health numeracy, Schapira et al.'s hierarchy was unique in its addition of the interpretive domain. They defined the interpretive domain as, "The ability to understand the strengths and limitations of numbers to represent health or disease states, the efficacy of an intervention, or other expected health outcomes" (Schapira et al., p. 507). In addition, the concept of uncertainty, representative nature of numbers and recognition of individual or biologic variation in expected outcomes is important to interpretive numeracy ability.

Interpreting BG values is a complex numerical skill to communicate and to comprehend. The efficacy of SMBG is likely influenced by both the health care provider's ability to communicate numerical information and the patient's application and interpretation of that information. In diabetes self-management, health numeracy may improve people's decision making and ultimately their metabolic control.

### Summary

This literature review considered the experience of living with T2DM in the context of 20 years of DM self-management research. I examined three areas of inquiry proposed to contribute to metabolic control: health care context, DM health promoting behavior, and personal knowledge. First, I considered the health care context of a person with non-insulin-requiring diabetes. Next, I explored the many contributions to and meanings of metabolic control. HbA1c is considered the best measure of effective diabetes management, although it is not without limitations. Finally, I considered how

illness experience, narrative, self-efficacy, and numeracy contribute to the process of personal knowledge development in T2DM.

In this review I recognized the role of health promoting behavior for metabolic control and accepted the AADE-7™ as a proxy for diabetes health promoting behavior. I focused on one health behavior, monitoring (SMBG), and its numeric contribution to pattern recognition and the DM illness experience. Several qualitative studies described people's DM self-management as a flexible experience moving in and out of performing DM self-management behaviors (e.g. Aujoulet et al, 2007; Jones et al., 2000; Rayman & Ellison, 2004; Tilden et al., 2005). This flexibility is consistent with the conceptualization of self-regulating efficacy. Self-regulating with SMBG is believed to influence the efficacy of SMBG for metabolic control (Clar et al., 2010).

This study is important because the experience of learning self-regulating with SMBG has the potential to influence the health outcomes of people with T2DM. Researchers (e.g. McAndrew et al., 2007; McGeoch et al., 2007; Simon et al, 2008) want to evaluate the efficacy of SMBG in T2DM. However, few qualitative or quantitative studies (e.g. Furler et al., 2008; Keogh et al., 2007; Siebolds et al., 2006;) were identified that examined SMBG in the context of a self-regulating intervention. In this study people recently diagnosed with T2DM who had experienced a self-regulating intervention using SMBG discussed their diabetes experience.

## CHAPTER 3

### METHODS

The research objectives of this study were to describe the meaning and function of SMBG among people with non-insulin-requiring T2DM who experienced a personalized self-regulating SMBG guideline for primary care practice (Appendix A). SMBG is a complex behavior, and its interpretation and application are context dependent. The characteristics of complexity and context dependence are congruent with qualitative methodology by allowing the exploration of phenomena holistically, while also focusing on the human experience (Thorne, Kirkham, & O'Flynn-Magee, 2004). The use of qualitative methodology was implemented in order to avoid early reduction of data that may have inadvertently prevented a fuller understanding of the SMBG experience for people with T2DM. The choice of this methodology was consistent with Polanyi's (1966) emphasis on the tacit dimension of knowledge. Polanyi's twofold focus is on the whole, with a suspicion of the particular for understanding truth and on the interpretive effort that creates meaning from the physical experience of living.

Approval from East Tennessee State University's institutional research review board (IRB) was obtained prior to initiation of the study. The researcher informed each participant of the study purpose and obtained written informed consent. The consent form (Appendix B) indicated that the study investigated the meaning and experience of self-monitoring blood sugar, the participants were not required to participate, and if they chose to participate, they could withdraw from the study at any time without penalty. All participants signed the consent form prior to participation in the study. They were given their identification number and the researcher's phone number. Participants could ask to

be removed from the study at any time prior to its submission to the graduate school by presenting their identification number to the researcher and asking to be removed. No participants chose to withdraw from the study.

In order to maintain privacy during the interview the researcher met with each participant in a private room. In order to maintain participant confidentiality the researcher maintained one file containing names and the corresponding consent forms. This information is stored in a locked file cabinet in the researcher's home office. Research documents contain an identification number corresponding to each participant's personal data sheet. Research materials including digital recordings will be maintained for at least 10 years in accordance with IRB policy.

In order to explore the experience of living with diabetes and the use of SMBG, the researcher interviewed participants with an open-ended interview guide (Appendix B). For example the researcher asked, "Tell me about being diagnosed with diabetes. What is the earliest memory of diabetes that you have?" Responses in one interview would influence questions asked in a subsequent interview. For example an early participant spoke about her fears related to diabetes. Others then were directly asked about fears if they did not initiate this topic. In this way the interviews evolved over time, although the central questions in the interview guide remained constant for all of the interviews. All interviews were digitally recorded. In addition to the audio recording participant logbooks were examined for material evidence of the SMBG experience. These logbooks were photographed or photocopied.

In her critique of qualitative description Sandalowski (2009) discussed the challenges of characterizing qualitative methods. However, she did not advocate for a



particular descriptive method. In contrast Thorne et al. (2004) outlined the objectives, mechanisms, and product of interpretive description for nursing research. They proposed use of interpretive description for the study of complex clinical phenomena. In turn the clinical usefulness of the research product was used as a measure of study rigor. In this study thematic analysis and interpretive description were used as research methods, allowing the focus of understanding to remain imbedded in the context of the participant's life even as the researcher worked to understand the meaning and function of a given SMBG experience.

### Sampling

The study participants were people with non-insulin-requiring T2DM managed in a family practice office. Theoretical sampling using Monnier et al. (2007) HbA1c categories was employed in order to represent the diversity of participant HbA1c levels at diagnosis. In this study Monnier et al.'s third (HbA1c 7.0%-7.9%) and fourth (HbA1c 8.0% - 9.0%) HbA1c categories were combined and defined as HbA1c  $\geq$  7.0%. Participants in this study were selected based on their HbA1c at diagnosis:  $\leq$  6.4%, 6.5%-6.9%,  $\geq$  7.0%. In addition to their HbA1c, participants were selected if they had been recently diagnosed (less than 2 years) with T2DM. People who have had a recent life changing experience such as being diagnosed with diabetes are likely to articulate their responses to that experience soon after the event differently than they would articulate the experience later due to the influence of history and personal interpretation (Fereday & Muir-Cochrane, 2006). Therefore, people diagnosed with T2DM within the past 2 years or who recently initiated SMBG were invited to participate. Although not a cultural group in the traditional sense, the primary care office and its pattern of T2DM

management was considered a shared experience for the purposes of this study. Sampling continued until data saturation was achieved as determined by the researcher and endorsed by the advisory committee.

### Participants

Fifteen people met the inclusion criteria and were invited to participate in this study. Eleven people chose to participate. Two of the four people who did not participate had agreed to be interviewed; however, they became unavailable for interview due to prolonged family or personal illness. The other two simply declined participation. Following study protocol they were not contacted again for inclusion. Of the two men and two women who did not choose to participate, one man and one woman did not routinely use SMBG. Although this study included one participant who did not often use SMBG, the decision not to participate by low frequency testers may indicate a different perspective on SMBG that is not as represented in this study. Other than this difference, the four nonparticipants had similar treatments and HbA1c levels to those who participated.

The seven female and four male participants were asked to describe themselves. Eight of the participants had lived with diabetes for less than a year. The median time diagnosed with diabetes was 6 months. The majority was self-described “country folk,” whose parents and grandparents had lived their lives in the southern Appalachian Mountains. Most participants had farming backgrounds. Two participants had lived more than 40 years in the county and were now retired from professional employments one as a minister and the other as a teacher. Three participants had more recently (5-30 years) moved to the area for retirement or employment in a trade such as a house

painter. Table 1 presents participant age, HbA1c, and BMI. Three participants were of normal weight. Five participants were overweight and three participants were obese. The three obese participants were also the youngest participants. The three normal weight participants were also the oldest. All participants who followed up had improved their HbA1c values (Table 1).

Table 1

*Participant Age, HbA1c, and BMI (n= 11)*

	Age	HbA1c at Diagnosis	HbA1c at Follow-up  n=10	BMI
Range	47-73	6.3-9.6	5.5-7.0	22.7-42.2
Mean	62	7.3	6.2	29.2
Median	63	6.9	6.1	26.6

Four participants achieved an improved HbA1c through diet and exercise alone. Another three participants used a total daily dose of 500-1500 mg of Metformin along with life-style changes such as diet and exercise. One participant was prescribed the maximum total daily dose of Metformin (2000 mg). Two participants combined the maximum dose of Metformin with either Glimiperide 4 mg or Actos 45 mg daily. One participant was unable to tolerate Metformin and used Glipizide 10 mg with lifestyle change to achieve improved glycemia. Despite the January end point of the study, when seasonal variations historically inflate Hba1c values (Dasgupta et al., 2007), all participants demonstrated improved glycemia.

## Study Setting and Context

All participants receive their medical care in a family practice office in southern Appalachia. These participants live in an area that is considered rural; however, a mid-sized university is also located within the county. The family practice is staffed by a Medical Doctor certified in family medicine, a Physician's Assistant, and a Registered Nurse certified as both a Certified Diabetes Educator and Advanced Diabetes Manager. The researcher developed a self-regulating SMBG guideline for primary care practice (Appendix A). The self-regulating SMBG guideline conformed to a structured 20-30 minute office visit with the Certified Diabetes Educator and focused on patient needs, mutually established goals, and diabetes educational principles. Approximately 1 year prior to the proposal for this study, this pattern of practice was loosely implemented in our primary care office. The self-regulating SMBG guideline for primary care practice was adapted to individual patient needs.

## Data Collection

My work as a diabetes educator and my role in designing and implementing the self-regulating SMBG guideline for primary care practice meant that I was both a researcher and an object of my study. Therefore as part of my data set, I reflected on my diabetes practice and wrote memos each week for 1 month prior to my data collection with participants. I discussed these written reflections with my advisor prior to beginning data collection.

## *Personal Knowledge*

In my practice I have heard many people's explanatory models for their diagnosis of diabetes. People living with diabetes value these stories, and I am honored to have

witnessed them. During the first visit to my practice a patient usually addresses the unspoken concern of “why do I have diabetes?” Having witnessed people struggle to understand their questions of “why me?” and “what is diabetes,” I often use SMBG to help each person define his or her diabetes story. One way I use SMBG is to help people confirm their diagnosis. In this way I have had a likely influence on the participants’ stories that I studied.

Following IRB approval I invited five people in each of the three HbA1c categories to participate in the study based on their recent HbA1c levels as documented in their medical records. Once selected they were given a letter of invitation and consent documents describing the purpose of the study. The following week a research assistant contacted people by phone and invited them to participate by stating the purpose of the study and reminding them that there was no penalty for nonparticipation. Participants were asked to bring their glucometers and logbooks to the interview at a mutually acceptable interview time.

Monnier et al.’s (2007) HbA1c categories informed the theoretical sample. This included four participants with HbA1c  $\leq$  6.4%, three participants with HbA1c 6.5% - 6.9%; and four participants with HbA1c  $\geq$  7.0%. After obtaining informed consent, the participants answered demographic questions and provided a participant self-description (Appendix D). Then I conducted a semistructured interview with an openness to interrogate topics that the participant brought to the interview. For example some participants had questions about other medical tests or needed prescriptions for blood glucose testing supplies. Some also talked about smoking cessation or the death of family members. I spent time listening to these concerns and addressing participant

needs. While the topic of SMBG was unlikely to create strong emotional reactions, participants were reminded during the interview that they were not required to continue if the conversation created discomfort for them. None of the participants appeared distressed or asked to stop the interview. Seven participants brought glucometers and logbooks; these were photographed or photocopied. Written notes about the logbooks and photocopies of the logs were made of selected materials.

### Data Analysis

Data analysis began with the writing of memos following the first participant interview. The memos generally took the following form: analytical notes including self-critique, impressions of significance, common and unique themes, and topics to investigate further. Notes were made during the interview and afterwards with an emphasis on other areas to explore in the subsequent interviews. Participants were asked to clarify or expand on their statements. Tentative findings or experiences were directly clarified or explored with later participants.

The digital recordings were transcribed verbatim following each interview. In addition photos and copies of BG logbooks were examined for further understanding of the diabetes and SMBG experience. Once transcripts were completed segments of text that contained units of meaning were highlighted using the comment feature in Microsoft Word 2007. I analyzed the recorded interviews by coding units of meaning using the constant comparison technique. I conceptualized this analysis as vertical within the individual interview. After the completion of the 11<sup>th</sup> interview, I performed an analysis that I considered horizontal. This analysis began by clustering units of meaning across interviews to form 21 themes. I continued to analyze the recorded interviews by coding

units of meaning using the constant comparison technique, at the same time focusing on the whole of the life story that the participant discussed. After clustering the units of meaning, I discussed thematic groupings with my advisor. Next, general and unique themes from all the interviews were selected and formed into a composite around three broader time periods in the diabetes experience: SMBG and diagnosis, SMBG and behavior change, SMBG and routine. In addition, the photos of logbooks were examined as documents and contributed to the data set of participant's SMBG experience. The visual data were compared to the narrative data for similarities and differences and incorporated into the analysis. Finally, an interpretation of the SMBG experience was developed and represented using participant language and theoretical groupings (Figure 1). In this way logical consistency was demonstrated through a step-by-step analytical process in formulating themes from participant data (Fereday & Muir-Cochrane, 2006).

This interpretation was placed in a diagram and shown to five people who had participated in the study and one person who had also experienced the self-regulating SMBG guideline for primary care practice (Appendix A) but had not participated in the interviews included in the study findings. The diagram included participant language and illustrated SMBG functions with flow chart symbols (Figure 1). Participants were also provided with a list of SMBG meanings derived from the data. They were asked to consider their experience and how it was similar and different to the interpretation. I took notes on their responses to the diagram and SMBG meanings. The section *Considers* was first represented with "It is just a mystery to me." Three participants said, "It wasn't a mystery to me. I knew why I had it." Although they applied this statement to the period

of diagnosis, and this statement was intended to reflect the beginning of behavior change, in order to clarify the diagram, this representation was changed to *Considers* “I just don’t know why it does that.” The new language was adopted after Figure 1 was shown to a participant with both the revised and original language. Figure 1 was folded vertically to emphasize the two distinct time periods (diagnosis and behavior change) represented in the diagram and the word choice was further discussed with a participant. This is one example of developing congruence between the researcher’s constructs and the experience of common-sense in the everyday life of participants (Fereday & Muir-Cochrane, 2006). In this way adequacy of the model was supported. Future adoption of the findings in nursing practice will be further evidence of adequacy.

