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Couple's Relationship with Diabetes: Transformation, Partnership, and Management

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The Couple's Relationship with Diabetes: Transformation, Partnership, and Management

by

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Each person whose signature appears below certifies that this dissertation in his/her opinion is adequate, in scope and quality, as a dissertation for the degree Doctor of Philosophy.

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CONTENT

FIGURES

Figures Page

TABLES

Tables Page

ABSTRACT OF THE DISSERTATION

The Couple's Relationship with Diabetes: Transformation, Partnership, and Management

by

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Doctor of Philosophy, Graduate Program in Marital and Family Therapy
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Dr. Colwick Wilson, Chairperson

This study used an MFT perspective to examine a model of three biopsychosocial constructs, seeking to depict key dimensions of what makes couples successful in managing the demanding self-care regimen of diabetes. The model includes a meaning- and emotion-oriented construct called *relationship with diabetes*, a psychosocial-relational construct of diabetes-specific *partnering support,* and their direct and indirect effects on an endogenous construct of success in *diabetes management*. Surveys from 118 adult couples with diabetes provided data to test the hypothesized path and measurement model. Correlational and multiple regression analysis examined variable relationships, factor analysis examined construct dimensionality, and structural equation modeling determined the model's goodness of fit. It was found that *relationship with diabetes* and *partnering support* are positively associated and have direct and indirect effects promoting successful diabetes management. The emotion component of *relationship with diabetes* was especially important to management success. The current quantitative study extends and tests grounded theory from a previous qualitative study. Outcomes from this study expand our current understanding of how couples manage

chronic illness and highlight the importance of developing a multidisciplinary approach to diabetes research, education, and intervention.

CHAPTER ONE

INTRODUCTION

Purpose Statement

Chronic illness is important to study in the field of Marriage and Family Therapy, because it has serious and complex systemic impacts on individuals, marriages, and families, and in turn those relationships have significant effects on illness management and outcomes. Diabetes is a chronic illness that requires particularly strict, demanding, and multifaceted self-care regimens of illness management, which impact strongly upon those who must live with its demanding requirements (Trief et al., 2003). Diabetes affects not just the person with the illness, but spouses, children, and all those in relationship with that person. To address the systemic complexity of personal and relational effects of diabetes, a meaning-oriented, biopsychosocial approach to chronic illnesses such as diabetes holds both challenge and promise to researchers (Snoek & Skinner, 2002; Campbell, 2002; Wynne, Shields, & Sirkin, 1992; Kowal, Johnson, & Lee, 2003; Kyngas, & Barlow, 1995; McDaniel, Hepworth, & Doherty, 1992; Morris, 2000; Peyrot, McMurry, & Kruger, 1999; Poss & Jeweski, 2002). Applying this biopsychosocial, meaning-oriented frame to couples' management of diabetes, this study seeks to measure three constructs: (1) an emotion and meaning-oriented variable, the married couple's *relationship with diabetes,* (2) a psychosocial and relational variable, the diabetes-specific *partnering support* that the non-diabetic spouse provides, and (3) a psychobiological variable, the couple's success in *diabetes management*. This study additionally seeks to test a model that proposes how these three variables interact.

These three constructs were conceptualized in a grounded theory, qualitative study, "Couple's relationship with diabetes: Means and meanings for management success," of 29 diabetic couples in Southern California (Houston-Barrett & Wilson, in press), based on qualitative data analysis and current theory in the relevant literature. This current study seeks to extend these qualitative findings and test these three constructs in a quantitative arena.

One of these constructs is the couple's *relationship with diabetes,* which is the framing, cohesive set of emotions, meanings, and narratives that the couple holds in regards to the disease; it may be transforming, accepting, rejecting, or a combination of these (Houston-Barrett & Wilson, in press). This study conceptualizes the couple's *relationship with diabetes* as a variable that ranges from least to most transforming in nature, as it varies on a spectrum from rejecting to accepting to transforming.

Related but distinct, *partnering support* from the non-diabetic spouse plays a role in the couple's diabetes management, which may be as a partner, pusher, avoider, or a combination of these (Houston-Barrett & Wilson, in press). Couples in the qualitative study who were most successful in diabetes management tended to have transforming relationships with diabetes, and they were most likely to have non-diabetic spouses who took a partnering role in support of the diabetes regimen (Houston-Barrett & Wilson, in press). The current study defines this variable as diabetes-specific *partnering support* that ranges from least to most partnering, as it varies on a spectrum from avoiding to pushing to partnering.

Diabetes management refers to how the couple manages adherence to a complicated regimen that includes oral medications and/or insulin administration, blood

glucose testing, dietary therapy, and exercise. Diabetes regimen adherence is chronically low, even in the face of known, serious consequences (Brennan, 1996; Murphy & Kinmonth, 1995; Peyrot, Rubin, Lauritzen, Snoek, Matthews, & Skovlund, 2005; Vermiere et al., 2005). Yet studies convincingly demonstrate that complications can be minimized if patients maintain normal blood glucose levels (DCCT Research Group, 1993; UKPDS Study Group, 1998). Therefore, it is a vital goal of research to find ways to help patients adhere to their diabetes management regimen (Trief et al., 2003). Outcomes of this study are expected to contribute to this fundamental goal of diabetes research.

Understanding what makes diabetes regimen management easier or more challenging for couples to achieve is of critical and key importance for researchers and clinicians (Cramer, 2004; Wing, Epstein, Nowalk & Lamparski, 1986). The current study seeks to advance understanding in this area by examining interactions of specific biopsychosocial and meaning-oriented variables and their direct and indirect effects on couples' success in diabetes management.

Background

Diabetes

The need for effective treatment approaches for diabetes is critical. Diabetes affects not only the 25.8 million people in the United States who have it (Centers for Disease Control and Prevention [CDC], 2011a), but also their family members and friends. Diabetes doubles the risk of death; it was the 7th leading cause of death in the United States in 2007, and further it appears to be under reported as the cause of death

(CDC). It has risks of serious complications, including blindness and amputation, and it is associated with decreased quality of life and mental health concerns, such as depression (CDC). The CDC estimates that the annual cost of diabetes in the United States is $174 billion. Additionally, diabetes rates are climbing dramatically: in a national sample, the age-adjusted incidence of diabetes increased 90% from 4.8 per 1,000 in 1995-1997 to 9.1 in 2005-2007 (Kirtland, Li, Geiss, & Thompson, 2008). If current trends continue, one in three Americans will develop diabetes sometime in their lifetime, and those with diabetes will lose, on average, 10–15 years of life (CDC, 2009).

Diabetes is also a health disparities concern. African American, Hispanic, American Indian, and Alaska Native adults are twice as likely as White adults to have diabetes (CDC, 2011a). American Indian women are particularly vulnerable to diabetes, with most cases being type 2: one study found that 70% of Pima Indian women 45-64 years old have diabetes (CDC, 2001).

Being married appears to have a protective effect on adults, decreasing the likelihood of having diabetes, and individuals with diabetes are more commonly unmarried than married (CDC, 2001a). For example, among middle-aged women with type 2 diabetes, 72.2% were unmarried and 58.3% were married (CDC, 2001a). This may be related to the finding that unmarried adults are far more likely to be sedentary/inactive that married adults (39.4% vs. 24.1%) (CDC, 2008).

Diabetes Regimen Management

Diabetes is a disease in which the body has a shortage of insulin or a decreased ability to use insulin, a hormone that allows glucose (sugar) to enter cells and be

converted to energy (CDC, 2011a). When diabetes is not controlled, glucose and fats remain in the blood and, over time, damage vital organs (CDC, 2011a). Thus, a major issue in diabetes care is how well the patient is able to follow medical directives about diet, exercise, medications, and blood glucose testing, which comprise the established medical self-care regimen.

Research suggests that adherence to treatment recommendations is low, and interventions to improve adherence have been largely unsuccessful (Brennan, 1996; Peyrot, Rubin, Lauritzen, Snoek, Matthews, & Skovlund, 2005; Vermiere et al., 2005). Estimate of non-adherence to health regimens range from one-third to three-quarters, despite the fact that the failure to manage the disease presents life-threatening prospects (Cramer, 2004; Wing, Epstein, Nowalk & Lamparski, 1986). For instance, in a large national sample of patients with type 2 diabetes, 24% of insulin-treated patients, 65% of those on oral medications, and 80% of those treated by diet and exercise alone either never performed self-monitoring of blood glucose or did so less than once per month (Li, Zhang & Narayan, 2008).

Interventions to improve adherence have been largely unsuccessful, as shown in a recent meta-analysis of 21 randomized controlled clinical trials, before-after studies, and epidemiological studies assessing interventions aimed at improving adherence to treatment (not to diet or exercise) recommendations, in people living with type 2 diabetes (Vermiere, 2005). The reviewers concluded that *current efforts to improve adherence do not show significant effects*, and thus the question of whether any intervention can effectively enhance adherence to treatment recommendations in diabetes remains unanswered (Vermiere, 2005).