Finally, the data are presented in Chapter 4 (Findings) with the participants’ own language directly quoted with acknowledgement of the context surrounding each narrative. This representation of the data and findings demonstrated rigor by preserving the participants’ subjective interpretation. This rigorous and iterative process of interviewing, concurrent clarification and exploration of both spoken and unspoken experiences of SMBG, self-reflection, thematic analysis of transcripts, comparing and contrasting interviews, generating findings, member checking findings, returning to the interviews and summarizing each as a whole resulted in a descriptive interpretation of the experience of SMBG for people with non-insulin-requiring T2DM who experienced a self-regulating model of care using SMBG. This description included findings of both the meaning and function of SMBG for self-management in the 2 years following a diagnosis of T2DM.



## CHAPTER 4

### FINDINGS

In this study all of the participants shared a recent experience of being diagnosed with T2DM. They were introduced to SMBG in a primary care office. The sample was theoretically selected based on the participant's HbA1c at diagnosis. The HbA1c provided an approximation of the physiologic variation in the pattern of deteriorating euglycemia.

Deterioration of postprandial hyperglycemia precedes deteriorating fasting hyperglycemia in those with the lowest HbA1c (Monnier et al., 2007). It was anticipated that this physiologically observed difference between HbA1c groups would influence the SMBG experiences of those who otherwise experienced a similar diagnosis and treatment. Surprisingly, those with the lowest HbA1c ( $\leq 6.4\%$ ) expressed more concern over unexplained fasting hyperglycemia than those with the highest HbA1c ( $\geq 7.0\%$ ). Based on Monnier et al.'s observation that fasting hyperglycemia deteriorated in the 6.5%-6.9% HbA1c group, the lowest HbA1c group ( $\leq 6.4\%$ ) would likely observe postprandial hyperglycemia prior to fasting hyperglycemia. Participants seemed to accept that eating would elevate their BG. However, it was the fasting BG readings that caused concern in the HbA1c  $\leq 6.4\%$  group. Indeed, those with the lowest initial HbA1c ( $\leq 6.4\%$ ) values expressed less acceptance of their diagnosis when compared to those with the highest HbA1c ( $\geq 7.0\%$ ). In addition to the influence of HbA1c on the diabetes experience, the experience of having or not having family members with diabetes appeared to shape participants response to diagnosis. Despite these observed

variations, the narratives surrounding the diagnosis of diabetes were similar across the theoretically determined groups.

The narratives and logbooks provided rich data to answer the research question: What is the meaning and function of SMBG among people with non-insulin-requiring T2DM? Because most participants had recently been diagnosed with diabetes, the meaning and function of SMBG was integrally related to the experience of being diagnosed and to initiating health behavior change. First, the diagnosis of diabetes was either expected or unexpected. The diagnosis itself was experienced as a “shock”, a “relief”, or a “wake-up call”. Participants worked to find an explanation for why they had diabetes. It was in this context that SMBG was introduced to the participants. Several participants explicitly stated that because of diabetes they no longer felt invincible. However, most were able to easily perform the SMBG test, and this made them express statements of competence. Participants who struggled to believe they had diabetes reported that SMBG confirmed their diagnosis by removing, “question marks.” As the experience of diabetes created a fear of loss of health, SMBG functioned to comfort participants when they were able to “see” their readings and know they were “some kind of O.K.” As participants worked to understand their readings, SMBG readings confronted them with questions like “what is it about your digestion or whatever makes it do that?” In addition SMBG caused them to consider new information in a variety of life situations, sometimes surprising participants that “one little item could make it go so high.” When people changed dietary and activity behavior, SMBG congratulated their efforts by rewarding them with improved BG values, “I just feel real happy when I make my numbers.” Participants did not want to test less than once a day if they could afford

test strips. To them SMBG meant they were in control and doing something about their health behaviors, “It is not that way anymore.” For these participants with non-insulin-requiring T2DM SMBG meant “I am competent”, “I am in control”, “I am doing something about it”, and “I know it is not that way anymore.” Furthermore, SMBG functioned to confirm diagnosis “the numbers say I have diabetes”; comfort “I am some kind of O.K.” and “I like to know where I am at”; cause consideration of health behavior “I just don’t know why it does that”; and congratulate “I am doing something about it.” (Table 2).

Table 2

*SMBG Meaning and Function*

Meaning	Function
I am competent.	It confirms my diagnosis.
I am in control.	It comforts me.
I am doing something about it.	It causes me to consider my behavior.
It is not that way anymore.	It congratulates me.

Diagnosis

*Experience: “I am no longer invincible.”*

For many the diagnosis of diabetes meant no longer feeling invincible. One man said, “Well it was kind of I thought, I was almost invincible. I didn’t think it would happen to me.” Likewise, a woman said:

I think all of us, probably in a little sense, want to be invincible. But then when it comes to roost at our doorstep, it is a little different because you hear people having this or that or doing this or that. You hear these stories about these

people who have to... taking 3-4 shots a day 3-4 pills a day. You think, 'I don't want to be there.' I mean, it is good if it's there because I need it [medication]; but I don't want to be there.

*"Unexpected" or "In the Back of My Mind"*

Although most participants were surprised by their diagnosis, those without diabetic family members and those of normal weight were especially unsuspecting. A participant without diabetic family members stated, "I always have had that stereotype thing that you have to be fat. There is nobody in the family that has diabetes, on my side of the family." Another participant said:

Well it was... it was very strange because I am the only one in my family that is diabetic. My grandparents were not. My parents were not; of course they died very young. My mother was 47 and my dad was 52. So [pause] and I have no cousins. But no, I have no cousins or anything.

In contrast other participants with family members who had diabetes spoke of wondering if they would be diagnosed. "My mom had diabetes, and I always wondered if I would get it." Others knew they were at risk but were still hopeful that they would not "get it":

Maybe you will be this generation that gets skipped. Maybe my sister had it and I won't get it. You think, you really, you think about the possibility, but then you kindly sweep it under the rug and hope it doesn't happen. But I have lived like I say, and had it in the family for basically all my life, or a big part of it, since I was a child. My father lost both legs. Probably a lot of it was from diabetes, but he had circulation problems, too.

Others described putting the thought of diabetes in the back of their minds. “I put the whole concept in the back of my mind, knowing that my mother died with it.” In addition another participant described being both surprised and suspecting:

I guess I was surprised, but my family has a history of it, so you almost wonder if in your life sometime, with it being kind of a hereditary thing, if it wouldn't happen.

It is something you never want to hear, because it can change your lifestyle.

One female participant was not shocked but did not welcome the news of her diabetes diagnosis, “I have really lived with the concept and seen about it, and I have a sister that's insulin dependent diabetes. It is not really a shocking thing, but I didn't want it.” Despite the knowledge of their risk most of these participants still experienced a combination of surprise and an acknowledgement that they had expected a diagnosis of diabetes. In this way expecting a diagnosis of diabetes was most often related to the context of family members with diabetes. However, it was the diagnosis itself that brought that distant thought out in the open and into the person's consciousness. Many people also identified the cause of diabetes as genetic, and this along with the high incidence of diabetes influenced their perception of personal responsibility for their health. “Well, for one, it is something that I inherited. So, you know, I don't take the blame. I would take the blame, if I totally ignored all the advice. Then, I think the blame would be on me...”

*“A Shock”, “A Relief”, “A Wake-Up Call”, “A Cold-Hard Realization”*

In addition to being shocked by the diagnosis, most participants reported being surprised because of a lack of symptoms that they identified as being related to diabetes prior to the diagnosis, especially when no family members had diabetes, or

when participants had normal weights. Most participants had no bodily symptoms that foretold their diagnosis. Only two people reported symptoms of diabetes, and they had the highest initial HbA1c readings. This participant expressed how she would have recognized her symptoms as diabetes if she had known more about diabetes. “I had it, if I had knowed better the symptoms really well.” Another participant said, “I am just thankful it was caught when it was because it could have went on and done damage to me.” In addition for some participants finding an explanation for symptoms brought simultaneous feelings of “relief” and “devastation”:

It was kind of devastating, but also kind of a relief. Because, that is why I am getting tired and that is why and my breast is sore right now, and they said that could be a sign of being overweight and having sugar.

Despite not recognizing diabetes related symptoms, many participants reported feeling significantly better once their hyperglycemia improved. However, the relationship between their bodily symptoms and the diagnosis of diabetes did not immediately present itself to the participants. Later as participants reflected on how they felt before and after diagnosis and treatment, some were able to see this connection between disease and symptoms.

Participants also interpreted the diagnosis experience as a “wake-up call.” Here, three different participants described how this wake-up call was also a call to action:

So, it [diabetes diagnosis] was a wake-up call, I think, to change some habits.

Yeah, it is kind of a wake-up call, you think, OK we want it 80 to 110 or 70 to 110, and here you’ve got 140 or even 130, that is not acceptable.

I hope that maybe it [diabetes] will extend it [life]. I hope that this is a, what do you say? I don't know, maybe this is a real, cold, hard, realization or something. Maybe it [knowing about diabetes and changing lifestyle] will extend it [life], because I do have enough gumption to make a difference.

Often participants followed initial descriptions of shock, unwelcome diagnosis, and loss of invincibility with stories of amputations and the death of people they knew and loved who also had diabetes. A common expression was that diabetes was a "death threat." One participant explained how this threat structured her initial response to the diagnosis:

This was sort of like a death threat at the beginning, and so you really did everything boom, boom, boom, you know? But then you feel ahh. It is not like your cholesterol. It is not like your blood pressure. I mean I can feel when my blood pressure goes up and down. But this sort of is sneaky.

Another participant said, "You know, [pause] it comes down to a point that it can kill you, you know?" and another male participant said:

It isn't like a terminal thing but you should be aware of diabetes, and what the traits are and test for family history and that sort of stuff too. I put the whole concept in the back of my mind, knowing that my mother died with it. She had diabetes.

One younger participant considered his life trajectory based on his diagnosis and anticipated living a shorter life:

They all had diabetes. They all had heart disease. I don't, I can't think of anybody from the past couple of generations who has lived past their mid 60's. Yeah, that was my frame of mind. Well, I figured that is how much time I have left, about 20 more years or so.

One participant described her response to being scared by her diagnosis:

*A time to "Look to the Lord for strength".* It really scared me. Well, for a while, I was just really confused. And, I don't know, I guess I run my blood sugar up, you know, with everything that was going on with my eye, and that the cancer in my family, and everything else. I usually, you know, look to the Lord for strength. And He has give it to me. I lost a son back in the year 2000. I couldn't have got through that without the Lord. Carried me the day of the funeral. I just I knowed I couldn't do it. My son had 3 little boys, and I knowed I had to be strong for them and for my husband. And I couldn't have without the help of the LORD. I knowed [sic] then that He could get me through whatever come into my life. Because... it is losing a child... it don't matter if he is 37...it don't matter how old they are, they are your baby. So anyway, I do look to the Lord a lot for help and manage to deal with all the things that comes on [home]. He has been a real strength for me.

As this narrative illustrated a diagnosis of diabetes was often a time when people reflected on other losses in their lives. In addition to the death of this adult son, two other women told stories about the deaths of teenage daughters. Participants who told stories of loss usually presented these narratives as a quest (Frank, 1995). In these examples the quest narrative ended with participants reporting being stronger because of their life difficulties. Participants evaluated their diagnosis with diabetes as a threat



but considered the experience of other life-difficulties as a resource for adapting to a change in health status

Many people indicated that the fear of amputations or death motivated them to pay attention to their own diabetes:

My husband used to work with somebody who was a severe case. He ended up dying of it. They were amputating more and more you know of his toes and feet and stuff like that. That was the worst case I have ever seen. He was really sick. Another participant said, “My father lost both legs. Probably a lot of it was from diabetes, but he had circulation problems too.” One participant clearly identified her fear of amputation along with the reassurance her nonsmoking provided:

Of course now, I don’t want to have my leg amputated, and things like that, so there might be some of that fear in the background, I could see that that is a possibility. I don’t smoke and stuff which my dad did which attributed [*sic*] to that, but I am sure the sugar diabetes did not help, I don’t want that.

One participant discussed a personal knowledge of the dangers of diabetes:

Yeah, it sure is because like I said, you know, I saw so many of my daddy’s family loose limbs. And right now, my last aunt that is left has got an infection in her leg; so, she is not doing real well, and so yeah I know the dangers of it.

The knowledge of a health threat was often combined with the feeling of no longer being invincible. In the following narrative a woman who valued “family taking care of family” described her decision to return her diabetic father to nursing home care because she did not believe her care was adequate. As the narrative developed she illustrated that the health professionals did not know how to help her father either. In her

opinion she recognized symptoms of impending health threats and impending death, not the health professionals:

*"I saw him suffer more than I ever saw anyone suffer".* Then I got my daddy out of the nursing home, and I was taking care of him. His big toe started turning black and I done everything. Health care nurse looked at it. So, I thought well, if I put him back in the nursing home, the doctors and nurses will know what to do about that since I can't do it. So, anyway, he ended up in the hospital with no circulation in his paralyzed leg, and they took it off. And they took that leg off, and then his bowels blocked up, they had to do a col... what do you call it? [Colostomy] Yeah, I stayed with him at the hospital when he was in bad shape, of course. Then, one day I went up to see him, and he was doing fairly well. I went to see him. He was rubbing his leg, and he said it hurt. So, I looked and there was a blue place on it. So, I called the nurse in and showed it to her. She said they would take him down and X-ray it, "It probably warn't [sic] anything." But, it was on the same leg with his black toe. So, I barely got home they called and said, "You have got to give us permission to take that leg off. He has got gastric gangrene." So they had to take it off plumb up to here [points to thigh]. They couldn't sew it up or anything. And he went on like that a little while, and then I noticed a bump, a place on his forehead; it looked kind of like what was on his leg. And he suffered terrible during all that. I know for three weeks straight I just lived at the hospital. Anyway, I asked the doctor about that on his head because I knew it looked like. "It is just an ol' pimple" but then, he said "You go on home and get some rest." And I said, "NO," and I went and picked up my paycheck

from work, and went back to the hospital, and he died in just an hour or two. So, I saw him suffer more than I ever saw anyone suffer. Now, I heard of his brothers and sisters and what they went through, having limbs taken off and stuff. And my grandma had it, but she got pneumonia and passed away before the sugar really got to her.

In summary the participants came to the experience of being diagnosed with diabetes with a variety of life experiences. While my approach focused on communicating about diabetes in a nonthreatening and problem solving manner, most participants perceived diabetes as a threat, and many perceived diabetes as a death threat. One participant who did not accept his diagnosis did not appear to be as threatened as the other participants. Perhaps this was in part because he had survived a traumatic head injury from which he had been told that he would not recover. In contrast to his previous experience diabetes did not threaten him. Those participants with family members living with diabetes had background awareness that someday they might also develop diabetes. However, this awareness was still mixed with an element of surprise or disappointment that they had developed diabetes. All of those without family members with diabetes were not expecting the diagnosis. These participants had a more difficult time accepting the diagnosis and trying to understand why diabetes was happening to them. In all participants, both those with and those without family members diagnosed with diabetes, the SMBG helped to confirm that they had a problem with their blood sugar. The moment of diagnosis was also a time of reflection on other health concerns (Table 3).

Table 3

*Health Concerns of Participants*

Health Behavior	Health Measures	Disease experience	Diabetes Related Diseases
Smoking Cessation	Cholesterol level	Family violence	Amputations
Mammogram Study	Blood Pressure	Sexual Abuse	Blindness
	Prothrombin Time	Mental Illness	Kidney Failure
		Head Injury	Death
		Seizures	
		Arthritis	
		Cataracts	
		Heart disease	
		Coronary Artery	
		Disease	
		Peripheral Vascular	
		Disease	
		Cancer	
		Death	

Diagnosis was a focused time of considering health behavior and disease experience. Participants spoke of other health and healthcare experiences that they thought about following a diabetes diagnosis. Meaning and function of SMBG during this experience of “I am no longer invincible” is discussed below.

## *Meaning*

### *“I am Competent”*

Three participants had previous experience testing other people’s blood sugar using a glucometer. A fourth person had seen a meter but had not used it. One participant had used one of the earliest blood glucose monitors with her father:

I remember we got my dad a meter, and I was the chosen vessel to check his sugar. I remember to get the book out. And the first ones, if you remember, were sort of like computers. They were big and, and they were different, and it seemed like everything had to be so precise. You better put the blood then, or you better forget it and get another strip. I can remember doing that and that was probably in the 70s or something, so um, but they kept getting better and my mother kept getting... they would update them and get better and better. So the ones now are so simple.

Another participant had worked as a certified nursing assistant and used a manufacturer’s call service to clarify her meter’s instructions:

Yeah, I got the [name-brand meter] down. It is really good. I had to call and ask them because it had been so long since you know, and meters back years ago were different than they are now. I had to call them and ask which end of the strip to put in where and how to drop of blood on the side. I got that one. It warn’t [*sic*] hard . . .

The BG testing experience was completely novel for six of the participants. Learning to perform SMBG was easy for all but one participant. He described his

experience as being complicated by a needle phobia and illustrated the bodily response “twinge” that he experienced. He stated:

I came into the office and they showed me to do it. I never really did test before that. I have always had a phobia about needles that is why I never did do it too much. Well I still do but [pause] [“Is there anything that helped you with that-- fear of sticking yourself?”] I, well it is not really a fear, I just don’t like it. It is just like a twinge. I don’t [pause] a lot of times it doesn’t really hurt. It is like your insides just tighten up.

At least two participants used alternate site testing. The use of the palm was found to be less painful:

Well ah it is kind of fun, I think, when you can see how your body is reacting to different things. It was not painful because you gave me one you can do in the palm of my hand, instead of my finger tips, because I really don’t like finger tip pricks.

Seeing blood was another concern that one participant experienced. “You showed me how easy it was. And the little pin prick. And I liked that because I really don’t like to see blood. So the little pin prick and how easy it was to do.” Two participants limited their testing due to cost. The majority of participants wanted to test more than the current Medicare provision of one strip per day. Participants spoke in a confident tone about the initial learning to SMBG. Although pain, fear of blood, and cost concerns were included in the narratives in general participants talked about the ease of testing and that they liked the memory feature of meters. The experience of SMBG and the ease of testing helped participants feel that SMBG meant, ‘I am competent’.

## *Function*

### *Confirms Diagnosis*

The diagnosis narratives contained one major difference between the theoretically sampled participants. The participants with the lowest HbA1c levels had the greatest doubts about their diagnosis. In general, the use of SMBG facilitated acceptance of the diagnosis intellectually although at least one participant in this group continued to struggle to accept his diagnosis. The participants all demonstrated fasting BG values > 125 mg/dl. One participant illustrated the function of confirming diagnosis when he said, “Well, the machine says [I have diabetes], and like I say, I have a family history on both sides, my father and mother.” In addition another participant spoke of how testing answered the question, “do I have diabetes?”

*“The numbers say I have diabetes”.* Yes I have this. No, no, no, there is no wonder anymore because you can see it [BG readings] flopping up and down. Now it’s like, OK I don’t know why I got this; but, it is alright to have because it is controllable.

A third person explained how testing removed “question marks” through SMBG. “I was very comfortable right away. It was like OK now there is no question marks [*sic*]. You know. You can sort of do the finger stick and see.” One participant described how she “played it safe” in response to conflicting information about her diagnosis of diabetes:

The doctor that I was going to said, “OK you are diabetic you have got to go on medication” and what not, because it was 6.9. Then I went to my OB/GYN [he or she] said, “That is ridiculous you are not diabetic till your A1c reaches seven.” So I had conflicting opinions as to whether I was diabetic. I figured, if one doctor said

yes and another one said no, I would rather be on the safe side and start the medication than to not and have the A1c keep going up and up and up. So I started the diet and the medication at that time, to play it safe.

Later this participant described how testing helped make her feel secure. The comforting role of SMBG was important because the diagnosis of diabetes frightened many of the participants.

### *Comforts*

Beyond confirming the diagnosis, SMBG comforted people who generally were anxious about their readings. SMBG supported people with T2DM by allowing them to see how their bodies responded to health behaviors. In a moment they could achieve a glimpse of what was happening inside their bodies. When people ate moderately they could immediately see the improvement on their blood glucose. In contrast change in body weight as a result of moderate eating can take weeks or months to achieve.

Most of the participants expressed ways in which testing improved their anxiety related to diabetes being out of control. People used the SMBG for security. Most found the information helped them know where they were and this provided a feeling of comfort. One participant explained how she moved her testing to a time when she could more reliably achieve a “normal” reading because these readings made her feel more secure:

I don't know what I would do without it. Let me see if I can explain why. First of all I think it is a safety gap. Second, even though I write down all the food. Umm. It's important to have some idea. Like if I have had a really bad 2 or 3 days. I like to



do the lunch time just to know that there is some time in my day when it is normal.

All participants had been asked to test twice a day on 3 days a week and not test for 4 days. Most people did not like this schedule of testing because it made them feel uneasy on the off days. They liked to see if they were “O.K.”

*“I am some kind of O.K.”*. I am not good at this idea. I would like some level of consistency. Whether this number is higher or lower, at least once a day I like to know what it is. And feel some kind of O.K. if it is high, or if it is low, or if it is just in-between. Why did that happen and what can I do to keep it that way tomorrow the same? Come down? Three days without a reading, I would not do good. I would not do well.

Another participant responded with her desire to test three or four times a day:

No, really I like to be sure it is in the range that it needs to be in. Well, I think about three to four times a day, if I could get the strips to do it with. Because, like I said, I saw what it could do and I don’t want mine, to [be out of control].

This man did not want to move to testing twice a day on 3 days a week either:

I don’t know. I don’t know being so new to it. I was comfortable doing it three times a day. Because, I guess, being new, I was scared that one day it could be way up there out of sight. I was a little bit uncomfortable moving to three times a week. Just because of that. I don’t think it would hurt anybody to test once a day. It wouldn’t bother me in the least.

Most participants wanted to test more frequently than the self-regulating SMBG guideline for primary care practice (Appendix A) recommended. Wanting to test more frequently was often related to the desire for reassurance that BG readings brought.

Although most participants indicated a desire to test more often, one man stated that he was not testing according to the self-regulating SMBG guideline for primary care practice because he often forgot to test. In addition, two women were not testing according to the self-regulating SMBG guideline for primary care practice due to cost concerns. In the following narrative one participant described how the cost of testing “closed a door” for her. She was not currently testing her blood sugar due in part to not wanting to file an insurance claim. Avoiding a claim would prevent her insurance company from having knowledge of her diabetes diagnosis.

*SMBG costs.* I would say the thing that is shocking is the price. I actually looked it up online to see if I could find refills. I could get it cheaper on e-bay. But, even like at Wal-Mart, it was horrendous, even like a dollar a prick. That takes the fun out of monitoring yourself. You know that is so expensive. You are curious, and it is fun to see what your body is doing at that kind of a price. You have to pay for it yourself. The misuse because I am sure they are not that expensive to make. I think it discourages people that are not known by the insurance company to have this disease to not monitor where they could. I'd say at least once a day to get an idea of my readings. If it is consistent for a second week, I think you do less and less and less. I think I would be curious to see if I am shaky what does it do? The different kinds of readings. That door kind of is closed because of the horrible price.

## Behavior Change

### *Experience: "Figuring it Out."*

Participants spoke passionately about how SMBG made them aware of their health behavior. Here a man discovered that he was "wasting" food as he chose to eat smaller portions:

I am really starting to see how much food I was wasting. Not necessarily wasting but eating that I didn't need. That is starting to show up now. I am pretty surprised at how much I was eating that I really didn't need to eat. Well, for instance day before yesterday we had spaghetti you know with, instead of hamburger or pork, we had chicken and spaghetti sauce And most of the time, of course my son has moved out too... to the college; but, before it always took at least 2 jars of spaghetti sauce and a pound or two of hamburger. And a day before yesterday she's goin', "I am not sure I cooked enough spaghetti." Well when it was all said and done when she, me, and my daughter had already ate. There was food leftover. We have a lot more leftovers now than we did. We are cooking less and still having leftovers that we didn't have before. It just came as a shock to me how much I was actually eating and all I can say is it was being wasted and turned into fat.

Many participants provided examples of how SMBG taught them about the foods they ate. This man discovered that juice contained a lot of sugar:

I know after I eat it is going to be a lot higher. I don't know really what range it is going to run to. But what surprised me the other day is that I come home and I hadn't really eaten and I drank some grape juice and I thought I would take my

blood sugar and it was like pooh 130 something and I said, “Why was it so high”? Well I drank that grape juice. So there must be a lot of sugar in it.

This woman described how she worked with SMBG to figure out what foods maintained her blood sugar in a normal range while considering other nutritional goals related to cholesterol:

Well, the main thing is to find the foods that keep your blood sugar in the normal range. That has been my main goal. I wish someone could give me a list and you know a breakfast menu, a lunch menu and so on... but you know you kindly have to figure that out for yourself because everybody eats different. I do eat meats sometimes you know the lean meats. So, and I know that cheese and things like that the carbohydrates ain't bad; but, it is bad on your weight and it's hard on your cholesterol. Which mine, cholesterol, is hereditary and it runs it always runs high.

Here a man surprised by an elevated blood glucose reading following a meal described how he figured out that the choice he made had elevated his blood sugar:

The last time, it was after eating barbeque and I was thinking. I thought I did good. “Don't eat the French fries, don't eat the hushpuppies. Don't eat this.” [pause] Barbeque sauce. I should have gotten the vinegar base. I should have. I didn't think none about that. I am not going to do that again. No, now you learn I should have known, I didn't think.

Here a participant described how SMBG surprised her and taught her that even one food could elevate her blood sugar. “I was surprised at somethings [*sic*]. That they went

so high on the level. Just thinking about one little item could really...I have been changing the way that I eat.”

A common experience and confusion for people newly diagnosed with T2DM is the role of dietary carbohydrates in elevating blood sugar. This woman talked about the experience of discovering by reading a book that carbohydrates, not just sugar, were limited in a healthy diet:

Like I said, the main challenge is to really get settled on the kinds of foods you need to eat and the portions and if you can have something. I know in that book It said that you could have a tablespoon of jam and you know, I always thought the main thing about diabetes was not to eat no sugar I didn't know about you didn't need all them carbohydrates. So the books was [sic] really informative about things like that.

In this narrative a woman described her experience with her treadmill. She found it much more difficult to use than she had expected. She described her confidence in her commitment to using it as a 5 on a 1 to 10 scale. She was actively trying to find a way to integrate use of the treadmill into her life by improving its location:

Let's give it a five. I have done the treadmill. It is really more difficult than I thought. These people on TV make it look like you can just get on there and run. Like run a marathon and it is so easy, But that is not true. That is a false concept. [laughing] I found out the treadmill was rather difficult at least when I have tried it. So we are going to get it out and see if we can... We found a new place to put it a little bit better place. We had it... we had a wood fire. We had it in there but it was too hot. So we are going to take it into another place and see what happens.

We had this for a little while and we have used it. (Does it go too fast for you or is it on an incline?) I don't know. I think I thought I could do like those people on TV. I think they blew my mind because I thought, "man this was going to be easy you just get on there and swish swish, sh". And it is not that way. But um we'll work with that.

In addition to learning about food and activity, this participant described how using SMBG led to her discovery that stress elevated her blood sugar:

Yeah, Yeah I know the morning I had eye surgery. They checked it at the hospital before surgery and I hain't [*sic*] eaten anything and it was 178 so when I got back home. You told me to check it and so I did and it was around 112. So I do know that stress... One morning I checked it that was right after I came to see you and I got the testing supplies and my husband and I were in [Town name]. I don't know why I was stressed maybe it was because he was a driving. But I was supposed to check it 2 hours after breakfast. Well, we was sitting in the mall parking lot and I checked. It was three-hundred and thirty-three. That is the highest it ever was with me testing.

#### *Meaning*

*"I can control it. It doesn't have to control me"*. Finally, more than half of the participants reported that testing gives them a feeling of control. "Well, It [SMBG] makes me feel like it don't have to control me I can control it now." This is the second meaning identified from the narratives, SMBG means I am in control. Participants experienced moving beyond diagnosis and entered the experience of considering behavior change and some people eventually established a routine.

## *Function*

### *Considering Questions*

Many participants indicated that SMBG answered questions they had about their body's response to eating certain foods, exercising, or being under stress. All of the participants wondered "How am I doing?" Testing helped them answer that background question. "I like testing twice a day. It would keep me more in contact with how I was doing. If I skip days, then I really in my own mind I am wondering, 'How did I do today?'"

Testing answered a question about the effectiveness of treatments:

O.K., I think we discussed that when I came in and it was 6.5 that I needed to do it daily, twice a day and get some readings so we could go from there about how to actually see what we needed to do. We discussed Metformin, medication or something. But, we decided to let it [pause] see what we could do with diet and exercise could do.

Several participants would document their explanations of elevated readings in logs:

I usually write down why I think it would have been that high on the extra information. I can't remember now what it was but umm, it well, after I ate I didn't get too many high ones after, well I guess it depends what you would call high.

For many people testing clarified their understanding of the relationship between their behavior and their SMBG result.

Sometimes participants could not think of an explanation for their readings. This was very confusing for them:

Sometimes you think, you know, I have checked it and I think, "I don't understand this." Because I find usually in the morning if I do it when I first get up, fasting

blood sugar is higher. I don't understand it. I think, "I haven't had anything to eat since last night. Why is it higher?" Sometimes I feel like I have done something wrong that makes that. But, I have asked other people and they seem to find that too.

And:

Well I think the morning testing is always too high and it don't matter what I eat for breakfast and that if it, you know when I test it 2 hours after breakfast and it is too high that pushes me to do the walking and you know better watch my foods. Even though I don't think that I am eating something bad. I think the only meal I tested it before I eat was breakfast and it was always too high.

And, "normally it is in range and maybe every now and then it would be a little higher or a little lower. That kind of surprises me because I just can't figure out what is causing it." Testing did not answer questions for several participants, "I just couldn't figure out why it would do that and how your digestion or whatever happened would do that. So, 2 hours after you are almost the same as before." Testing created confusion for another man:

You know I was real confused the other day when I asked you, "Why, when I eat certain things, I have such a reaction now?" and you explained it to me. I didn't have a clue. Why now all of a sudden I could tell when I ate too much sugar. Six weeks ago I didn't have an idea. I knew very little until now.