Regimen adherence is challenging for many because diabetes treatment is not a simple matter of medical management. Diabetes has complex, interactive effects on health, relationships, lifestyle, and many other psychological, emotional, contextual, and social factors (Snoek & Skinner, 2002). Thus blood sugars fluctuate in largely unpredictable ways, making diabetes management and control difficult to achieve. The course of the disease, from prediabetes to end-stage complications, is not the same in all patients, especially for vascular complications (Stolar, 2010). Additionally, it seems that many people are able to reconcile the belief that diabetes is a serious condition with less than full adherence to medical lifestyle advice (Murphy & Kinmonth, 1995). Therefore, it is insufficient to examine diabetes management solely from an individualistic and biological perspective; there are other essential parts of this picture (Brennan, 1996; Elgen, 1979; Sperry, 2008).

Current research has expanded the field of view from a focus on the physical, biomedical management of diabetes to include relational, emotional, and meaning-oriented aspects of living with and managing the disease (Snoek & Skinner, 2002). In particular, family and couple relationships have received increased attention in the research literature, with results indicating their substantial importance for diabetes management (Aalto & Uutela, 1997; Butler, 2003; Campbell, 2002; Campbell, 2003; Fisher, 2006; Kowal, Johnson, & Lee, 2003; Lo, 1999; Miller, Wikoff, Keen, & Norton, 1987; Trief et al., 2003). This study uses a relational, biopsychosocial approach to study how couples manage diabetes.

Rationale

Previous studies have provided evidence that, in married couples, diabetes management is strongly affected by meanings, beliefs, and attitudes held about the illness by both the diabetic and the non-diabetic spouse (Snoek & Skinner, 2002). Additionally, strong support has been found that a partnering or collaborative type of support (not just any support) provided by the spouse is particularly important to diabetes management (Fisher, La Greca, Greco, Arfken, & Schneiderman, 1997; Houston-Barrett & Wilson, in press; Miller & Brown, 2005; Trief et al. 2003). This study seeks to build on this body of research, as well as to continue the author's mixed methods course of research, to test a model that seeks to explain significant factors and structures affecting diabetes regimen management. Specifically, this study tests a model that proposes that interactions of direct and indirect effects of the couple's *relationship with diabetes* and diabetes-specific *partnering support* are strongly predictive of the couple's degree of success in *diabetes management*.

Objectives of this Study

Understanding why regimen adherence is so low, even in the face of known, serious consequences, is of critical importance. As the literature makes clear, there is still a great deal we do not know about what makes diabetes management so difficult to achieve, and what can be done to help. Approaching this question from a biopsychosocial and meaning-oriented, narrative perspective, we examine factors that hold promise to predict or explain couples' success in diabetes regimen management. The purpose of this study is to measure the married couple's relationship with diabetes to determine to what

degree it is *transforming*, to measure the diabetes-specific support provided by the diabetic's spouse to determine to what degree it is *partnering*, and to test via structural equation modeling the hypothesized and alternate models of how these psychosocial couple-dyad variables affect each other and ultimately both directly and indirectly affect the couple's degree of success in diabetes regimen management.

Therefore, based on the grounded theory developed earlier (Houston-Barrett & Wilson, in press), based on application of the biopsychosocial model for chronic illness (described further in the literature review), and based on literature suggesting the importance of emotions, meanings, and social support, the construct model shown in Figure 1 is proposed. In the current study, this model (expanded in Figure 3) and associated hypotheses are tested via structural equation modeling (SEM) and other analysis.

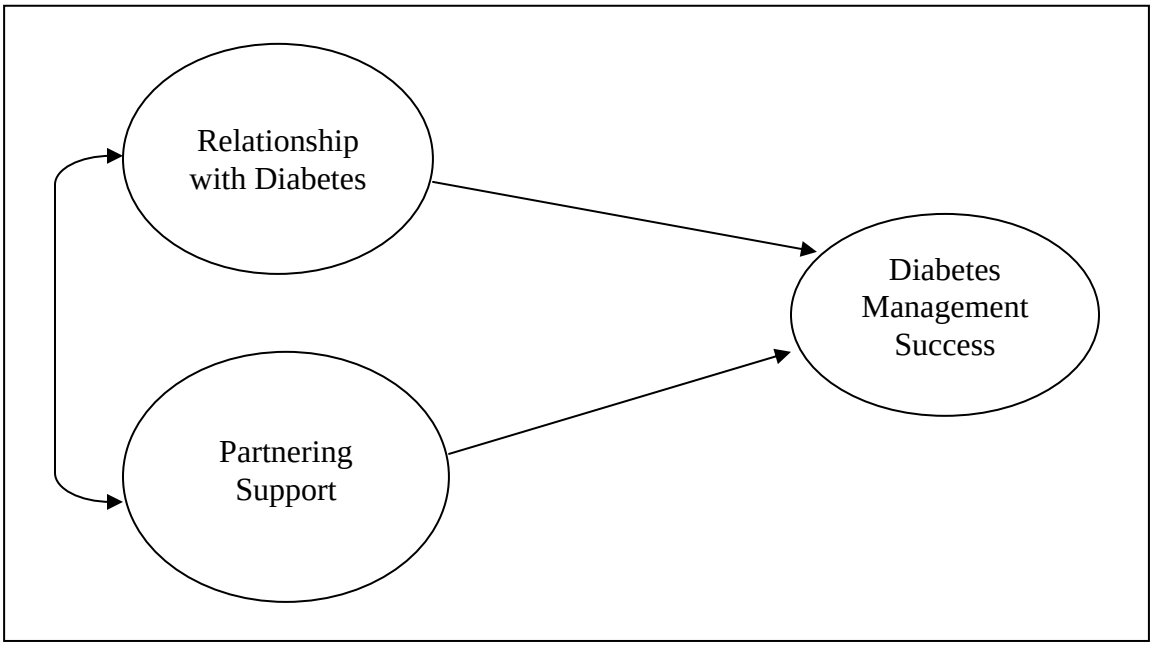


Figure 1. Study constructs model: couple's relationship with diabetes, partnering support, and diabetes management success.

Hypotheses

The model is congruent with the following hypotheses.

1. The degree that the relationship with diabetes is transforming is positively correlated with diabetes-specific partnering support provided by the non-diabetic spouse.
2. The degree that the relationship with diabetes is transforming is positively correlated with success in diabetes regimen management.
3. The degree of diabetes-specific partnering support that the non-diabetic spouse provides is positively correlated with diabetes management success.
4. Effects of the couple's relationship with diabetes and diabetes-specific partnering support significantly explain the couple's degree of success in diabetes regimen management.
5. The path and measurement model proposed in this study will have good fit with the data.

CHAPTER TWO

THEORETICAL FRAMEWORK: A MEANING-ORIENTED, BIOPSYCHOSOCIAL APPROACH

The Biopsychosocial Model

The biopsychosocial model is a comprehensive, integrative, holistic, systemic model that explicitly includes the biological, psychological, and social in understanding a person's functioning on all levels (Sperry, 2008). It includes the incorporation of key elements of the more limited biomedical and psychosocial models of health from which it evolved, while it further encompasses all factors and systemic relationships that affect the physical and mental health of a person (Sperry, 2008; Walker, Jackson & Littlejohn, 2004). When applied to chronic illness, the biopsychosocial model suggests that psychosocial processes can influence health directly, as well as indirectly through health behaviors, and the effects of stressors can be mediated by psychological processes (Rose, Fliege, Hildebrandt, Schirop, & Klapp, 2002). The systemic perspective of the biopsychosocial model is highly congruent with the systems theory paradigm in the field of Marriage & Family Therapy.

The biopsychosocial model gained widespread acceptance after the publication of Engel's (1977) classic article (Sperry, 2008), in which Engel argued successfully that the then-prevalent biomedical model was reductionist and limited, and that it should be replaced with the biopsychosocial model in order to encompass all factors of illness. In the biomedical model, derived from the 17th-century mechanical model of Newton, Descartes, and Bacon, phenomena are viewed in "dualistic, reductionistic, and linear causal terms" (Engel, 1985, p. 9). It was promoted by Christian teachings of mind/body

dualism in the middle ages, and with the advent of germ theory and technological innovations, it was embraced by Western society (Brennan, 1996). However, Engel (1977, 1985, and 1997) made the case that the biopsychosocial model is a more fitting means of scientific inquiry into the human perspective, because it includes not just biomedical, but also human psychosocial and subjective experience as essential data.

A Biopsychosocial Approach to Chronic Illness

The experience of chronic illness, such as heart disease, cancer, rheumatoid arthritis, and diabetes, has multiple causes and treatments, and it depends on multidimensional biopsychosocial factors, "including biomedical, personality, coping, and cultural factors" (Sperry, 2006, p. xi-xii). In the conceptualization, research, and treatment of chronic illness, the systemic biopsychosocial model is replacing the linear biomedical model in which health problems are viewed as objective reality with a single cause and single treatment (Sperry, 2008). The biopsychosocial model suggests that psychosocial processes can influence health directly, as well as indirectly through health behaviors, and the effects of stressors can be mediated by psychological processes such as one's ability to cope with the stressor (Rose, Fliege, Hildebrandt, Schirop & Klapp, 2002).

The biopsychosocial model has been widely promoted and adopted, such as for rehabilitation medicine (Mullins, Chaney & Frank, 1996), Family Systems Medicine (Steinglass, 2006), medical family therapy (McDaniel, Hepworth & Doherty, 1992), a unifying paradigm for psychotherapy (Anchin, 2008), chronic pain management (Harland & Lavallee, 2003; Nicholas, Molloy & Brooker, 2006), genomic research (Rolland &

Williams, 2005), and diabetes (DeCoster, 2008; Peyrot, McMurry, & Kruger, 1999). For example, in some studies, the biopsychosocial model has been used to conceptualize a vulnerability model in chronic illness, in which minor chronic stressors promote disease progression through aspects of personality, coping efficacy, social functioning, and immune and neuroendocrine function on illness behavior and disease progression (Kiecolt-Glaser, McGuire, Robles & Glaser, 2002; Lutgendorf & Costanzo, 2003, Walker, Jackson & Littlehon, 2004; Zautra, Hamilton, Potter & Smith, 1999).

A Biopsychosocial Approach to Diabetes

Because diabetes has complex, reciprocally interactive effects on all life dimensions, it has become commonly accepted in the research literature that a purely biological orientation is insufficient to address the complex issues around diabetes management (Brennan, 1996). In the biomedical model, the patient is viewed as the accepting recipient of medical care and obedient performer of medical regimen directives (Leventhal & Cameron, 1987). It presumes a linear sequence of knowledge, attitude, and skills (Van Parijs, 1980). However, studies have repeatedly demonstrated that diabetes self-management is poorly explained by compliance-based, simplistic models (Glasgow & Eakin, 1998). The biomedical model omits the psychosocial elements of diabetes, its compliance behaviors, and its demands for lifestyle modification which are crucial in diabetes management (Brennan, 1996). Specifically, the psychosocial impact of diabetes was found to be one of the five strongest predictors of mortality in diabetic patients, stronger than many clinical and physiological variables, in a longitudinal study (Davis, Hess, Van Harrison, & Hiss, 1988). Further, in a review of psychology and behavioral

research on diabetes over the previous decade, the authors concluded, “The greatest challenge to contemporary diabetes treatment [is] overcoming the many psychobehavioral and social-environmental barriers to optimal self-management” (Gonder-Frederick, Cox & Ritterband, 2002, p. 611).

Clearly, in order to understand this largely self-managed disease, we must explore it in all its dimensions: physical, social, contextual, spiritual, and psychological. The biopsychosocial model for physical disorders such as diabetes is widely promoted (Bateson, 1979; Campbell, 1993; DeCoster, 2008; Kowal, Johnson, & Lee, 2003; Kyngas, & Barlow, 1995; McDaniel, Hepworth, & Doherty, 1992; McMurry, & Kruger, 1999; Morris, 2000; Peyrot, Poss & Jeweski, 2002; Snoek & Skinner, 2002; Walsh, 1998). In a systematic review of the literature on coping with diabetes management, the authors concluded that psychological, emotional, behavioral, and quality of life factors are important in diabetes management and metabolic control, and are worthy of attention in their own right (Fisher, Thorpe, DeVellis & DeVellis, 2007). The current study uses a biopsychosocial perspective as it seeks to understand how couples live with and manage diabetes. Figure 2 illustrates the general biopsychosocial model for health and the application of that model for diabetes in the current study.

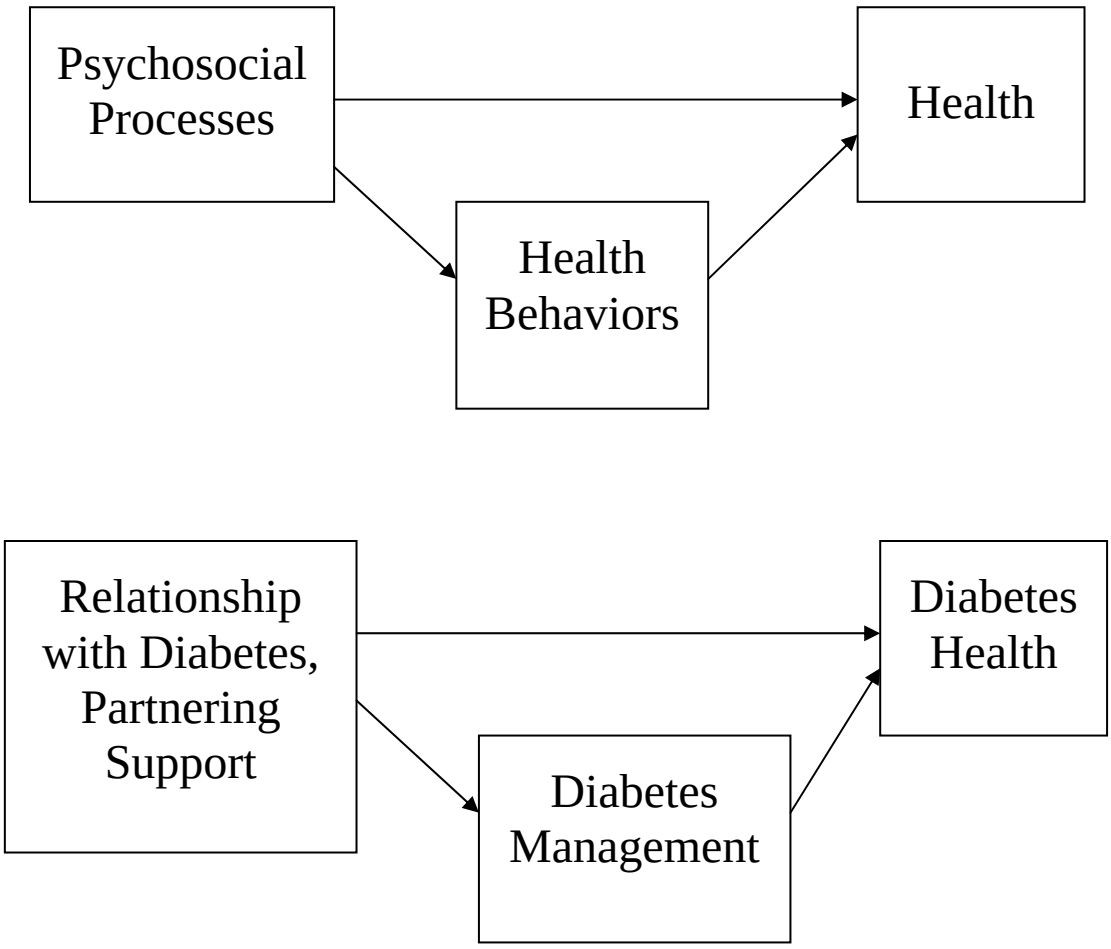


Figure 2. General biopsychosocial model for health (above) and for diabetes in the current study (below).

A Meaning-Oriented Biopsychosocial Approach to Diabetes

A body of theoretical and empirical support is found for a meaning-oriented, biopsychosocial approach to diabetes treatment. For example, Wynne, Shields, and Sirkin (1992) contend that it is "appropriate to conceptualize and work with illness as a narrative placed in a biopsychosocial context" (p. 3). Similarly, Brennan (1996) makes the case

that a biomedical model is inadequate, that "conceptualization of diabetes, coping style, and appraisal of the illness state" (p. 1064) are key to diabetes management, and that important factors include the "adequacy of the medical regimen, familial, social, and cultural factors, coping styles, and, most importantly, the personal meaning of diabetes" (p. 1062). In this vein, Walsh (1998) calls for an orientation that integrates cultural traditions and spiritual beliefs to strengthen family resilience in the face of such adversities as physical illness, stating in her chapter titled, "Belief systems: the heart and soul of resilience," that, "We cope with crisis and adversity by making meaning of our experiences" (p. 45). Congruently, many articles advocate for medical providers to incorporate narrative and postmodern perspectives in their approach with diabetic patients and to collaborate with patients and families around personal belief systems and expectations (Delamater, 2006; Elwyn et al., 2003; Snoek & Skinner, 2002; Shapiro & Ross, 2002). This study continues to build upon these perspectives by employing a meaning-oriented, biopsychosocial approach.

Empirical Support for Meanings and Narratives about Chronic Illness

Evidence has accumulated to support the value of research and treatments that address beliefs, illness stories, attitudes, explanatory styles, and other processes of meaning construction about illness experiences. This is often called a narrative approach, which is a social constructionist therapeutic approach developed by Michael White and David Epston (1990) in which society's and client's stories and language are believed to powerfully frame and shape their experience. Most studies in this area are qualitative

(Cattich & Knudson-Martin, 2009; Ford, Havstad Brooks, & Tilley, 2002; Gillibrand & Flynn, 2001; Hornsten, Sandstrom, & Lundman, 2004; Murphy & Kinmonth, 1995; Papathanassoglou & Patiraki, 2003; Paterson, Thorne, Crawford, & Tarko, 1999; Schwartzberg, 1993). Quantitative outcome research has also been reported (Christensen, Moran, & Wiebe, 1999; Williams, McGregor, Zeldman, Freedman, & Deci, 2004).