In addition to clarifying or confusing participants, testing caused this participant to consider the question, "Why was it [BG] so high?":

But what surprised me the other day is that I come home and I hadn't really eaten and I drank some grape juice and I thought I would take my blood sugar



and it was like poo 130 something and I said, “Why was it so high?”. Well I drank that grape juice. So there must be a lot of sugar in it. Well, it kind of makes me wonder you know what should I be eating? What not to eat and, you know? It just makes me wonder about that.

And another participant described the blood sugar response as a mystery:

Well, it just makes me more conscious about what I eat. As far as testing, it is just a mystery to me. ‘Why is it up this high? Why is it low?’ because I feel the same. I have to figure out what is causing it. What I eat or what I don’t eat [pause] A lot of times I had questions about why even though a lot of times I could tell if my blood sugar was up.

Although much of the wondering is about elevated blood glucose, the following is a narrative about hypoglycemia. Without SMBG this kind of active learning would not easily take place.

*“And I don’t know why it does that”.* Well it and it happens sometimes at night. I will wake up and I’ll know it is low, I will wake up and be kind of jittery or shaky and I will check it and it will be like 60-65 or something. Sometimes it will be 2 or 3 o’clock. I check it a lot before I go to bed just to make sure I am ok before I do go to bed you know And it doesn’t happen very often maybe a couple of times a month or so once a month. And I don’t know why it does that [pause] don’t know why it does what it does. I will check it sometimes a couple of hours after I eat dinner and it will be like 110 and most of the time it is O.K. When I get up in the morning, It will be I will check it before I eat breakfast and It will be 90’s 89, 90, or

something like that. And then sometimes when it's that way. Like I say, when it goes low, I don't know why it goes low. I never figured that out.

Here a woman illustrated the mental work of trying to make sense of unexpected blood sugar readings:

I could trace it to something I ate. Sometimes it wasn't [related to eating] and I know for a long time I was wondering why. Because I discovered along the way, probably very early on, if I got on my bicycle, my exercise bicycle not a real bicycle, I could go 20 minutes. I could bring it down 100 points. But then I didn't understand why if I didn't eat anything after that why it would still go back up over night. But I guess your stomach is still digesting stuff and it is still going through you. I guess that is why.

Participants were actively working to understand their SMBG results:

I usually write down why I think it would have been that high on the extra information. I can't remember now what it was but umm it [pause]. Well after I ate I didn't get too many high ones after, well I guess it depends what you would call high.

Few of these participants stated that they could tell when their blood glucose was elevated:

I was O.K. if it was, I would like it to be under 100. I checked it sometimes after I had eaten to see [pause] But I haven't done that in a while. I don't think that I can tell when it is high. Or maybe it has never been high for me to tell.

Interpreting the readings was also made difficult for participants when they found multiple target ranges printed on diabetes related written materials. "Some of the books,

I asked for a book when I lost that one. They gave me a different one and it had a lot higher readings to be O.K.”

People searched for explanations for their readings. It was unsettling for people to obtain readings they could not explain. The most confusing readings for participants were elevated fasting readings. People questioned the reliability of their meters when they could not explain the result. The most important use of testing as reported by participants was the information meters provided them about how food impacted their blood sugar control. In addition testing kept them in contact with how their body was responding to life experiences and health behavior. In this way SMBG strengthened personal knowledge for health behavior change.

#### *Contemplating Behavior Change*

Although the comforting role of SMBG was ongoing across the illness experience, one woman described her consideration of transitioning from testing for comfort to testing for behavior change. This consideration came about in part due to the decreased availability of test strips:

Now it is trickier with only one [test strip], much trickier from my point of view, because one gives you nothing. One just says, “O.K. I am here right now”. And what do I do to keep it? So now I am beginning to say I can’t do it before lunch because I always know before lunch I’m pretty good. It is always the same. What good is that doing me?

In addition to keeping participants in contact with how their blood glucose was generally, SMBG was also used to help participants understand the effect of different behaviors specifically:

First to me when I was able to get more [test strips] it helped me to know when I did something, whether it was eat a certain thing or [pause], it helped me to know what the results were. I can remember telling you that I needed more in order to know that. That was probably the most helpful thing that I did, is to do it [testing] more often to see how different things affected me.

This participant also used the readings to make food choices:

Well, I like to do it in the morning before breakfast so I know where I am starting out and that kind of gives me an idea of what I can eat that day. And then I do it a couple of hours after lunch a couple of hours after dinner. But I've. You know, you just have got to know what it is. Like I say if I could tell by how I felt when it gets high, but I can't, I don't know, I can tell when it gets low but I can't tell when it gets high without testing.

These decisions were not made with a formula. Instead people estimated how much to eat based on personal beliefs and experience with SMBG.

Participants most often discussed SMBG in relation to how it informed dietary changes. However, stories of the impact of stress and exercise on blood glucose readings were also told by the participants. Self-monitoring itself changed eating habits in ways not previously known to this investigator. The anticipation of testing blood glucose 2 hours after a meal prevented snacking. One person also seemed to believe that she had to eat in order to test her blood sugar. She had a pattern of not eating breakfast or lunch and so she often ate in order to test her reading 2 hours afterward.

In addition to dietary, activity, and stress management behaviors, participants discussed their experience with smoking. Both smokers and former smokers were

proud of their current smoking or nonsmoking behavior. One participant currently smoking had once quit during a workplace supported smoking cessation program. After a stressful experience she returned to smoking but stated she smoked less than other people she knew and told stories of others who were more addicted to smoking than she. Two of the men discussed the role of smoking in their workplace. A quitter told how he encouraged others he worked with to 'find the right time' to quit. A smoker told how he smoked a cigarette only at work. Smoking behavior was discussed in relation to family members and farming.

*Motivators.* Participants began to consider health behavior change as they adjusted to their diagnosis of diabetes and learned about their body's response to their health behavior. The forces that enable change for any one individual may vary over time or from person to person. Participants had intrinsic and extrinsic motivators for their health behavior (Table 4). The intrinsic motivators included internal processes. Extrinsic motivators included the SMBG numbers combined with a desire to achieve BG targets and short-term goals such as losing weight for an event.

Table 4

*Health Behavior Motivators*

Intrinsic	Extrinsic
Determination and self-talk.	Special events.
Fear of DM consequences.	Elevated BG values.
Fear of 'being a burden'.	BG keeps DM 'out in the open'.
Personal satisfaction with achieving BG targets.	Knowledge of people with DM related amputations or death.

People had varied motivations to make lifestyle changes but a common theme was “made up my mind”:

You just have to make up your mind that you are just going to do that. It is just a different lifestyle of eating. I mean you have got to change the way you eat. You have just got to get to the point where you can do that. It is not a, I mean, you can't just turn it on. You have got to work at it. Yeah it does, it takes a while.

People who were actively engaged in lifestyle change expressed a feeling of determination to control their blood glucose despite challenges such as eating out in restaurants or a desire to return to previous eating habits. “I just feel determined to keep it under control. Like I said, I am a pretty determined person. My granddaughter called me ornery.” One strategy a patient used was self-talk, “I made it yesterday. I can make it today.” Despite this seemingly strong determination, when asked how committed they were to a health behavior, participants who were actively engaged in behavior change indicated that they were committed “midways” or a 5 on a 1 to 10 scale. In this way even those who were determined demonstrated the ambivalence or distrust of their own commitment and the challenge of maintaining behavior change.

In addition to a determination to change, a fear of the effects of diabetes, “I don't want to be a burden”, motivated participants:

Well, I was aware of a lot of the consequences. I knew about the amputations and I knew that it affected your eyes, I already had glaucoma I didn't want anything else. It affects um well it affects your whole lifestyle. I want to be as healthy as I am able to be for as long as I am able to be that. I don't want to be a

burden for my family. I went through that with my parents. And I choose not to do that, if there is any way I can.

The numbers themselves and the reminder that they brought of the consequences of diabetes out of control motivated this participant to maintain blood glucose control:

Yeah, the readings if they are too high it means you know if I don't try do what my diabetic nurse says and what I knowed [sic] I need to do; than I could end up like my daddy and you know that is why I want to do everything I am supposed to... to keep my blood sugar levels down. And ah, I just know how terrible the blood sugar, what kind of shape it can get you in. And ah, I really want to keep it under control.

This participant described how self-satisfaction and fear worked together to motivate her weight loss:

I wanted to prove to myself that I could. You know that [pause] of course now, I don't want to have my leg amputated and things like that, so there might be some of that fear in the background, I could see that that is a possibility. I don't smoke and stuff which my dad did which attributed [sic] to that but I am sure, the sugar Diabetes did not help, I don't want that. I guess you could say that it is a little bit of fear. But then I wanted to prove to myself that I can accomplish this. I know still there is help there if I try my best or [pause] and then it doesn't work.

This desire to prove one's ability to achieve euglycemia was a powerful intrinsic motivator.

Although SMBG was one extrinsic motivator, this female participant identified another motivation for her health behavior change, a reunion with her son:

I had another motivator. I had a son that I hadn't seen in 2 years and I felt very fat and I wanted to be [pause] feel better about myself. So that was a good motivator too. I just wanted to lose 10 pounds before I saw him again. Because, it is here. It is everywhere actually; but especially in my face. I see pictures on my old driver's license and the new one. You can definitely see there is a difference. I feel better about myself not being as heavy as I was.

The experience of living with T2DM included situational events that come and go and may account for variations in commitment to change.

Participants' narratives provided numerous examples of how SMBG functioned to support their health behavior change. Many times adopting new health behavior began with a moment of insight experienced with SMBG. Participants then experimented with SMBG in their life context and with new health behaviors in order to 'figure out' how their body responded. During 'routine' participants spoke about how SMBG functioned to maintain their new health routines. People expressed a satisfaction when they could 'make their numbers'. Several participants reported that 'numbers made' them take action for their health benefit. Participants reported both intrinsic and extrinsic factors that motivated their health behavior. The most common explanation for motivation involved the intrinsic characteristic of becoming "determined" or being "stubborn." In addition to these self-descriptions, many participants told stories of other people with diabetes. These stories became a type of intrinsic motivator when participants stated. "I don't want to end up like..." One participant described an upcoming special event as a motivator (extrinsic). Once again the extrinsic quality of SMBG, "keeping diabetes in



sight”, was important to behavior maintenance and the readings themselves got at least three participants, “out walking.”

The process of health behavior change was similar across all of the behaviors: healthy eating, being active, handling stress, smoking cessation. The process was fluid. SMBG functioned to spark awareness, suggest adjustments, provide alignment, advise movement, and account for restraint. In these recently diagnosed participants, SMBG was central to sparking awareness of a need for change. In this way the numbers created a paradigm shift for participants. Next, as participants experienced making changes, the BG numbers played a role in their figuring out of the body’s response to various contexts by suggesting adjustments and providing alignment.

#### Routine

*Experience: “I Make My Numbers.”*

The participants experienced behavior change in the context of their routines. People who were able to control their blood glucose expressed a deep satisfaction from that accomplishment:

Well, I am real pleased when I make my numbers. I am pleased with myself. It just makes me feel that I am staying within the guidelines that I am really concerned. And um that I am pleased that I can stay within the guidelines.

The experience during routine was one of maintaining health behavior and restraining old habits. Participant narratives illustrated how routine could both facilitate and be a barrier to behavior change. Testing itself influenced routines. One person reported not eating during the 2 hours following BG testing when she was instructed to test 2 hours after eating. She said:

Then it was nicer to do one at night especially the one after supper. Because first of all then you had to have 2 hours where you didn't eat, and my worse time of eating is after supper. [Right.] So I am more prone to think that that helps both ways. I'm going to try that for next week. Because, then you have to have 2 hours after you eat. And after 2 hours you don't want to eat anyway. Where it is those 2 hours that you continually want to munch.

Another person had difficulty testing 2 hours after breakfast because she often delayed eating. "I have to take my pills. I have to and I can take the test and stuff. But, you have to eat before, 2 hours before you test it." The idea that you have to eat 2 hours before testing instead of viewing testing as an event following eating was one way that confusion about testing and its purpose in diabetes was evident. This participant described how she must be vigilant when eating out to prevent "hidden sugars" from sabotaging her diabetes management efforts. But now an event she enjoyed has been transformed by the need to be careful, "I try and watch":

I get frustrated. Because you know, because, I like to go out with friends and eat and what not. And yet, they hide so many things in the foods that they serve you to help with the taste and everything to make it more enjoyable. I just get frustrated because. I try and watch. But then you cannot watch everything when you are eating out whereas at home you can control it. Like sometimes the sliced carrots will have more sugar in them. And then sometimes, I always have to be very careful about asking for sugar-free iced tea because sometimes the waitresses make a mistake and you end up. But then I always mention to them so that I do get the right container.

The experience of transforming eating routines included having foods that were not part of a previous diet and limiting foods. Bread was one of the more challenging foods. This participant said that SMBG helped her to maintain her new routine of limiting bread. Evidence of the transformation is her statement about her previous bread eating, “I really haidn’t [sic] missed it”:

So the numbers, the numbers will make you go on and do things that you need to do. And also and watch what you eat. I have been reading carbohydrates. It is a mess trying to shop. Well I really haidn’t [sic], I was a big bread eater But, I really haidn’t [sic] missed it and sometimes I go the whole day without eating any bread. I been eating some grapes and I eat some cantaloupe you know the portion size. Sometimes I will eat an apple sometimes a banana so ah, Well it just helps me if it is high I know I need to cut down on something. Now if it is low now, one time after lunch I checked it, it was down to 80 some so you know I knowed [sic] I needed to eat something.

She had not missed eating bread, but SMBG helps her to maintain her behavior. Another woman also transformed her bread eating behavior. She described how cornbread that was an everyday staple of her diet became “something special”:

Well, I think and I still overeat. I am not going to lie and say sometimes I don’t overeat. We try to make changes in the way we eat. We are country folks, we are country folks and we eat corn bread. I mean, you know, that was a staple on our table. Because it was fast number one and we work on the farm and have all this stuff. You run in at 8 o’clock or 9 o’clock and you say, “what can I eat?” Oh, O.K. so you throw a cake of corn bread in the stove and we will have cornbread and

something, milk something. That was a no-no for me. That was one of the things the breads that really [elevates blood sugar]. So instead of having it every night, now we have it about twice a month. It is special. It is special to you then. So, we found out, I think, that because I think, your eating habits can do lots of things, and of course it's put a lot of weight on me. And I still need to lose a lot of weight. I am thankful for what I have lost.

A man discussing how he adjusted to eating less bread:

Well it was, the biggest thing was I [pause] I couldn't eat without bread, had to have bread. That was the hardest thing to put down. That was harder than the deserts and that kind of stuff. But I finally got to where that didn't bother me.