For example, the importance of couples' meaning making about chronic illness was illustrated in a qualitative study of 20 couples with breast cancer (Skerrett, 1998). The personal meaning the couples constructed seemed to be critical, giving beneficial direction and coherence to their coping efforts. Similarly, irrational health beliefs appeared to be significantly linked to poor health practices in a study of 392 undergraduate psychology students (Christensen, Moran & Wiebe, 1999).

Empirical Support for Meanings and Narratives about Diabetes

As with other chronic illnesses, diabetes self-care is largely affected by perceptions, attitudes, meanings, and beliefs (Brennan, 1996; Snoek & Skinner, 2002). Empirical evidence has accrued to illustrate the link between meaning making and diabetes management from both qualitative and quantitative research, as described in the following paragraphs.

In one study, narrative interviews and content analysis of 44 diabetes patients in Sweden, aged 47-80 found that the important themes affecting their management of diabetes were image of the disease, meaning of the diagnosis, integration of the illness, space for the illness, responsibility for care, and future prospects (Hornsten, Sandstrom & Lundman, 2004).

Meaning making was again seen to be significant in a study that used semi-structured interviews and narrative analysis techniques to explore the life experiences of 30 individuals with diabetes (Goldman & Maclean, 1998). Participants described their perceived meaning of diabetes to be an assault on personal identity, experiencing a socially shaped struggle that affected their ongoing adjustment to diabetes.

Beliefs were similarly seen to be significant to diabetes management in a quantitative study of undergraduate psychology students with diabetes (N=107): irrational health beliefs were significantly associated with worse HbA1 levels and with worse self-reported regimen adherence (Christensen, Moran & Wiebe, 1999).

Beliefs and expectations were again found to be key when researchers (Talbot, Nouwen, Gingras, Bélanger, & Audet, 1999) examined the mediating role of "illness intrusiveness" (the illness' disruption of valued activities and interests) in the relationship between the physical characteristics of the illness and psychosocial problems such as depression. They concluded that interventions to reduce diabetes intrusiveness were particularly helpful to psychosocial well-being when they included *redefining personal goals and priorities and cognitive restructuring of irrational beliefs and expectations*.

Similarly, illness narratives and meanings were found to be crucial to illness management in a qualitative study that found that when diabetic patients storied themselves as autonomous and competent, they seemed to achieve better diabetes self-management and glycemic control (Williams, McGregor, Zeldman, Freedman, & Deci, 2004). Self-monitoring of blood glucose seemed to be particularly associated with personal perceptions of self-efficacy (Aalto & Uutela, 1997).

Emotions, meanings, perceptions, and beliefs held for diabetes are influenced by cultural and family contexts. This was seen in a qualitative study in which African Americans described having a greater sense of loss associated with diabetes than did white Americans (Ford, Havstad, Brooks, & Tilley, 2002). Further, culture modifies how emotions and meanings affect diabetes management, as seen in a prospective study of type 2 diabetes in 104 European American and 57 Latino patients (Chesla et al., 2003): while emotion management in families improved disease management in both groups, the two cultural groups differed in the ways that world-view affected disease management; that is, culture seemed to be a moderator in the relationship between world-view and management.

Cultural and family contexts significantly affect the ways in which individuals respond to providers and the treatment process (Fitzgerald et al., 2000; Sperry, 2006). One specific way that culture affects diabetes management is in the cultural and social functions of food (Fitzgerald et al., 1997). For example, in a survey study of African-American and Caucasian patients with type 2 diabetes (N=178), correlation and regression analyses were used to examine the relationship between dietary adherence and 15 other scales in the Diabetes Care Profile, an instrument that assesses psychosocial factors associated with diabetes and its management. Analysis revealed that self-care adherence was the most significant predictor of dietary adherence for African Americans, while support was the most significant predictor for Caucasians: this demonstrates a significant cultural difference in which psychosocial factors most strongly affect diabetes management.

Culture was again seen to influence health beliefs in a qualitative study of the explanatory health beliefs about type 2 diabetes among Mexican Americans living in El Paso County, Texas, on the U.S.-Mexico border (Poss & Jeweski, 2002). Participants described their cultural belief that *susto* (fright) changed the bodily state, making a person more vulnerable to the onset of diabetes. Similarly, a recent dissertation study asserted that, for the Latino population, addressing emotions in diabetes management is culturally important because many continue to hold the indigenous belief that negative emotions can cause diabetes and its complications (Concha, 2008). To investigate the relationships among SES, years lived in the U.S., stress, depressive symptoms, discrimination, health behaviors, and weight status, path analysis was conducted for both Mexican and White respondents of the Sinai Chicago Community Health Survey 2003-2004 (Concha). Results revealed that perceived stress was associated with unhealthy eating and depressive symptoms for both groups, but weight status only for the White group (Concha), indicating again the importance of including racial/ethnic and cultural factors in models of diabetes management.

Meaning making about diabetes also seems to vary by age or cohort group. This was seen in a cohort study that examined meaning making by age group in a random sample of 1,109 adults aged 45 and over with diabetes (O'Connor, Desai, Solberg, Rush, & Bishop, 2003). Those aged 65 and older “had better glycemic control, better health-related behaviors, and perceived less adverse impacts of diabetes on their quality of life despite longer duration of diabetes and a prevalence of cardiovascular disease twice that of younger patients” (p. 16). The researchers ascribed this to differences they found in explanatory models between the older and younger groups.

Transformational Meanings in Illness Narratives

This study focuses on meaning making about diabetes, and specifically about a certain type of meaning making called *transforming*. The term *transformational* or *transforming* is used to describe new, positive, and helpful meanings that people come to give to their beliefs about their experiences with illness. Having a transformational meaning about a chronic illness seems to have powerful positive effects on the ability to cope with the illness effectively, as seen in multiple studies.

Paterson, Thorne, Crawford, and Tarko (1999) promoted transformation as "presented in many research studies as the epitome of living with chronic illness" (p. 786) and as "a means of mediating the impact of disease by altering one's cognitive and affective response to it" (p. 787). They used narrative therapy techniques of reframing and normalizing to achieve a shift they called *restructuring*, in which a person shifted their view of the disease from a threat to a challenge.

Similarly, in phenomenological interviews with eight critically ill persons, participant narratives described spiritual growth in which attitudes toward the illness and death were highly transformed with beneficial results (Papathanassoglou & Patiraki, 2003). This effect was also seen in intensive clinical interviews of 19 HIV-positive gay men that revealed how they "made sense" of their illness experience (Schwartzberg, 1993). Some viewed HIV transformationally, as a catalyst for personal growth, while others viewed HIV as punishment. The transformational view of HIV as a catalyst for positive change seemed to help them to adapt well and cope more effectively.

The positive effects of transformational meanings were also seen in the meaning-making activities engaged in by cancer patients who demonstrated particularly strong

resilience (Baum, Cohen & Hall, 1993). Those who had longer survival, slower progression of the disease, and improved quality of life during and after treatment engaged in transformational reappraisals and meaning making early in their treatment.

In a qualitative study of couples with diabetes, meaning making and connection with each other and with God were found to be important to how couples managed diabetes (Cattich & Knudson-Martin, 2009). In particular, the authors identified *opportunist* couples who perceived diabetes as a positive opportunity for growth, and described how these couples seemed more active, optimistic, and creative in managing the illness.

While these studies illustrate positive effects of transforming meanings for other chronic illnesses, little is known about how transforming meanings may affect illness management in diabetes, making this an intriguing area for research. Further, in the author's qualitative study on couples with diabetes, those couples who had transforming *relationships with diabetes* appeared to be the most successful in achieving successful management of the illness (Houston-Barrett & Wilson, in press). This study seeks to pursue and expand on this promising avenue of research, examining links between transforming meanings in the couple's *relationship with diabetes* and the couple's success in *diabetes management*.

The Current Study: Transformation, Partnership, and Management

This study employs a meaning and emotion-oriented, biopsychosocial frame to examine constructs that hold promise to explain couples' success in managing the

regimen requirements of diabetes in their lives. Specifically, it examines quantitatively how two psychosocial constructs – the couple's *relationship with diabetes* and diabetes-specific *partnering support* of the non-diabetic spouse – interact and/or produce direct and indirect effects on the couple's success in *diabetes management*.

CHAPTER THREE

LITERATURE REVIEW

Social Support and Chronic Illness

The relationship between social support and chronic illness is well established (Arfken & Schneiderman, 1997; Bernard & Krupat 1994; Campbell, 2002; Cella, Bode & Hanrahan, 2010; Fisher, La Greca, Greco, Tillotson & Smith 1996; Gallant, 2003; Hahn, Penninx, Kriegsman, Miller & Davis, 2005; Schreurs & de Ridder, 1997; van Eijk, Boeke & Deeg, 1996; Westaway et al., 2005). Research has increasingly focused on how family relationships affect chronic illness (Campbell, 2003), and family variables have been found to have significant effects on management of chronic disease (Fisher, 2006; Fisher & Weihs, 2000; White, Smith, & O'Dowd, 2005), such as for diabetes (Armour, Norris, Jack, Zhang, & Fisher, 2005; Denham, Manoogian, & Schuster, 2007; Lo, 1999; Tovar, 2007; van Dam, Knoops, Ryckman, Crebolder, & BHW, 2005).