A man adjusting his portion size said, "I still eat some desserts from time to time but I don't eat much. I found out a couple bites is just as good as eating a big piece of pie." A man describing self-education, reading labels to identify carbohydrates, and reading books:

Well you know you just need to watch the carbs [*sic*], you know. I read labels. I go to the grocery store and read labels on all kinds of stuff. You just need to determine what you need to do. I am pretty settled now. It takes probably a year to get familiar with all the foods. I used to have a, you know I still have got it, a book that lists all the carbs [*sic*] and the servings and all that. I used to look at that quite a bit.

The ease of cooking a meal was also important to other women. In this narrative a woman described the challenge of not having ingredients on hand, taking more effort

to shop, and the difficulty of planning meals. But now she is using some of the recipes that had been so difficult at first, evidence of her transformed routines, “not ordinary”:

I was trying to use those recipes and it was driving me berserk. I was having to go and buy things that I didn't ordinarily have in the house. It was taking me forever to buy it, figure out what I was going to have, make it, and I was serving it to whoever was there, whether it was my husband--just my husband--or one of my kids. Some of them were great recipes. I still use some of them.

Although routines related to eating were most common, activity routines were also discussed by participants. Weather and other time commitments such as company are common complications for maintaining activity routines:

Yeah, and I walked more than I wrote down. I walked unless, one day I had two visitors and I didn't get to walk any that day. I try to walk every day. I can't walk sometimes. If the weather is right I can walk a half a mile at one time; but, a lot of time I do a quarter of a mile. But I do at least four a day if not more plus I walk down under the hill to the fish pond. I walk to my sister in laws. I try to get in all the walking I can.

Activity was a new response to stress for this participant:

I even went out last night for a little walk. Just on the top of the driveway because we live on a hill, because I was so frustrated that I had all this work to do and [my husband] couldn't do a thing to help me. I was ready to smash the dishes. So I just walked outside and said, 'O.K. I can't walk up the hill because my back, my hip hurt too much.' So I just walked around the cars back and forth up and down

10 to 15 minutes. Looked at the flowers and said, 'O.K. I am good. I can take this another day'.

The physical limitations she faced were common. Many people have conditions that make activity difficult. But now she uses activity to handle stress and this makes her able to keep going another day.

### *Maintaining and Restraining*

In addition to the experience of restraining behaviors such as eating differently, the SMBG was important to help participants maintain the changes they had adopted.

This participant viewed SMBG as maintenance work:

People are um they have habits that are good and bad in life so it is very hard for some people to break their habits. It is like maintenance work. It is called preventive maintenance to maintain the flow, the right way; you know what I am saying?

Habits made change difficult. "I am trying to, like I say, we are creatures of habit so it is very hard to change basically routine. I think about it every day." For some testing had become so integrated into their routine that it was no longer thought about. "Well I usually always try to do it before I eat breakfast in the morning, and whenever I think about it. I don't think about it anymore."

Several people spoke of how routines influenced their success with behavior change. Some people were able to integrate changes into a routine and that improved their health behavior. Others were not able to change their routines to accommodate new health behaviors. Daily routine was important to testing behavior. People did not like varying testing from day to day. They considered what the future season might

mean to their ability to maintain healthy routines or adopt new routines. Many participants expressed hope but not confidence in their ability to adapt to a new routine.

Forgetting was a barrier to testing:

It doesn't really bother me to test now or anything. Now, I just have to remember now to do it. I get in routines and it is hard. Sometimes, I will sit down and maybe drink something, eat something, and ah "I forgot to get the reading". And I have to wait a little bit and see where it is at. Sometimes I need to remind myself, "You need to do this before you eat and after."

### *Meaning*

#### *"It is Not That Way Anymore"*

During routine, SMBG meant that behavior change had taken place and therefore, 'It is not that way anymore':

Well, yeah, I think, maybe I used to make a humongous pot of spaghetti so now I make a little pot of spaghetti [laughter]. You know, I think. I was cooking for three. It takes a little while to adjust that, that there are not three there anymore. I have a friend who grew up with 11 children and she said she helped her mother cook. So when she got married she made the same amounts as she did with all those children. She said she had all this food we have to throw away. I thought we had to make huge amounts. Hey, that is not the way it is any more. So we are cutting down even what we cook. Sometime you think I don't want this leftover, I will just eat it. I will just eat it. That is not good. So you are better not to have it.

More evidence of adapting to a new pattern of living:

No, it is getting easier. It is not as frustrating now as it was at the beginning. [And what has made it easier?] Just knowing my choices in food, watching my carbohydrates and knowing what is in them, before I even eat them, the portions I eat, and the exercise I get. So that's really like I said motivates you to do things like that when you know what it could do.

Success in one area of health behavior change rarely meant success in all areas.

Here a participant who lost 50 pounds discussed her difficulty in maintaining an early evening meal pattern and her concern that the winter season will make her exercise and eating behavior more difficult:

Well, I fess up that sometimes we still get into that pattern. I tried. That is one thing in our lifestyle that we have tried to change, is to go in and have something at 5 or 5:30 instead of 9 or 9:30 but sometimes we still get caught and that happens. We will be working on this again when it starts getting dark early and we have to go inside. I am a little bit, I don't know what the word is, concerned or I don't know I am worried about the winter months. You know you are inside and sometimes it seems like you think comfort food or you think, "Hey it is in here and I just want something to eat." I guess we will just have to see how I manage that during the winter. Hopefully, I can keep everything at least where I am.

Despite the uneven integration of health behavior, a new routine emerged for most participants. It is this new pattern born out of the experience, appraisal, and rational intuiting that is the strongest evidence that SMBG contributed to the personal knowledge and experience of living with T2DM.



## *Function*

### *Congratulates*

*"I am doing something about it"*. SMBG provided people with a perception that they were doing something about their diabetes. All of the participants in the two highest HbA1c groupings (HbA1c  $\geq$  6.5%) told stories of people who were not taking care of their diabetes:

It just blows my mind today how people take it so nonchalantly. I was, I visited, I probably shouldn't say where, cause... but anyhow. You see people that are really grossly overweight and I was just talking to this fella [*sic*] and he said that morning his bloods sugar was 400 or something. I am thinking. "There is something that you can do about that" but it didn't seem like, He was just taking his medicine. I don't understand that.

SMBG helped participants feel secure and demonstrated their efficacy in contrast to the stories they told of others who either did not test their BG or were not demonstrating healthy behaviors. Here a woman explains how SMBG helped her prove to herself that she was actively doing something about her diabetes and knowing where her BG readings were:

But I guess it made me realize that this is something I needed to do to improve, to get more healthy. And Just sticking your finger even though this stick is nothing like the one in the hospital, like I said. It makes you realize that, what I don't know, I hadn't thought about it. Well, that is a way of proving where you are one way or the other. And what you are doing about it.

SMBG motivated continued health behavior by advising movement or accounting for restraint as satisfaction in the numbers themselves maintained and restrained behavior. The behavior of SMBG was satisfying. It assured participants that they weren't like those "others" who were not concerned or not testing. Participants expressed satisfaction in making their numbers.

### *Comforts*

*"Knowing where I am at"*. SMBG comforted participants providing them with a feeling of security. Experience with testing resulted in anticipated readings:

But I have got to where I kind of know where I am at. According to what I had to eat I will check it a lot of times before I eat to see where it is. Well it makes you feel [pause] If you keep your blood sugar where it's supposed to be you feel a lot better, you really do I mean, I get really concerned when it gets high. If it gets around 150 I will back up and do something to get it down.

Or helped participants who tested in the morning to know where they were at in order to plan their day. "Well, I like to do it in the morning before breakfast so I know where I am starting out and that kind of gives me an idea of what I can eat that day." This helped participants feel secure. This man described this function of testing as keep him "in contact":

Well the numbers that they gave me to check with was 120 in the morning, 180 two hours after lunch and 140 in the evening 2 hours after snack about ten, between ten or eleven. And I pretty much could stay within those points. I like testing twice a day. It would keep me more in contact with how I was doing.

The congratulating and comforting function of SMBG motivated the “figuring it out” of behavior change and the ongoing maintenance work of routine by rewarding those who could “make their numbers” (Table 5).

Table 5

*SMBG A Motivator During Routine*

Behavior Process	Narrative	Summary
Motivating action	“It (SMBG) gets me out a walking. Sometimes my legs, my hips, my back don’t feel like it but I push myself to do it as much as I can and every day that I can.”	Spark Plug
Motivating restraint	“It (SMBG) holds me accountable for one thing. If I didn’t have to do that, If I didn’t feel bad. I might not. I would be tempted to cheat and to not do.”	Guard Rail

This male participant provided insight into how SMBG, as a visual reminder, functioned to motivate behavior by keeping diabetes out in the open when other physical symptoms of disease were not evident:

A little bit, out of sight, out of mind, I think not. People generally need a little bit of a reminder. Because if you don’t feel bad and you’re not doing it [SMBG] then you are more likely to mess up I believe.

Finally, participants discussed the importance of routine as either a barrier to or a facilitator of behavior change. Despite the success experienced by many of these participants, not one described his or her efforts at behavior change as permanent.

Most discussed their day-to-day struggle to continue with changes or reported their likelihood of initiating or maintaining a change as “midways.” Consistent with other findings (e.g. Aujoulet et al, 2007; Jones et al., 2000; Rayman & Ellison, 2004; Tilden et al., 2005), this honest assessment illustrated the fluid and challenging experience of maintaining health behavior change for people with T2DM. As behavior change became routine, SMBG functioned to maintain and restrain routines (Table 6).

Table 6

*SMBG Maintaining and Restraining Routines*

Maintaining (Alignment)	Restraining (Brake)
<p>“Well, I am real pleased when I make my numbers. I am pleased with myself. It just makes me feel that I am staying within the guidelines that I am really concerned. And um that I am pleased that I can stay within the guidelines.”</p>	<p>“Then it was nicer to do one at night especially the one after supper. Because first of all then you had to have 2 hours where you didn’t eat, and my worse time of eating is after supper. So I am more prone to think that that helps both ways. I’m going to try that for next week. Because, then you have to have 2 hours after you eat. And after 2 hours you don’t want to eat anyway. Where it is those 2 hours that you continually want to munch.”</p>

Analysis of the Logbook

Seven of the 11 participants brought in blood glucose logbooks. Six of the seven actually had written logs and one participant brought his meter with its electronic memory. Two male and two female participants did not bring in logbooks. Three of the four participants not bringing logbooks were in the lowest HbA1c group. The fourth participant who did not bring a logbook was in the highest HbA1c group.

Three people used the glucometer manufacturer’s logbook to keep records. Three women created their own logs. These self-made logbooks were very detailed and

included additional health information such as a food diary with carbohydrate counts, blood pressure readings, weight, minutes of activity, and medication records. Even those who used the manufacturer's logbooks included additional information such as weight or minutes of activity. Sometimes when people obtained unexpected readings, they would record possible explanations in the logbooks. In addition to providing examples of figuring out diabetes with applied numeracy, the logbooks demonstrated interpretive numeracy processes with symbols such as question marks, exclamation points, smiling and frowning faces. One participant drew a frowning face next to an elevated reading. When asked about this notation she said she thought I might not be happy to see that number but then modified her story to say that she was not happy with it either. Some people were very precise in their documentation for example, 2:38 PM. Others, used 5-minute increments and still others just used the designations before or after. These participants had saved all their logbooks. In addition to her logbook, one participant brought in books and other materials she was using to help her understand diabetes. Although participants with logbooks reported that they were very useful, even those with the most detailed logbooks had periods in which they did not use the logs. Logbooks seemed to support both the experience of "figuring it out" and "maintaining and restraining" health behavior.

The study findings were organized around the three time periods of SMBG: *Diagnosis, Behavior change, and Routine*. Within each time period the experience of living with T2DM was summarized and the meanings and functions of SMBG during the time period were represented. Some elements of the richness of this data were necessarily excluded. You, the reader, cannot hear the intonation of each participant

nor see the subtle mannerisms that communicated along with words. I have tried to be faithful to both the spoken and unspoken representations of the participants. When participants were presented with the study findings, they responded by spontaneously pointing to the diagram (Figure 1) and saying, "This is where I am at." This response confirmed the ability of participants to recognize their experience in this representation. This process of verification strengthened the credibility of the study findings. Participants confirmed that Figure 1 represented some aspects of their SMBG experience.

## CHAPTER 5

### DISCUSSION

The themes derived from the process of narrative and logbook analysis were used to represent the participants' stated meaning and function of SMBG during the 2 years following a diagnosis of diabetes. Figure 1 illustrates three time periods of this lived experience of T2DM. Metaphors reflect the participants' appraisals of future and past performance and are integrated with Schapira et al.'s (2008) hierarchy of numeracy framework. The outcome of personal knowledge is the recognition of a new pattern (Sweeny, 1994). This outcome was evident in the participant expressions "but now" and "It is not like that anymore." This chapter places the study's findings in relation to research findings for three theoretical processes of personal knowledge: experience, appraisal, rational intuiting. Procedures including memoing and discussion of findings with content experts and participants strengthened the study findings; however, an important measure of rigor for studies using methods of interpretive description is the application and adoption of findings to clinical practice (Thorne et al., 2004). Therefore this chapter concludes with suggestions for nursing practice, nursing education, and future research surrounding the use of SMBG in T2DM.