Close relationships and chronic health conditions appear to be reciprocally interacting, as revealed in a review of literature: "That is, just as close relationships affect the onset and course of chronic illnesses, chronic illnesses influence close relationships" (Kowal, Johnson & Lee, 2003, p. 301). Living with chronic illness affects the nature of the relationships and the patterns of interaction with family members and others close to the person with the illness (Kowal et al., 2003). Chronic stress, such as chronic illness, specifically affects marital communication, marital satisfaction, and the development of close relationships (Neff & Karney, 2004; Story & Bradbury, 2004). Additionally, marital distress exerts significant and deleterious effects on immune functions and health outcomes (Kiecolt-Glaser, 2010; Robles & Kiecolt-Glaser, 2003).

The nature of the social support seems to be important, with some kinds of support appearing to be more or less beneficial to illness management, and some kinds appearing to be non-helpful (Trief et al., 2003). A review of literature on social support and chronic illness indicated that positive perceived social support is more beneficial to disease course than functional and structural support (Penninx, Kriegsman, van Eijk, Boeke & Deeg, 1996). For diabetes, when family members behaved in ways that supported the care regimen, diabetics were more satisfied with their adaptation to the illness and reported less interference in role function due to emotional problems (Trief, Grant, Elbert & Weinstock, 1998). Specifically, when 74 diabetics and spouses were asked to define support in a qualitative study, dietary control and regimen specific support, general relational support, and reminders were reported as helpful, and nagging, problems with diet management, and poor communication were reported as non-helpful (Trief et al., 2003).

Couples Relationships and Chronic Illness

Couples relationships are significant to chronic illness experiences and outcomes, with health outcomes significantly related to marital interactions and support (Coyne & Smith, 1994; Fisher, 2006; Groth, Fehm-Wolfsdorf & Hahlweg, 2000; Kiecolt-Glaser & Newton, 2001; Manzoli, Villari, Pirone, & Boccia 2007; Schmaling & Sher, 2000; Williams & Umberson, 2004; Wing, Marcus, Epstein, & Jawad, 1991). Research has consistently linked improved health status to being married (Berkman & Breslow, 1983; Berkman & Syme, 1979), and particularly to good marital quality (Burman & Margolin, 1992; Gottman & Notarius, 2000). Additionally, a systematic review of couple's health

concordance studies reported that research reveals that couples have concordant mental and physical health statuses, and health behaviors (Meyler, Stimpson & Peek, 2007), suggesting that couples often share in their health attitudes and behaviors. Therefore, the importance of examining chronic illness from the perspective of couples is clearly indicated.

Poor relationship satisfaction in couples is associated with poorer outcomes in chronic illness, such as diabetes, cardiovascular disease, asthma, and depression (Fisher, 2006). A review of marital interactions studies concluded that the most consistent and powerful negative effects on disease management are poor couple conflict resolution skills, low relationship satisfaction, high inter-spouse conflict, high criticalness, high hostility, and a lack of congruence in disease beliefs and expectations (Fisher, 2006; Klausner, Koenigsberg, Skolnick, et al., 1995). These associations may be explained by findings that marital distress is linked with suppressed immune function (Kiecolt-Glaser et al., 1987; Kiecolt-Glaser, Malarky, Cacioppo, & Glaser, 1994), cardiovascular arousal (Brown & Smith, 1992; Ewart, Burnett, & Taylor, 1983; Ewart, Taylor, Kraemer, & Agras, 1991; Gottman, 1994; Gottman & Levenson, 1992; Levenson & Gottman, 1983, 1985), and increases in stress-related hormones (Kiecolt-Glaser et a1.,1994). A biopsychosocial explanation has been proposed that “negative dimensions of marital functioning have indirect influences on health outcomes through depression and health habits, and direct influences on cardiovascular, endocrine, immune, neurosensory, and other physiological mechanisms” (Kiecolt-Glaser & Newton, 2001, p. 472).

The individual-focused, stress-and-coping theories of the 1970s and 1980s (Lazarus & Folkman, 1984) are being expanded by more recent theories of how families

and couples cope with life stresses such as chronic illness (Kayser, Watson, & Andrade, 2007), including couple dyad coping theories (Bodenmann, Pihet & Kayser, 2006). Spouses are usually the closest and first person to provide ill partners with day-to-day practical assistance and support, as well as emotional and cognitive support (Revenson, Schiaffino, Majerovitz & Gibofsky, 1991; Sandberg, Trief, Greenberg, Graff & Weinstock, 2006). How this support is given and received, as well as the marital interactions that accompany this support, impact both marital quality and health functioning.

The ways that couples cope with illness is an emerging topic that has been of particular interest to researchers, attracting a growing number of theoretical contributions and empirical studies since the nineties (Bodenmann, Pihet & Kayser, 2006). While couple's coping can be been studied from an individualistic perspective of how one partner's method of coping with a chronic illness affects how the other partner adjusts to it (Kuijer et al., 2000), this study examines couples' coping as a couples' phenomenon, called dyadic coping or couple coping. *Dyadic coping* can be defined as ways that couples share, appraise, and cope with stressors (Berg et al., 2008; Berg & Upchurch, 2007; Bondenmann, Feldman & Broussard, 2006). "Couples engaged in dyadic coping are affected by broad sociocultural factors (culture and gender) as well as more proximal contextual factors (quality of the marital relationship and the specific demands of the chronic illness)" (Berg et al., 2007, p. 920).

In a longitudinal study, dyadic coping in dealing with stress was significantly associated with marital quality over 2 years (Bodenmann, Pihet & Kayser, 2006). The dyadic coping perspective has been used in many studies of chronic illness, for example,

when coping with breast cancer (Kayser, Watson & Andrade, 2007; Skerrett, 1998; Zunkel, 2002), prostate cancer (Berg et al., 2008), and diabetes with osteoarthritis (Yorgason et al., 2010).

Couples who actively manage the diabetes together often report better disease management (Fisher et al., 1998; Gilden, Hendryx, Casia & Singh, 1989; Miller & Brown, 2005; Trief et al, 2003). Collaborative coping, a kind of dyadic coping which occurs when spouses pool resources and problem solve jointly when dealing with an illness, seems to be particularly beneficial in couple's adapting to chronic illness (Berg et al., 2008; Berg & Upchurch, 2007). Collaborative coping was also found to be more frequent among couples who reported greater marital satisfaction (Berg et al., 2008). The current study looks at a kind of couple's dyadic coping which is collaborative coping and actively managing the diabetes together, called couples' *partnering support* in managing the diabetes regimen.

Couples Relationships and Diabetes Management

Couples relationships are particularly important to diabetes management, because the self-care regimen of diet, exercise, testing, and medications is managed in their home and shared lives. The positive association of marital satisfaction and diabetes management has been demonstrated (Fisher et al., 2006; Trief et al., 2006; Trief, Orendorff, Himes & Wienstock, 2001; Trief, Ploutz-Snyder, Britton & Weinstock, 2004; Trief, Wade, Britton, & Weinstock, 2002). Feeling emotionally supported within the marriage seems to be particularly significant in maintaining adherence to regimen

(medication, exercise, diet, and blood glucose monitoring) and in lifestyle satisfaction (Trief et al., 2002; Coyne & Smith, 1994).

Studies have examined the effect on treatment efficacy of spouse participation in diabetes-related interventions. For example, patients whose spouses participated with them in a diabetes education program showed greater improvements in knowledge, blood glucose control, and stress level (Gilden, Hendryx, Casia, & Singh, 1989). Similarly, in a weight control program for obese, diabetic women, those whose obese spouses participated with them lost more weight than those who participated alone (Wing, Marcus, Epstein, & Jawad, 1991). These studies demonstrate the helpfulness of spouse's support that takes an active form of joint participation in diabetes related activities.

Additionally to this kind of instrumental support, the meaning-making, emotions, and beliefs between the couple members seem to be significant. This was illustrated in a study of 60 American Indian diabetics that looked at demographic and medical variables, attitudes, perceived beliefs of others, and coping strategies (Miller, Wikoff, Keen & Norton, 1987). They found that *the patient's perception of their significant other's belief* was the best predictor of overall adherence to the diabetes medical and behavioral regimen. The strong impact of the non-diabetic partner emotions on diabetes management was also seen in a study by Wearden, Tarrier, and Davies (2000), which found that the partner's expressed emotion was significantly related to regimen adherence and glycemic control.

A study that investigated couples' perspectives on the role and impact of diabetes in their lives, found that when couples had a shared perception of diabetes, it seemed to improve diabetes management (Beverly, Penrod, & Wray, 2007). Thus it is of interest

that an earlier, mixed-method study found that illness-related perceptions were positively correlated with marriage duration; that is, the longer couples were married, the more similarly they viewed diabetes (Peyrot, McMurray, & Hedges, 1988).