#### Related Research Findings

##### *Experience*

Researchers have identified three processes of integrating self-identity and illness experience: integrating, separating, and vacillating. (e.g. Aujoulet et al., 2007; Jones et al., 2000; Rayman & Ellison, 2004; Tilden et al., 2005) In this study all three process were evident as people experienced a desire for control alongside an

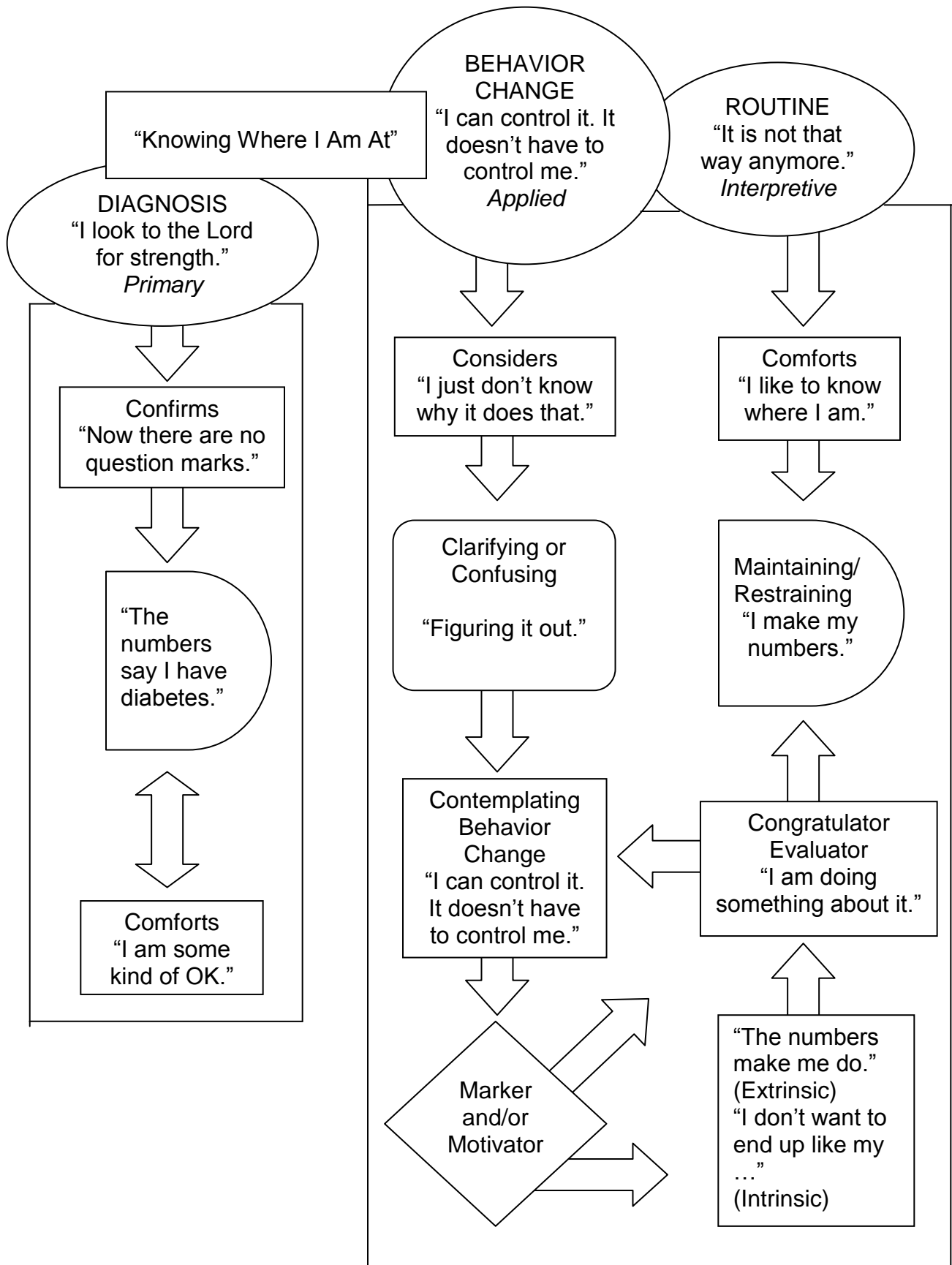


Figure 1 Self-Monitoring Blood Glucose Function



acknowledgement of contingencies that prevented total adoption of management ideals. For example having company (a contingency) might prevent a participant from maintaining a walking goal (management ideal) on some days. Participant narratives of the experience of SMBG and T2DM generally described three time periods: *Diagnosis*, *Behavior change*, and *Routine*. These time periods usually but not necessarily flow from one into the next. For example one participant who had not accepted his diagnosis made behavior changes. A more common expression of vacillation came during *Behavior change* and *Routine*. Participants who predominantly experienced *Routine* would at times reconsider *Behavior change*. The findings confirmed a fluid process of adaptation though out the T2DM illness experience.

Although not focused on SMBG, a recent qualitative study examined the experience of diabetes nurse check-ups as narrated by people with T2DM in Sweden (Edwall, Hellström, Öhrn, & Danielson, 2008). They interpreted these narratives as nurse visits influencing patients' experience in an interlinked chain: being confirmed, being guided within the disease process, becoming confident and independent, and being relieved. The current study confirmed a similar illness experience. For example in this study participants used SMBG to confirm their diagnosis. They used SMBG to guide their behavior change and said that SMBG meant that they were competent. They also expressed relief that they were "some kind of O.K.". In this way many of same processes that were attributed to the nurse visit (Öhrn et al.) were attributed to SMBG in this study. The influence of the nurse-patient relationship and the use of SMBG may be difficult for participants to separate and likely both have influenced the T2DM illness experience.

Clar et al. (2010) reviewed the evidence base surrounding the value of SMBG and reported the random control trials (RCTs) included in their review did not acknowledge that SMBG is not necessarily an intervention without education, feedback, and behavior adjustment. They defined significant improvement in metabolic control as a change in HbA1c  $>0.5\%$ . Their review concluded that the RCTs did not analyze the context (patient characteristics and situations) in which SMBG is most helpful. In this study use of SMBG was clearly defined in a self-regulating model and focused on the participant's life-context and experience of diabetes self-management through discovery. This study defined the context of the function and meaning of SMBG during *Diagnosis, Behavior change, and Routine*. In addition 8 of the 10 participants who followed up for care significantly improved ( $>0.5\%$ ) their metabolic control as defined by Clar et al. Both of the two participants with nonsignificant changes were in the lowest HbA1c group (HbA1c  $\leq 6.4\%$ ) meeting the American Association of Clinical Endocrinologist target for metabolic control, HbA1c  $< 6.5\%$  (Jellinger et al., 2006). One had a Hba1c improvement of 0.4% and the other had a 0.2% improvement. Although a small cohort, the participants in this study demonstrated significant metabolic improvement with this model of self-regulating using SMBG to educate, provide feedback, and support behavior change.

### *Appraisal*

Researchers concluded in their qualitative study of narratives from 119 people living with diabetes that central to participant moral discourse were expressions of control (Broom & Whittaker, 2004). In addition they identified chaos narratives as primary to their participants' narrative appraisal. In this study chaos narratives were

evident in some participants' narratives. However, restitution narratives were most common as participants coherently stated a problem solving experience with a beginning, middle, and end. These restitution narratives illustrated participants' control over T2DM while those with the chaos narratives demonstrated their absence of a coherent story and contained emotional overtones of events being out of control.

Researchers (Schlenk & Boehm, 1998) used contingency contracts to strengthen the self-efficacy beliefs of participants. Contingency contracts make an individual aware of potential barriers to behavior performance while planning to overcome these performance barriers. The current study framed self-efficacy as an appraisal of future performance. Frank (1995) used the term contingent as the end point along the control continuum. In this study the expression, "It doesn't control me. I can control it", was a common appraisal of self-efficacy among participants. This expression would be found on the predictable end of Frank's control spectrum while, "I just don't know why it does what it does" reflected feelings of being out of control and toward the contingent end of the spectrum. In this study evidence of both appraisal of past experience as being out of control and appraisal of future experience with expectations of control were reflected in participant appraisal of their commitment to behavior change as "midways." This finding is consistent with one of Frank's body problems, control. It also demonstrates participant acknowledgement that contingent experiences prevent predictable control.

In a review of 26 RCT Clar et al. (2010) observed that both patients and providers did not use SMBG to recognize the impact of changes in dietary and exercise behavior. In contrast participants in the current study were encouraged to use SMBG to appraise their BG response to behavior changes including diet, exercise, and stress

management. It is likely that this self-regulating experience contributed to the finding that participants expressed both being in and out of control during the process of behavior change.

### *Rational Intuiting*

Finally, rational intuiting is bounded in this study by numeracy literature and communication of health information (e.g. Ancker & Kaufman, 2007). Since this study was developed, the numeracy literature has grown exponentially. Among these newer publications, Schapira et al (2008) conceptualized three processes occurring in health numeracy as a hierarchical triangle of primary, applied, and interpretive processes. This model appears to have a good fit with the numeracy experiences of participants in this study. Rational intuiting was expressed as, “the numbers say I have diabetes”, “figuring it out”, “the numbers make me do”, “and I don’t want to end up like my...”, and I am happy when “I make my numbers.” All three numeracy processes were evident in the study findings. Applied numeracy processes were found in the logbooks as participants recorded minutes of exercise (counting). Applied numeracy processes in logbooks were evident when participants aligned their consumption of carbohydrates to the number of carbohydrate grams prescribed for each meal. Participants demonstrated the third numeracy process, interpretive numeracy, when they told cautionary tales of others with diabetes and concluded that they “didn’t want to end up like that.” In this way this study’s findings confirmed Schapira e al.’s conceptualization of numeracy.

Prior to this completing this study I would have agreed with the conclusion, “...there is no point in collecting data on blood glucose levels if nothing is done with the data” (Clar et al., 2010, p. 45). The problem with this statement is that health care

providers have difficulty observing internal self-regulatory processes and conclude that “nothing” is being done with the data. The participants in this study reported that even when there was no external evidence of behavior change interpretive numeracy processes were at work helping participants maintain behavior change or restrain old habits. This finding is also congruent with the conceptualization of personal knowledge as knowing more than can be told (Polanyi, 1966).

#### A Framework for SMBG Function in T2DM

The three time periods of the illness experience were experienced as, *Diagnosis*, when “I look to the Lord for strength”; *Behavior change*, when “I can control it. It doesn’t have to control me”; and, *Routine* when “It is not like that anymore.” Within these time periods the metaphors derived for the appraisal of T2DM included the numeracy processes “the numbers say I have it”, “figuring it out”, “the numbers make me do”, “numbers mean I won’t end up like . . .”, and I like it when “I make my numbers.” Recognizing a new pattern as a result of experience, appraisal and rational intuiting is evidence of personal knowledge (Sweeney, 1994). All of the participants, even the one participant who had not yet accepted his diagnosis, provided narrative evidence of adopting a new pattern. SMBG contributed to pattern identification during all three time periods.

#### *Diagnosis*

When newly diagnosed with any illness people commonly question why do I have this disease (Kleinman, 1988)? In this way people search to find explanatory models for their medical conditions. Participants in this study made appraisals of their risk for DM by considering if they had family with DM. If they did not, they expressed more difficulty

answering the question, why? Participants overwhelmingly stated their belief that diabetes was genetic and one participant put it bluntly that because she inherited it, diabetes was not her fault. In the absence of symptoms of disease, both participants with and those without diabetic family members used SMBG to answer the question, do I really have diabetes? All used SMBG to confirm that they had diabetes during the diagnostic time period. In this way SMBG answered participants in this common illness experience of asking why? and really? with the appraisal, “the numbers say I have diabetes.”

Participants described the experience of being diagnosed with T2DM as a “shock.” Although those in the lowest HbA1c group (HbA1c  $\leq$ 6.4%) experienced less belief in their diagnosis and those in the higher two HbA1c groups (HbA1c 6.5%-6.9%, HbA1c  $\geq$ 7.0%) experienced diagnosis as more of a “wake-up call”, they all used primary numeric processes to identify if their BG readings were on target. Numbers were used following diagnosis to confirm the existence of T2DM.

Once participants confirmed their diagnosis they were asked to use SMBG to identify times that BG elevated. This was uncomfortable for participants who wanted reassurance that they were alright. Researchers (Simon et al., 2008) also observed this experience of testing to obtain a normal reading in the Diabetes Glycaemic Education and Monitoring study (DiGEM, 2008). Two of 40 participants in the qualitative arm of the study reported timing their testing to achieve their best readings (Simon et al., 2008). This discomfort with abnormal readings is consistent with the ideal of the disciplined body that seeks control and predictability (Frank, 1995). Once participants began testing at various times, they experienced clarification or confusion with their readings in

contrast to the predictability they sought. They began to consider their life-context and the effect their behavior had on blood glucose readings. Participants in all three HbA1c groups reported moments of clarity when they “figured out” what was making their blood sugar go up or how to make it go down. They began applying numeracy processes to make health behavior decisions. For example, those in the two lowest HbA1c groups (HbA1c < 7.0%) found elevated fasting readings puzzling. While those in the highest HbA1c (HbA1c ≥ 7.0%) group did not find fasting readings difficult to understand but described many other testing circumstances as a mystery to them. Thus, the appraisal of “figuring it out” was expressed by all three groups, but in different contexts.

### *Behavior Change*

Once their problem was out in the open, participants began considering active behavior change (Table 7) dependent on what they had learned through testing. During *Behavior change* the numbers functioned as an extrinsic motivator and an intrinsic motivator for action. Participants appraised this function by saying that the “numbers make me do.” Evaluating a reading as at or not at target made some people maintain health behavior. For example people initiated activity or restrained health behavior such as eating less. This is in contrast to Peel, Douglas, and Lawton’s (2007) interview of 18 patients over a 4-year period. Researchers concluded that there was little evidence that participants in the UK were using SMBG to effect and maintain behavior change (Peel et al., 2007). This difference is likely due to the exposure participants in this implementation of a model of primary care in which SMBG was introduced in a personalized, educational, and problem-solving approach.

Table 7

*SMBG for Health Behavior Change*

Health Behavior	Narrative	Summary
Marker and Motivator	“It [SMBG] gives you a tracking device, a daily tracking device. So that you can tell how to adjust your eating, or your resting, or you know going out for a walk or whatever [it] takes you to reduce your stress to being more level the next day.”	Global Positioning System
Evaluator and Congratulator	“It [SMBG] makes you aware that eating healthfully is important and the blood sugar testing gives me a way to check if I am doing it.”	Traffic Light
Maintaining and Restraining	“Oh gosh, helps me manage it, well, I know I have to do a little more exercise if my numbers are higher. I know I have to be a little more careful when I go out to eat. So it [SMBG] keeps me in line for me personally.”	Alignment and Brake

In addition participants made appraisals of others as evidenced by their stories of family members or friends who had suffered with diabetes or who had experienced diabetes related illnesses and deaths. These narratives were consistent with Frank’s (1995) characterization of other-relatedness. The dyadic relationship could be an emotional base for constructing self-management (Furler et al., 2008). For some participants the numbers brought forth memories of these negative illness-related



consequences and functioned as intrinsic motivators, “I don’t want to end up like...” The BG readings also functioned as a marker to participants that they were doing what needed to be done to control their diabetes unlike those “others” who were out of control or experiencing an unwelcomed illness contingency.

Finally, the numbers congratulated those who changed their behavior and became a source of self-satisfaction, “I am real happy when, I make my numbers”. The cycle of change and congratulating and evaluating was ongoing and fluid. Evidence from logbooks demonstrated that people applied numeracy processes such as counting carbohydrates, keeping track of minutes of exercise, and actively using SMBG information to evaluate their body’s response to health behavior. People were not confident that they could maintain behavior change. Even those who demonstrated successful weight loss or dietary change reported that they were only “midways” certain that they could continue.

### *Routine*

The third time period for those living with diabetes was the experience of *Routine*. The desire to “know where I am at” was expressed by participants when SMBG became routine. This finding is consistent with Peel et al. (2007) who identified reassurance and habit as reasons for continuing with SMBG. In addition to SMBG dietary changes such as no longer eating bread at meals were most often reported as now routine. Activity changes were reported such as walking after evening meals. Participants noted this in their narrative appraisals with phrases such as “But now I” and “It is not like that anymore.” Participants provided narrative evidence of former behavior and contrasted it with current behavior. Participants employed interpretive numeracy in

their decisions to continue with health behaviors and made SMBG routine. They evaluated their perceptions of risk and benefit as they appraised their own likelihood of maintaining their health. Once a SMBG routine was established, SMBG functioned to comfort participants. To them SMBG meant that they were in control. They were no longer using SMBG to change behavior but to maintain their new health behavior or restrain their old habits. All participants, even the one participant who did not fully accept his diagnosis, considered various new healthful patterns. Evidence of personal knowledge is the recognition of a new pattern (Sweeney, 1994). The new pattern is an outcome that likely influences HbA1c. Although useful for periodic assessment of metabolic status, the HbA1c does not provide the day-to-day evaluation and problem solving potential of SMBG. Diabetes health professionals can listen for the “But now” that indicates health behavior change and provide a strong emotional base for people striving to continue in maintaining health routines. They can guide patients’ use of SMBG to establish health behaviors that lead to improved metabolic control.

### Practice Implications

*Align SMBG goals.* One goal of the self-regulating SMBG guideline for primary care practice was to identify when blood glucose was most problematic (ie. postprandial BG). Participants did not like answering this question. Their goal in testing was to provide comfort during a time when they felt extremely threatened by a diagnosis they associated with death, loss of limb, and suffering. Despite this discomfort, most participants eventually became confident enough to begin “looking for trouble.” One participant clearly stated how she was aware that she transitioned from testing to comfort herself to testing to guide health behavior change. It is important to consider

how numeracy information is presented to patients (Ancker & Kaufman, 2007). Acknowledging the common desire to test for comfort may be the first step towards open discussion of the participant's readiness to begin testing for health behavior change instead of testing for comfort. Health professionals should shape the way they introduce problem solving recognizing, that testing in order to identify problem blood glucose readings is difficult for patients. Researchers concluded that patients did not perceive that practitioners believed SMBG to be important and that patients did not often act on their numbers (Peel et al., 2007). In addition patients expected practitioners to use SMBG information to change diabetes therapy, and practitioners expected patients to use the SMBG information to change their health behavior (Peel et al., 2007). Awareness of these differences in patient and provider perceptions is critical to shared understandings that have the potential to improve health communication. Negotiating clearly communicated goals for SMBG is likely to strengthen the efficacy of SMBG for metabolic control.

*When patients see they believe.* Participants expressed satisfaction with the factual and exploring approach used to teach them about their T2DM. Although those with the lowest HbA1c ( $\text{HbA1c} \leq 6.4\%$ ) had the most difficulty believing their diagnosis, they said that seeing the numbers helped confirm their DM diagnosis. Also, after weeks of monitoring her BG response to eating and exercise one woman began taking Metformin to treat T2DM. Seeing the response her BG had to the medication helped her accept medical treatment for diabetes. Perceived treatment efficacy is particularly problematic for people with T2DM (Polonsky & Skinner, 2010). If she had not started with SMBG to learn about her problem, she may not have accepted or continued with

medical treatment. Polonsky and Skinner (2010) recommend “home experiments” similar to those used in this study to strengthen acceptance of diabetes related treatments. Allowing a period of time for participants to test their blood sugar at different times and under different situations appeared to improve the acceptance of diabetes diagnosis and treatment. In this way the illness experience of integrating the AADE-7™ health behavior, taking medication, is supported with SMBG.

*Transform the chaos narrative.* Congruent with my clinical experience and Frank’s (1995) conceptualization of illness narratives, most participants presented either chaos narratives or restitution narratives surrounding their life or T2DM experiences. To a lesser extent elements of a quest narrative were also evident in the transcripts. In my clinical experience the chaos narratives are the most difficult to hear. In the chaos narrative participants do not present a coherent story (Frank, 1995). They present themselves with a list of experiences jumping from topic to topic seemingly without insight and without a discernable beginning, middle, and end (Frank, 1995). This is different from the person who is moving in and out of behavior change or who otherwise might be struggling with an aspect of self-management. People who present with a chaos narrative do not often recognize a new pattern, although they may be actively making behavior changes. They appear to experience much of life as haphazard. They rarely interpret changes they have made as a new pattern or communicate to others that this change has occurred. Along with being a witness to the chaos narrative, one possible response to the chaos narrative is to restate the story that the participants themselves cannot verbalize with a beginning, middle, and end. If a person presents to a health care provider, at least one “story” (and often many more) exists that a provider

can offer to a patient. The action of keeping an appointment should be viewed as a positive health behavior. “You found out you have diabetes, you learned how to test your blood sugar and you came today because you want to pay attention to your health.” One of the two participants who presented with a chaos narrative made a number of dietary changes. It seemed important to support these changes by stating the “But now” for the participants that they were unable to state for themselves. For example, “You used to eat donuts all the time; but now, you haven’t eaten a donut in months.” Participants with chaos narratives are unable to organize their experience into a whole. Therefore, they are the least likely to find patterns in their blood glucose readings. It is especially helpful to interpret these BG readings for them in ways that maintain their integrity and promote self-regulating efficacy.

*At times less education is more productive.* Once participants began testing “to figure out” diabetes, they began to ask difficult questions. Despite being told about the liver’s role in glucose regulation, most of the participants with HbA1c < 7.0% were still puzzled by early morning hyperglycemia. It is possible that understanding the hepatic contribution to hyperglycemia is counterproductive for health behavior change early in the T2DM experience. Ancker and Kaufman (2007) have reported the importance of framing to improve comprehension of health information. Participants in this study were told that the liver was like a snack bar that was open all night to feed them. Despite this simplistic frame, hepatic contribution to hyperglycemia was not an accepted explanatory model for those newly diagnosed with T2DM. Participants did not accept that anything except food or stress would elevate their BG. It is possible that the confusion fasting hyperglycemia creates motivates behavior change. Therefore, teaching about the

hepatic contribution to hyperglycemia may be less important during the period of early learning following a diagnosis of T2DM. In contrast, participants were pleased with the response that their bodies had to exercise. They were motivated for activity to “make their numbers.”

*Patients value routine testing.* As the novelty of SMBG wore off people began to be able to predict how their body would respond to various foods or activities. At this point the self-regulating SMBG guideline for primary care practice attempted to move people to testing twice a day 3 days a week. However, participants did not like to test less than once a day even though some participants stated that one test alone did not provide enough information. They did not want to save one day’s test strip to test twice on 3 days. They wanted to test as a marker (sign) so that diabetes didn’t become “out of sight out of mind” but they no longer had strong emotional reactions to elevated blood sugar readings. If readings were elevated participants considered eating a little less or differently and exercising more. They stated that they could “make their numbers” but they were less confident that they would. None of the participants wanted to test less often than daily if they could afford the test strips. The routine of testing helped keep them in line with their own goals. Participants criticized others with T2DM who were not testing because testing was perceived as taking control of diabetes. However, people with longstanding diabetes may have different processes of evaluating their health behavior. Reinitiating testing to solve a particular problem may meet the needs of adult learners who are actively questioning the efficacy of diabetes interventions. People with longstanding T2DM may not benefit from testing the way that those with a more recent

diagnosis benefit. Participants in this study stated that daily testing was essential to “know where they were at.”

*Listen to the journey.* Using SMBG was framed as an exploration of the body’s response to eating, activity, medication, and stress. Participants’ findings were discussed during a medical visit in the primary care office. Participants stated that the personal nature of their health care was important to them. One participant described it as “It is the listening that I want.” Another participant found it helpful that information was presented to her factually and then she was asked to see what she could do. She described this as “not patronizing.”

What I have really liked about your approach is that you don’t patronize; but, you give people the facts. You tell them this is possible. And you kind of, you leave it up to them to make the changes. It is a form of encouragement without feeling like I am being treated like a baby. The last time I came here, you said, “if you keep losing weight...another eight pounds and you will be in the normal range.” I felt like I can do that. “Give yourself a year”. I didn’t feel like I had to do that within the week. It is not that you say, “You can do this”. But you give the fact. I felt like it was up to me to make those changes. That to me was very encouraging. I felt, “Yeah, I can do that.”

The belief “I can do that” reflects the need for control that is common to illness experiences (Kleinman, 1988). The desire to have diabetes care personalized is consistent with Furler et al. (2008) who reported that it is the relationship more than the educational classes that are important for behavior change. One participant was critical of a former health care provider who pointed him to the internet for diabetes related

information. Participants in this study expressed a desire to have their T2DM management personalized to their lives. Nurses can learn to help those early in the disease process to appraise T2DM through SMBG.

*“Good” and other moral judgments.* If diabetes health professionals listen to people with T2DM, they can hear deeper and often unstated functions and meanings of SMBG. The moral implications of SMBG were explored by Broom and Whittaker (2004). Their study of Australians with diabetes found that diabetes was not as stigmatized as it was 10-25 years ago. Broom and Whitaker reported that a common explanatory model for a diabetes diagnosis among their Australian participants was “lifestyle” unlike this study’s participants who focused on the genetic etiology of diabetes with a nod to their own personal responsibility.

An example of moral overtones in participant description of BG readings is their assessment of readings as “good” or “unacceptable.” In practice patients often respond with one word to the question of, “what are your BG readings?” That word is “good.” In order to avoid the personal or professional moral judgment of BG readings, framing of this discussion requires more planning. For example asking “Are your BG readings first thing in the morning between 80 and 120?” avoids a moral response. This question provides context (morning) specificity (between...) and personalization (your). It avoids either personal or professional judgment and educates by defining the target range.

Moral judgments are best made by participants themselves as they clarify their own values. At the conclusion of an interview, one participant told a story about a man and wife who died and went to heaven. The moral of the story was that healthy behavior delays your good life in heaven. This fable’s conclusion is in contrast to today’s focus on



healthism. Healthism interprets failed health behavior as a personal moral failure (Crawford, 1980). Later this participant did not return for his follow-up appointment. I do not think that he knew at that moment that he was not going to follow-up. However, perhaps as he listened to his own story he discovered what he thought about his health behavior. The role of listening to patients helps them to clarify their own goals and expectations and gives providers insight to health processes.

Peel et al. (2007) concluded that women more than men use readings as a proxy for good or bad behavior. Patients who respond to the question “what are your blood glucose readings” with “O.K.” or “good” are measuring their behavior. Their response may reflect the need that people with T2DM have to feel reassured in relation to their health status. This need was also represented in logbooks with pictures of smiley faces next to readings on target. Likewise, self-judgments or comments such as “lazy” were found in the logbooks of women. The nurse can have an important role in supporting this concern while creating a safe environment for beginning health behavior change. Asking patients if they are ready to find out how their body responds in different settings, “Now that we know your readings are on target before lunch, I wonder if you would consider checking 2 hours after a meal?” Prior to this study I did not appreciate the need for reassurance and the importance that patients placed on achieving a target reading. Disregarding or minimizing when patients achieve a target blood glucose reading threatens patients need for control (Polonsky & Skinner, 2010). Achieving a target can be viewed as providing agency for future testing when the readings may not be as satisfying. Limiting testing to achieve a good reading has been reported in other studies (Peel et al., 2007; Simon et al., 2008). Participants’ need for control prevents

them from testing at different times, risking an off target reading and considering health behavior change.

*“But now, it is not that way anymore”*. Applying numeracy skills by presenting SMBG as a self-regulating intervention has potential for supporting behavior change. Evidence of a new pattern of behavior and personal knowledge of diabetes in the narratives was found in the expression, “but now” and “It is not that way anymore.” Letting go is the other side of control (Kleinman, 1988). Recognizing a new pattern is the outcome of SMBG for people with T2DM. This outcome is challenging to measure because even those who perform healthy eating and exercise behaviors admit that they are only “midways” confident that they can continue in their behavior. Evidence of SMBG’s influence on behavior is inconclusive (French et al., 2008). However even studies that are unable to conclude that SMBG changes health behavior acknowledge that SMBG has the potential to contribute to metabolic control by supporting behavior change (Clar et al., 2010).

It is difficult to create a credible mathematical model that captures the health impact of walking after an evening meal in response to elevated BG readings. However, the participants who used SMBG made statements indicating that SMBG provided a measure of protection for their health. When health practitioners hear a form of the expression, “But now”, it is evidence that active behavior change has occurred. Efforts to support and maintain this change should be considered. The application of numeracy skills to “figure out diabetes” is clearly important and the most evident role of SMBG to most practitioners (Clar et al. 2010). However, from my perspective, the time these participants applied numeracy to behavior change seemed brief. Participants spent

most of their time in one of two places; either confirming their diagnosis with functional numeracy or comforting themselves that they were maintaining their numbers with interpretive numeracy.

### Implications for Nursing Education

Nurses at all levels and across many specialties encounter people with diabetes. Nurses need to be instructed in use of SMBG as an interface between technology and the human experience. SMBG is a psycho-motor skill. The physical performance of SMBG was easily performed by patients and nurses alike. Nurses need to learn how to use self-regulating interventions with SMBG. Teaching patients how to interpret and use SMBG information is a valuable expression of the art and science of nursing. Nurses can implement person-centered plans such as the self-regulating SMBG guideline for primary care practice (Appendix A) wherever T2DM is diagnosed. Nurses need to be taught to frame the communication of diabetes health information while considering the functions and meanings of SMBG for people during the first 2 years following T2DM diagnosis. Nurses need to be taught to listen and identify the patient's illness narrative in order to tailor the intervention to the person's life-context and to support the "But now" of behavior change.

### Research Considerations

Evaluating the efficacy of SMBG in T2DM has been at best inconclusive (Clar et al. 2010). Studies that have examined the relationship between testing and HbA1c have not adequately controlled for these different time periods and the impact that a health provider has in interpreting and influencing SMBG behaviors and health promoting behavior (Clar et al, 2010). Although some studies create models of analysis meant to

control for variables such as medication usage, no study could be identified that separated out the efficacy of SMBG in the lived time of *Diagnosis*, *Behavior change*, or *Routine* (McAndrew et al., 2007) To improve the measurement of the effect of SMBG researchers could use these time periods to strengthen future studies by recognizing that SMBG is not the same across the T2DM experience. When participants were shown Figure 1, they often pointed to a box on the diagram and said, “This is where I am.” Researchers could use Figure 1 to identify where participants are in their use of SMBG. Studies comparing people who use or do not use SMBG during each of these time periods may provide a clearer picture of the efficacy of SMBG in T2DM.

People initiate SMBG under a wide variety of circumstances. Some people initiate testing on their own, others are given glucometers in medical offices without the integration of SMBG and diabetes education. Some are instructed in pharmacy programs separate from the medical office. None of the SMBG efficacy studies examined how people were instructed in the use of SMBG (Clar et al, 2010). In this study SMBG was introduced in a framework of problem solving and exploration. Variations in the method of framing diabetes education in relation to SMBG likely influence the efficacy of SMBG in T2DM. Research on the influence of the framing of SMBG education on outcomes is needed to understand the efficacy of SMBG in T2DM.

*Limitations.* This study provided detailed information about the experience of SMBG and living with T2DM during the first 2 years following diagnosis. The functions and meanings of SMBG identified may not be applicable to those who have lived with T2DM longer than 2 years. Although limited to rural southern Appalachian participants, the processes were similar to those identified in a Sweden, Australia, and Scotland

(Edwall et al., 2008; Furler et al., 2008; Peel et al., 2007). Therefore, some of the findings may be more universal than the apparent limitations of this small group of participants.

*Strengths.* This study is one of few (e.g. Peel et al., 2007; Peel, Parry, Douglas, & Lawton, 2004) that consider patient perspectives on SMBG. In addition most of the RCTs examining the efficacy of SMBG do not consider the educational context of SMBG (Clar et al, 2010). This study was placed in the context of a personalized, self-regulating SMBG guideline for primary care practice. This study is unique in limiting the description to the first 2 years following a diagnosis of diabetes and describing the impact of SMBG on diet and exercise.