Gender has been shown to be related to the nature of support from the non-diabetic spouse, with wives being more supportive than husbands in accommodating to diabetes regimen requirements. For instance, wives of diabetic men seem more likely to adopt their husband's diet than do husbands of diabetic women (Probert, Maddison, & Roland, 1990). However, both women and men appreciate having spouse's support in dietary management (Sandberg, Trief, Greenberg, Graff & Weinstock, 2006). Women and men tend to view support somewhat differently, with men using more directive and authoritative language and women using more accommodating and collaborative language (Sandberg et al., 2006).

The nature of the couple's partnership in managing dietary requirements of type 2 diabetes was examined from a couple-dyad perspective in a qualitative study of 20 couples (Miller & Brown, 2005). They found that couples were either cohesive with a teamwork approach, enmeshed with the non-diabetic spouse responsible for the diet, or disengaged with diabetic spouses solely responsible for the diet management. The current study does not use the Circumplex model to label types of couple support as this study did, but it is based on research that has similarly found a teamwork, partnered, or collaborative style of support to be most helpful (Berg & Upchurch, 2007; Berg et al., 2008; Houston-Barrett & Wilson, in press).

Support from the spouse is not universally beneficial; rather, only certain types of support have been found to be helpful, with others having the opposite effect on diabetes

management (Revenson, Schiaffino, Majerovitz & Gibofsky, 1991). For example, in an outcome study of diabetes education, overprotection had a negative effect on diabetes management improvement, especially for women with diabetes (Hagedoorn et al., 2006). In a qualitative study, regimen specific support, general relational support, and reminders were described as helpful behaviors for dietary control, and nagging and poor communication were described as not helpful (Trief et al., 2003). These findings underscore the importance of studying partner support in detail, rather than globally, to determine the dimensions that affect diabetes management. The current study examines specifically the *partnering* dimension of the spouse's role of support in diabetes management.

Research focused on the couple dyad is scarce, but promising (Lister, Fox, & Wilson & Fox, manuscript). Existing studies indicate that examining diabetes management success in regards to couple-level variables, particularly from a couple-dyad perspective, is likely to be an important and fruitful approach (Lister, Fox, & Wilson, manuscript). The current study examines the effects of two couple-level variables: the couple's *relationship with diabetes*, and the spouse's *partnering* support in the couple's management of diabetes.

Associated Psychosocial Problems of Diabetes

A biopsychosocial study pertaining to diabetes management must include consideration of associated mental health problems that often complicate diabetes management (CDC, 2011; Katon et al., 2004; Kruze, Schmitz, & Thenfeld, 2003). These include depression, anxiety, and stress, as well as psychosocial and quality-of-life

concerns that affect regimen adherence (CDC, 2011; Davis, Hess, Van Harrison, & Hiss, 1988; Gonder-Frederick, Cox & Ritterband, 2002; Peyrot, McMurray & Kruger, 1999; Talbot, Nouwen, Gingras, Bélanger, & Audet, 1999; Thomas, Jones, Scarinci, & Brantley, 2003; Tillotson & Smith, 1996; Tovar, 2007). In the current study, these mental health issues are conceptualized as being encompassed within the study construct, the couple's *relationship with diabetes*, which includes meanings, emotions, and the psychosocial elements that are so commonly associated with this illness (Chesla et al., 2003; Christensen, Moran & Wiebe, 1999; Fitzgerald et al., 1997; Ford, Havstad, Brooks, & Tilley, 2002; Goldman & Maclean, 1998; Hornsten, Sandstrom & Lundman, 2004; Houston-Barrett & Wilson, in press; O'Connor, Desai, Solberg, Rush, & Bishop, 2003; Snoek & Skinner, 2002; Williams, McGregor, Zeldman, Freedman, & Deci, 2004). For example, a couple may have a "rejecting" *relationship with diabetes* that includes a strong dislike for dietary restrictions that oppose cultural preferences, or for fear about dreaded outcomes, or that includes financial constraints that make it difficult to obtain medications or testing supplies or to carry out prescribed exercise or diet (Houston-Barrett & Wilson, in press).

A volume of studies has examined the association of diabetes with various psychosocial issues, for example, depression (Katon et al., 2004; Knox & Britt, 2004; Palinkas, Lee, & Barrett-Connor, 2004; Talbot, Nouwen, Gingras, Bélanger, & Audet, 1999); negative emotions (Kiecolt-Glaser, McGuire, Robles & Glaser, 2002); psychoneuroimmunology (Kiecolt-Glaser, 2010; Lutgendorf & Costanzo, 2003), anxiety (Mitsonis, Dimopoulos & Psarra, 2009), and stress (Ellis et al., 2005; Peyrot, McMurry & Kruger, 1999; Riazi, Pickup, & Bradley, 2004; Surwit, 2002). In one such study, a

biopsychosocial model was used to study how glycemic control in diabetes is related to stress, coping, regimen adherence, and psychosocial risk factors (Peyrot et al., 1999). They found that better chronic glycemic control was associated with being self-controlling rather than emotional, being married, having more education, and having positive coping styles. In another study that employed a biopsychosocial frame with psychoneuroimmunology, it was shown how stress can lead to making unhealthy food choices while also exacerbating maladaptive metabolic responses to unhealthy meals which can in turn affect mood as well as proinflammatory responses to stressors (Kiecolt-Glaser, 2010; Kiecolt-Glaser, McGuire, Robles & Glaser, 2002). "…vagal activation can directly and profoundly influence metabolic responses to food, as well as inflammation; in turn, both depression and stress have well-documented negative effects on vagal activation, contributing to the lively interplay between the brain and the gut" (Kiecolt-Glase, 2010, p. 365).

Further, depression, stress, and anxiety increase utilization of medical care, as Knox and Britt (2004) reported, based on a national study in Australia that surveyed a cluster sample of 10,755 patients through a random sample of 379 general practitioners. The average number of doctor's visits was 8.8 per year. Patients with diagnosed depression averaged 2.2 visits more per year, and patients with diagnosed anxiety averaged 2.7 more visits per year.

Two major areas of study on the associations of mental health problems and diabetes are the relationship between depression and diabetes outcomes, and the relationship of anxiety and stress with diabetes outcomes. Since the current study focuses on how psychosocial and meaning-oriented variables relate to diabetes management, it is

relevant to explore some examples of current research on depression, stress, anxiety, and diabetes outcomes, which follows.

Depression and Diabetes

Depression is prevalent in people with type 2 diabetes, with rates at least three times higher than in the general population (Talbot, Nouwen, Gingras, Bélanger, & Audet, 1999). Approximately 11% to 15% of patients with diabetes are diagnosed with major depression. Depression is associated with poor glycemic control and adverse medical outcomes (Katon et al., 2004), and with poorer adherence (Elliott, 2003; Wing, Phelan, & Tate, 2002). It further affects quality of life and relationships, which in turn can affect diabetes management. Therefore, since the current study examines the couple's *relationship with diabetes,* diabetes-specific *partnering support*, and *diabetes management* success, depression is expected to be present and affecting each of these variables.

It is possible that having diabetes precipitates depression; it is also possible that depression has a causal effect on diabetes. In fact, a prospective, longitudinal study (N=971) found that depression preceded diabetes, but not vice versa (Palinkas, Lee & Barrett-Connor, 2004). Thus they drew the rather surprising conclusion that depressed mood is more likely to be a risk factor for type 2 diabetes in older adults than the reverse. This may appear in the model hypothesized of the current study, in that depression may be adding to correlation and reciprocal causation (bidirectionality) in the paths among all three study variables. Recent research in psychoneuroimmunology supports the finding

that negative emotions seem to increase the risk of getting type 2 diabetes (Kiecolt-Glaser, McGuire, Robles & Glaser, 2002; Lutgendorf & Costanzo, 2003).

In a study of the rate of recognition and type of care provided to diabetic patients with major depression at a Health Maintenance Organization (HMO), Katon et al. (2004) found that only about 51% of those with both conditions were recognized as depressed. Of those 51% who were recognized to be depressed, 43% received one or more antidepressant prescriptions, but only 6.7% received four or more psychotherapy sessions during a 12-month period. This under-diagnosis and under-treatment of diabetes-associated depression is shocking, especially given that research indicates treatment is likely to be helpful. For example, in a systematic review of the effects of psychotherapy on depression with diabetes, Snoek and Skinner (2002) concluded that psychotherapy is effective in the treatment of depression in type 2 diabetes patients, both in reducing depressive symptoms and in managing HbA1c, the standard medical marker of glycemic control.

While the current study does not directly measure depression's effects on diabetes management, depression is conceptualized as strongly affecting the couple's relationship with diabetes, which in turn the study model hypothesizes will strongly affect diabetes management. Therefore, the literature's evidence that psychotherapy to reduce depression also helps with diabetes management is consistent with the current study's model.