One of this study's strengths was that the participants knew the researcher. Participants were critical of elements of the self-regulating SMBG guideline for primary care practice such as wanting to test more often and preferring to test when they could achieve a normal value. This criticism indicated a degree of openness in the discourse between participant and researcher.

Many of the participants in this study had storytelling as an important role and experience in their families. This made the open ended and narrative form of research very comfortable and appropriate for participants. This study differed from other studies of SMBG and T2DM because the participants all shared a common diagnosis and treatment plan. In addition this was the first study to examine this experience in relation to a model of primary, applied, and interpretive numeracy.

## Conclusions

*“Knowing where I am at”*. Once SMBG became routine a common interpretive numeracy function was “knowing where I am at.” Participants used numeracy skills in an interpretive and holistic sense to define their T2DM experience. This is consistent with Polanyi’s (1966) philosophy of personal knowledge where a person knows more than he or she can tell and in which the whole is more instructive than the particulars. When participants used SMBG during *Routine*, the whole was more important than their knowledge of the pieces. “Knowing where I am at” a person with T2DM created small adjustments in behavior and experienced a feeling of security. Participants were not actively applying numerical processes such as counting carbohydrates or timing minutes of exercise. Instead, they were using numbers as an estimator to help “keep them in line” as they maintained healthy behaviors or restrained unhealthy behaviors.

Prior to listening to my participants I had thought that testing in *Routine* was unnecessary because I could not hear the active use of BG readings evident during *Behavior change*. One participant called SMBG “preventive maintenance”. Now I understand that “knowing where I am at” is important to a person living with T2DM as it maintains the person’s new health behavior and restrains old habits.

The year following a diagnosis of diabetes appears to be a fertile time for health behavior change. People no longer feeling invincible consider other health concerns during this time and reflect on how diabetes may impact their life. During *Diagnosis*, SMBG functions to confirm the T2DM and make it real for the participants. Expression of anxiety upon receiving the T2DM diagnosis was common and greater in those with HbA1c > 7.0%. Participants who could identify one time of day that their readings were

on target found that SMBG functioned to comfort them at that time. Once participants accepted their diagnosis and believed that they would be “some kind of O.K.,” they were able to move on to explore how their bodies responded to food, activity, stress, and smoking. Successful and less successful experiences as evaluated with SMBG helped motivate participants toward action or restraint. In the end SMBG congratulated successful managers when they could “make their numbers.”

I had begun the research process believing that many people just tested their blood glucose without thinking or reacting to the values they received. After listening to the participants in this study I learned the important ways that SMBG motivated them to continue with behavior change. I now believe that it is the process of implementing SMBG that is important to SMBG efficacy. I have concerns that as people have access to receiving SMBG devices outside of a healthcare relationship (e.g. pharmacy programs, mail order medical equipment suppliers), the testing may not be as beneficial. Now pharmacies are required by Medicare to obtain logbooks of BG testing results from Medicare recipients. These logs are not discussed or examined for clinical purposes. The administrative burden of providing Medicare recipients with more than the allowable number of strips (one strip per day for non-insulin-requiring T2DM) has prevented me from recommending more frequent testing. I now believe that people newly diagnosed with diabetes need more test strips during the 2 years in order to establish healthy routines. More study is needed to determine the frequency of testing needed during the extended maintenance period in the years that follow diagnosis. Perhaps cost savings can be incurred during these years. However, this study found that during the first 2 years following a diabetes diagnosis, SMBG initiated in the primary

care office with the support of a nurse appears to be influential for forming health beliefs and behaviors. SMBG at least once a day could establish a foundation for a lifetime of improved diabetes management.

Participants in this study shared an experience of being diagnosed with diabetes in a primary care practice. All participants were exposed to a self-regulating model of practice using SMBG to learn more about their diabetes. Participants were asked to use SMBG to answer their question, “Do I really have a problem?” They reported that testing removed question marks and confirmed their diagnosis. In addition they were asked to “Look for trouble.” They moved testing around their daily life to evaluate different testing circumstances. Participants did not like “looking for trouble” as they preferred to test at times when their readings were at target. They liked to know they were, “some kind of O.K.” Eventually most participants did begin to explore their bodies’ response to food choices by testing 2 hours after meals. They learned that foods such as spaghetti and juice elevated their blood glucose. They considered health behavior changes as they made observations and asked questions about their readings. This active application of numeracy processes helped them to “figure out” how to control diabetes. For participants the SMBG meant that diabetes didn’t control them, they controlled it. They did not want to use SMBG less than once daily as they described testing as a “daily tracking device.” Participants used interpretive numeracy processes during *Routine*. In addition the SMBG functioned to motivate participants. The numbers “made them go walking” and were interpreted as a reminder of others that did not have favorable diabetes health outcomes.



Participants made statements that SMBG helped them achieve their goals, improve health behavior, improve HbA1c results, and achieve weight loss, although they appraised confidence in their future ability to maintain their goals as “midways” on a scale of 1 to 10. The participants’ enthusiasm to use SMBG daily and often and the indifferent appraisal of future behavior seems incongruent. However, I believe this reflects two different embodiments of illness. SMBG represents the need of the disciplined body to have control. While the appraisal of future ability to maintain health behavior represents the need of the communicative body to have other-relatedness (Frank, 1995). Actually this “midways” is a healthy response to the monadic limitations of the disciplined body. Acknowledging the possibility of not relinquishing oneself to the duty and regimen of the disciplined body leaves the person with T2DM able to be open to contingencies that may not conform to the prescribed health behavior for people with T2DM. Accordingly, “knowing where I am at” may actually facilitate a healthy fluid self expression between the desire for control and the need for relatedness.

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## APPENDICES

### Appendix A

#### Self-Regulating SMBG Guideline for Primary Care Practice

Visit #/Day	Visit Focus	SMBG Purpose	SMBG Pattern
Visit 1 Day 0	<p>Instruct in SMBG testing. Focus on a brief explanation of disease process.</p> <p>Provide target BG for fasting/premeal and 2 hours after meals.</p>	Purpose: “Looking for trouble” and “Do I really have a problem?”	<p>Day 1 Bedtime. Day 2 Fasting and 2 hours after Breakfast. Day 3 Before mid-day meal and 2 hours after mid-day meal. Day 4 Before evening meal and 2 hours after evening meal. Day 5 Off Day 6 Off Day 7 Off (Patient’s choice—after exercise? After a snack? Stressed?) Week 2 Repeat starting at Day 1</p>
Visit 2 Day 14	<p>Identify problem times from two weeks of testing.</p> <p>Focus on Nutritional guidelines. Set patient centered goals. Ask patient to bring a 3 day dietary diary to next visit.</p>	Purpose “Dietary contribution to elevated BG”	<p>Test once daily at problem time for 2 weeks. Or Test twice daily, before and 2 hours after a meal 3 days a week and fasting one day following the day that the evening meal was tested.</p>
Visit 3 Day 28	<p>Review BG results and Diet diary.</p> <p>Ask patient in what ways the BG testing and diet diary help them in DM self-management.</p> <p>Focus on Activity guidelines. Set patient centered goals. Ask patient to bring activity diary to next visit.</p>	Purpose: “Does testing help me achieve my goals?”	<p>Set BG testing based on patient answers.</p> <p>Not helpful: Ask patient to test based on practitioner needs.</p> <p>Helpful: Continue with patient determined testing.</p>
Visit 4 Day 90	<p>Answer patient questions Review progress towards activity and dietary goals. Set patient centered goals</p> <p>Focus on patient goals (activity, dietary, stress management).</p>	Purpose: “Did behavior changes improve my BG, my weight?”	<p>Check HbA1c</p> <p>Set BG testing using Monnier’s guidelines and patient preference.</p> <p>HbA1c &lt; 6.5 % lifestyle change alone HbA1c ≥ 6.5 ≤ 6.9 % consider Metformin HbA1c ≥ 7.0% start Metformin</p>

## Appendix B

### Consent

#### **EAST TENNESSEE STATE UNIVERSITY VETERANS AFFAIRS MEDICAL CENTER INSTITUTIONAL REVIEW BOARD**

This Informed Consent will explain about being a participant in a research study. It is important that you read this material carefully and then decide if you wish to be a volunteer.

PURPOSE: You have been invited to take part in a research study titled, The Experience of Self-Monitoring Blood Glucose for People with Non-Insulin-Requiring Type 2 Diabetes. The purpose of this research study is to explore the way that people use blood sugar results to manage their diabetes. Your experience provides a unique perspective on this issue, and will help health professionals understand the usefulness of blood glucose testing from the patient's perspective for people with type 2 diabetes.

DURATION: You will be asked to schedule an interview appointment. This research interview may last about one hour or longer depending on how much you want to say about the topic of blood sugar testing.

PROCEDURES: The procedures, which will involve you as a research subject, will include talking about your experience with blood sugar testing during a research interview. Your interview will be recorded using a microphone and a computer. You will be asked to describe yourself. You will be asked to show your blood sugar log (whether you use a written log or keep your readings in your blood sugar meter). A photocopy and/or photo of some of the pages/meters will be made.

ALTERNATIVE PROCEDURES/TREATMENTS: This study does not involve a treatment but focuses on what you are already doing to test your blood sugar. The alternative is not to participate in this study.

POSSIBLE RISKS/DISCOMFORTS: It is not likely that you will feel uncomfortable talking about your experience; but if you feel uncomfortable you can stop the interview at any time. There is no reasonable expectation that this research causes risks to fetuses or embryos.

POSSIBLE BENEFITS: There is no direct benefit to participating in this study. A possible benefit from your participation is that you will be informing health providers more about how people with diabetes use blood sugar information. Your participation may benefit other people with diabetes as we learn from your experience.

FINANCIAL COSTS: There are no additional costs to you as a result of participating in this research study.

## VOLUNTARY PARTICIPATION

### Participation in this research experiment is voluntary.

You may refuse to participate. You can quit at any time. If you quit or refuse to participate, the benefits to which you are otherwise entitled will not be affected. Participating or not participating does not impact your care at Mountain Family Medicine, PA.

You may quit by calling Dana Brackney, whose phone number is 828/262-1800. You will be told immediately if any of the results of the study should reasonably be expected to make you change your mind about staying in the study.

CONTACT FOR QUESTIONS: If you have any questions, problems or research-related medical problems at any time, you may call Dana Brackney at 828/262-1800; or Kathleen Rayman at 423/439-4589. You may call the Chairman of the Institutional Review Board at 423/439-6054 for any questions you may have about your rights as a research subject. If you have any questions or concerns about the research and want to talk to someone independent of the research team or you can't reach the study staff, you may call an IRB Coordinator at 423/439-6055 or 423/439-6002.

CONFIDENTIALITY: Every attempt will be made to see that your study results are kept confidential. A copy of the records from this study will be stored in a locked computer file at the researcher's residence for at least 5 years after the end of this research. The results of this study may be published and/or presented at meetings without naming you as a subject. Although your rights and privacy will be maintained, the Secretary of the Department of Health and Human Services, and personnel particular to this research have access to the study records. Your medical records will be kept completely confidential according to current legal requirements. They will not be revealed unless required by law, or as noted above.

By signing below, you confirm that you have read or had this document read to you. You will be given a signed copy of this informed consent document. You have been given the chance to ask questions and to discuss your participation with the investigator. You freely and voluntarily choose to be in this research project. By signing below, you confirm that you are giving consent to the photographing/photocopying of your blood glucose logbook and/or blood glucose meter and the audio recording of your interview.

---

SIGNATURE OF PARTICIPANT

DATE

---

PRINTED NAME OF PARTICIPANT

DATE

---

SIGNATURE OF INVESTIGATOR

DATE

---

SIGNATURE OF WITNESS (if applicable)

DATE



## Appendix C

### Self Monitoring Blood Glucose Interview Guide

I am interested in learning more about how people who have type 2 diabetes use blood sugar testing to help them manage their diabetes. But first I would like to know how you found out that you had diabetes. What was that experience like for you?

**Could you tell me what you remember about how you learned to test your blood sugar?** How do you decide when to test your blood sugar? Do you have target blood sugar levels? Do the blood sugar numbers mean anything to you? What advice would you give to someone who is just learning about their blood sugar?

What do you understand about your blood sugar readings? How often do your readings surprise you? Can you ever think of an explanation as to why your readings are as they are? **How does testing your blood sugar effect how you feel about yourself or diabetes?** What do your readings mean to you?

Sometimes people learn that a certain feeling means their blood sugar is high or low. **Do you think that you can tell by a feeling if your blood sugar is high or low?** Have you ever confirmed your feeling with blood sugar testing? Could you tell me more about this experience?

**Do you feel like your doctor or nurse judges you because of your blood sugar readings?** Why or why not? **How does blood sugar testing help you manage diabetes? Is there any way that blood sugar testing does not help you?**

## Appendix D

### Participant Self-Description

Number

People who live in Western North Carolina have had a variety of life experiences. Some people have lived close to where they were born all their life. Other people have moved to this area for employment. Some people move here for retirement or other reasons. How would you describe yourself?

Race

Gender

Age

Insurer

Years/months with diabetes

HbA1c      1.              2.              3.

Medications for diabetes

Reported blood sugar average pre-meal

Reported blood sugar average post-meal

Primary medical manager of diabetes

Family Practice

Endocrinologist

Advanced Practice Nurse

Health Department

Other

## VITA

### DANA ELISABETH BRACKNEY

- Education: B.S. Liberal Arts and Nursing, Wheaton College, Wheaton, Illinois 1987  
B.S.N. Nursing, Rush University, Chicago, Illinois 1987  
M.S.N. Nursing, The University of North Carolina, Chapel Hill, North Carolina 1991  
Ph.D. Nursing, East Tennessee State University, Johnson City, Tennessee 2010
- Professional Experience: Charge Nurse, University of North Carolina Hospitals; Chapel Hill, NC 1987-1990  
Skill Lab Instructor; University of North Carolina at Greensboro; Greensboro, NC 1992-1993  
Clinical Instructor, North Carolina A & T State University; Greensboro, NC 1995  
Clinical Nurse Specialist–Diabetes, Wesley Long Community Hospital; Greensboro, NC 1991-1996  
School Nurse, Emmanuel Christian Academy; Kettering City Schools, Kettering, OH 2001-2003  
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- Honors and Awards: 1985-1987 Dean’s List, Rush University  
1987 Sigma Theta Tau, Rush University  
1987 Community Service Award, Rush University  
1988-1990 Johnston Scholar Fellowship, University of North Carolina-Chapel Hill  
1991 Professional Achievement Award for Excellence in Nursing, Wesley Long Community Hospital  
1993 North Carolina Great 100 Nurses  
1994 October Employee of the Month, Wesley Long Community Hospital  
2007 College of Nursing Scholarship, East Tennessee State University  
2010 Dissertation Grant, Sigma Theta Tau, East Tennessee State University