Stress, Anxiety and Diabetes

The link between diabetes and stress goes in both directions: diabetes creates stress in patients' lives, and stress exacerbates the symptoms of diabetes. To complicate it

further, stress affects HbA1c unpredictably in amount and timing (Riazi, Pickup, & Bradley, 2004). A review of literature found anxiety to be associated with poor glycemic control, poor regimen adherence, and accelerated rates of coronary heart disease (Mitsonis, Dimopoulos & Psarra, 2009). In the reviewed studies, anxiety was present in 41.7% of diabetic patients, and it was significantly higher in diabetic women than in diabetic men. The review also found that treatment of anxiety was associated with improved glycemic control, particularly in the subgroup of patients with severe anxiety.

It has been hypothesized that reducing stress would lead to improved regimen adherence and glycemic control, but according to a systematic review of literature on this topic, numerous attempts to demonstrate this effect through individual-focused psychological interventions have failed (Angermayr, Melchart, & Linde, 2010). The reviewers found seven trials of stress management interventions, and they concluded that, "compared to participants in 'usual care' control groups, there were no consistent effects on lipid levels and blood pressure and small effects on body mass index and glycated hemoglobin (HbA1c)" (p. 49). A few studies did find limited success; for example, a small, but significant reduction in HbA1c for those who had stress management training, in a randomized, controlled clinical trial of patients with type 2 diabetes (n=108) (Surwit et al., 2002). A systematic review of studies of the use of yoga-based programs to reduce stress and improve diabetes outcomes found somewhat more positive results, although limitations of the studies precluded firm conclusions (Innes & Vincent, 2007).

Even more positive results were seen in a recent study using a family therapy called Multisystemic Therapy (MST). MST both reduced stress and improved adherence and metabolic control (Ellis et al., 2005). The researchers attributed the success of MST

to its biopsychosocial approach: intervening in relationships with family members, physicians, and other systems. This again provides evidence that a biopsychosocial approach is most likely to capture the systemic connections of causation that affect diabetes management in couples, as is used in this study.

Demographic Factors and Diabetes Management

Demographic factors such as age, duration of diabetes (time since diagnosis), gender, SES, length of marriage, and race/ethnicity seem to be associated with diabetes management success (Adams, 2005; Anderson & Fitzgerald, 1993; Connolly et al., 2000; Connolly & Kesson, 1996; Fisher et al., 2000; Gary, 2004; Hartweg, 1993; Karter et al., 2002; Kirk et al., 2006, Korbel, 2007; Ludlow & Gein, 1995; Moore, 1993; O'Connor, Desai, Solberg, Rush, & Bishop, 2003; Oster et al., 2006; Probert, Maddison, & Roland, 1990; Ross et al., 2007; Sandberg, Trief, Greenberg, Graff, & Weinstock, 2006; Sayeed et al., 1997; Sousa, Zauszniewski, & Musil, 2006; Thackeray, 2004; Whitford, Griffin, & Prevost, 2003). This study measures these demographic factors, in order to see how model fit is affected when these effects are partitioned out.

However, some or all of this partitioning may be argued as unnecessary or even counter-intuitive, because in the current study demographic factors are conceptualized as being intrinsically part of the *relationship with diabetes*. Demographic factors help to shape culture, world-view, beliefs, attitudes, and other influences that help to comprise the *relationship with diabetes.* In other words, variations in demographic factors are conceptualized as creating contextual and cultural differences that affect diabetes management *through* affecting the *relationship with diabetes.* A study illustrates this

point: in examining associations between family variables and disease management in four ethnic groups – African Americans, Chinese Americans, European Americans, and Hispanics – in a sample of 500 diabetic patients, although how family and health dynamics were expressed and experienced varied across groups, the same health-related family characteristics were linked to the same disease management behaviors across all four ethnic groups (Fisher, 2005). Therefore, the associations among the variables remained stable, even as a demographic changed (ethnicity) and affected the variables individually. In a similar way, in the current study, varying demographic variables are expected to affect individual variables (i.e., the three constructs in this study's model), but they are not expected to affect the *relationships* among the constructs in this model, which is the focus of the study. By analyzing the data for potentially confounding covariates, we tested this expectation. In other words, this dissertation empirically explored the role or relevance of demographic factors as intrinsic factors of the latent constructs I am theorizing, contrasted to their independent roles.

Age and Duration of Diabetes

Age appears to be positively associated with improved diabetes regimen management (Anderson & Fitzgerald, 1993; Hartweg, 1993; Moore, 1993; Musil, 2006; O'Connor, Desai, Solberg, Rush, & Bishop, 2003; Penick, 1998; Sousa, Zauszniewski, Trief, Grant, Elbert, & Weinstock, 1998). One explanation was proposed that older individuals with diabetes usually have a longer duration of diabetes and so could be expected to be more capable of managing their diabetes (Sousa, et al., 2006). Another explanation ascribed the improvement with age to differences in explanatory models

between older and younger groups of diabetics (O'Connor et al., 2003). In the current study, I similarly propose and test the theory that the effects of age and durations of diabetes on diabetes management are expressed through effects on meaning and coping variables: *relationship with diabetes* and *partnering support*.

Gender

The incidence of diabetes among adults aged 20 years or older is 12.0 million or 11.2% of men and 11.5 million or 10.2% of women (CDC, 2007b). Studies on the effects of gender on diabetes management show varying results. Adolescent females (compared to males) were found to be more depressed and have poorer management behaviors (Korbel, 2007). However adult women were found to have better management behaviors than adult men (Ludlow & Gein, 1995), and to have higher levels of diabetes satisfaction (Trief, Grant, Elbert & Weinstock, 1998). More recently, no strong associations were found between gender and management practices (Fisher et al., 2000; Ross et al., 2007). Interaction effects between depression and gender (Korbel) and between culture/race/ethnicity and gender (Fisher) may account for some of these differences in results. Additionally, the nature of support given by the non-diabetic spouse and desired by the diabetic spouse appears to be associated with gender (Probert, Maddison, & Roland, 1990; Sandberg, Trief, Greenberg, Graff, & Weinstock, 2006). Further, wives are more likely than husbands to become actively involved in management of their spouse's diabetes (Knudson-Martin, 2009).

In the current study, the diabetes-specific support given by the spouse is defined and measured in terms of how *partnering* it is: that is, to what degree the non-diabetic

spouse actively participates in diabetes management with the diabetic spouse. Given the above previous research findings, it is likely that *partnering support* is associated with gender; in fact, this study theorizes that the primary effect of gender is expressed through this *partnering support* and *relationship with* diabetes constructs. The current study includes analysis to examine the independent role of gender contrasted to gender's role in the model.

Race/Ethnicity

Diabetes is more common in many minority groups. National survey data, 2004-2006, indicates that 6.6% of non-Hispanic Whites, 7.5% of Asian Americans, 10.4% of Hispanics, and 11.8% of non-Hispanic Blacks had diagnosed diabetes (CDC, 2007b). These rates continue to grow, with 2007 estimates that 9.8% of non-Hispanic Whites and 14.7% of non-Hispanic Blacks had diagnosed or undiagnosed diabetes (CDC). There was insufficient data to provide reliable estimates for Native Hawaiians and other Pacific Islanders (CDC). Data from the 2005 Indian Health Service user population database indicate diabetes rates in adults from 6.0% of Alaska Native to 29.3% among American Indian in southern Arizona (CDC).

Diabetes management varies significantly by race/ethnicity (Kirk et al., 2006; Oster et al., 2006). When compared to White diabetics, African Americans (Adams, 2005; Kirk et al., 2006, Utz et al., 2006) and Hispanics (Oster et al., 2006; Thackeray, 2004) have consistently been found to have poorer self-management practices, suffering from higher rates of poor glycemic control than do Whites (Harris, Eastman, Cowie, Flegal, Eberhardt, 1999). Biological, socioeconomic, and quality-of-care factors have

been proposed to be primary variables affecting self-management behaviors (Gary, 2004; Karter et al., 2002). The model in the current study is examined for fit overall, and for the covariate effect of race, but again it is conceptualized that the effects of this demographic may be seen in the model primarily as affecting the constructs of *relationship with diabetes* and *partnering support* rather than having a strong direct effect on *diabetes management.*

SES

Socioeconomic status (SES) is commonly defined as a composite variable comprised of education, income, and occupation (Liberatos, Link, Kelsey, 1988); however, using education and income to indicate SES has been found to be equivalent (Deonandan et al., 2000). The redundancy of including occupation is likely due to the high correlation between occupation and income in most situations. In this study, SES is indicated by education and income.

The prevalence of type 2 diabetes is negatively and significantly associated with SES. This relationship holds in both developing (Sayeed et al., 1997) and developed (Connolly et al., 2000) countries. The likelihood of developing diabetes risk factors, as well as the risk of developing chronic diabetes complications are linked to low SES (Connolly & Kesson, 1996; Whitford, Griffin, & Prevost, 2003). This can be explained by the expansion and contraction with SES of resources needed to manage diabetes, such as access to, opportunity for, and affordability of healthy diets, exercise, medical care, and educational resources. SES was also postulated in the current study to impact the

relationship with diabetes, and so SES was examined as a covariate with the hypothesized predictor variables via regression analysis.

In order to see whether the current study's model holds across a range of SES levels, the sample was selected to include participants whose SESs cover a broad range. It would be desirable for the model to also be examined to determine whether it holds for moderate SES levels, but breaks down at the high and low extremes, where resources for diabetes management are exceptionally rich or scarce (and so *partnering support* and *relationship with diabetes* may have less effect on and relevance for diabetes management). However, the current study's sample size was not able to support this multi-level analysis.

Diabetes Psychosocial Instruments and Predictors

This section provides an inventory of psychosocial instruments commonly used in current diabetes research, obtained via an extensive literature review. It also provides a summary, based on a separate extensive review, of quantitative research findings on predictors of diabetes success in management, adherence and/or control.

Established Instruments for Diabetes Management and Related Psychosocial Factors

The requirements of this study include the need to operationalize the conceptualized constructs within the study model. An extensive search of the literature was performed in order to discover instruments, scales, and items that could be used in this study to provide confidence that the constructs to be measured are well represented

(construct validity), reliable, and relatable to previous research findings. The instruments are listed in Appendix A. These instruments were explored to identify and select items and scales that are as similar as possible to the constructs of this study; additional items were then added to create the scales needed to operationalize this study's constructs (see the Methods section for details of operationalization).

Predictors of Diabetes Success in Management, Adherence, and Control

Because this study seeks to make a meaningful contribution to current knowledge about what causes couples to be more or less successful in managing diabetes, and in order to situate this study within the related body of research, an extensive review of the literature was performed on current quantitative empirical research to identify significant predictors of diabetes management, regimen adherence, and/or glycemic control. These results are organized Appendix B. The predictors fall into four categories: cognitions (beliefs, attitudes, and expectancies); barriers and stressors; resources, personal characteristics, and abilities; and social, family, and relational influences. The current study's endogenous (predictor) constructs include elements of each of these categories.

Established Diabetes Psychosocial Instruments Used in this Study

In order to measure the psychosocial and demographic variables of interest to this study, established instruments with known psychometric properties were used, where ever possible. The evaluation of instrument measurement properties includes tests of reliability, validity, and responsiveness (Fitzpatrick, Davey, Buxton, & Jones, 1998;

Streiner & Norman, 1995). Literature research and evaluation identified two established diabetes instruments that will be helpful to this study. These are the Diabetes Care Profile and the Appraisal of Diabetes Scale. These were chosen based on their established usage in research, their strong psychometric properties, and their brevity, as found in two reviews of health-related quality of life measures in adult diabetic patients (El Achhab, Nejjari, Chikri & Lyoussi, 2008; Watkins & Connell, 2004), as well as on their relevance to the current study. The following paragraphs describe these two instruments. Details about using scales from these instruments, along with newly developed scales, to operationalize this study's constructs as measurable variables are given in the Methods section.

Diabetes Care Profile

The Diabetes Care Profile (DCP) (Davis, Hess, & Hiss, 1987) is a self-administered questionnaire that assesses psychosocial factors related to diabetes and its treatment. The DCP includes questions assessing problems controlling diabetes, the social and emotional impact of diabetes, barriers to adherence, understanding the benefits of adherence, complications, and social support. This instrument is intended for use with individuals with type 1 or type 2 diabetes. It includes questions of multiple-choice, yes/no, fill-in-the-blank, and Likert-type 5-point scales.

Two studies with separate populations and methodologies were conducted to determine the reliability and the validity of the DCP (Fitzgerald et al., 1996). Cronbach's alphas of individual DCP scales ranged from 0.60 to 0.95 (Study 1) and from 0.66 to 0.94 (Study 2). Glycohemoglobin levels correlated with three DCP scales (Study 1). Several

DCP scales discriminated among patients with different levels of disease severity. The results of the studies indicate that the DCP is a reliable and valid instrument for measuring the psychosocial factors related to diabetes and its treatment.

Additionally, the DCP has been validated for specific populations, including among African Americans (Fitzgerald et al., 1996; Fitzgerald, Havstad, Brooks, & Tilley, 2000) and among Hispanic veterans (Cunningham et al., 2005) with type 2 diabetes.

In the DCP (Davis, Hess, & Hiss, 1987), there are a total of sixteen scales. These scales assess the patients' control problems (e.g., “How many times in the last month have you had a low blood sugar (glucose) reaction with symptoms such as sweating, weakness, anxiety, trembling, hunger or headache?”), social and personal factors (“How often has your diabetes kept you from doing your normal daily activities during the past year (e.g., couldn't: go to work, work around the house, go to school, visit friends)?”), positive attitude (“Diabetes doesn't affect my life at all”), negative attitude (“I feel I'm not as good as others because of my diabetes”) self-care ability (“I keep my blood sugar in good control”), importance of care (“I think it is important for me to keep my weight under control”), self-care adherence (“I do the things I need to do for my diabetes (diet, medicine, exercise, etc.)”), diet adherence (“How often do you follow a meal plan or diet?”), medical barriers (“Has your health care provider or nurse ever told you to follow an exercise program?”), exercise barriers (“How often do you have trouble getting enough exercise because: it makes your diabetes more difficult to control?”), monitoring barriers (“When you don't test for sugar as often as you have been told, how often is it because: you don't believe it is useful” understanding management practice (“How do you rate your understanding of: diet and blood sugar control”), long-term care benefits

("Taking the best possible care of diabetes will delay or prevent: foot problems"), support needs ("My family or friends help and support me a lot to: take my medicine"), support ("Who helps you the most in caring for your diabetes? Spouse, friends, doctors"), and support attitudes ("My family or friends: listen to me when I want to talk about my diabetes"). See Appendix K for the complete DCP questionnaire.

This study uses specific items from the DCP as indicators of study constructs. Details of which specific items are used to operationalize study constructs as measurable variables are given in the Methods section. DCP items were also used to collect some of the demographic information: age, race, gender, and duration of diabetes.

Appraisal of Diabetes Scale

The Appraisal of Diabetes Scale (ADS) is a single-index, 7-item scale derived from stress-and-coping theory, which aims to measure individuals' appraisal of the stressful impact of diabetes on their personal lives (Carey et al., 1991). These items assess the couple's perception of the stressful impact of diabetes by asking how upsetting particular aspects of diabetes are, on a 5-point Likert scale from "not at all" to "extremely upsetting." The items include, "How much uncertainty do you currently experience in your life as a result of being diabetic?" "How likely is your diabetes to worsen over the next several years?" and "To what degree does your diabetes get in the way of your developing life goals?"

The scale's reliability and validity were tested with a sample of 200 adult male, primarily Caucasian outpatients, attending a US Veteran's Administration Medical Center diabetes clinic (Carey et al., 1991). In this sample, reliability and internal

consistency of the scale were good, with test-retest correlation of 0.85-0.89, item-total correlation of 0.28-0.59, and Cronbach's alpha of 0.73, which exceeds 0.7, the criterion recommended for studies involving groups of patients (Fitzpatrick, Davey, Buxton, & Jones, 1998). The ADS was moderately to strongly correlated with related measures of both general and diabetes-associated distress (especially depression), indicating good validity for this scale. It was weakly associated with regimen adherence and HbA1c (a standard measure of blood glucose) levels.

This study uses all items from the ADS as indicators of study constructs. Details of how the ADS scale is used to operationalize study variables are given in the Methods section.

Summary

Diabetes is a disease that is far more than an individual, physical, or biomedical problem. Its management requirements include complex components that are relational, social, contextual, emotional, meaning-oriented, and psychological. Not enough is understood about what makes diabetes management successful, as regimen adherence continues to be chronically low despite treatments designed to improve diabetes self-care. However, promising avenues of research are apparent in the current literature. These include examining diabetes management from a biopsychosocial-, meaning-, and emotion-oriented perspective, and examining diabetes management as a couple's dyadic coping phenomena. This study seeks to test such a model, measuring and analyzing the interactions of the couple's meaning-and-emotion comprised *relationship with diabetes*

and diabetes-specific *partnering support*, as well as direct and indirect effects of these two constructs on the couple's success in *diabetes management.*

CHAPTER FOUR

METHODS

Research Design

This dissertation study represents the second stage of an ongoing mixed methods research project that sought to understand, explain, and model how couples have varying degrees of success in managing diabetes in their lives. In the first stage, a model of three constructs was conceptualized as grounded theory developed in a qualitative study of 29 diabetic couples in Southern California, based on study findings and current theories and evidence in the relevant literature (Houston-Barrett & Wilson, in press). The current study represents the second stage of this mixed methods program of research, in which I sought to extend and test those qualitative findings quantitatively, with a larger sample. In this way, the current study tested the hypothesized model in order to confirm or modify understandings based on the earlier findings, increase generalizability of findings, and better situate findings relative to the body of research in this area. The research design for this study included considerations for sampling, recruitment, data collection, measurement (operationalizing constructs), analysis, and the making of appropriate inferences from data analysis results, based on best practices for validity and reliability in social science research, as described in the following sections.

Sampling

Generalizability of Results from Random vs. Convenience Samples

Although random sample selection is the gold standard for empirical studies, studies in the psychological and social sciences most often use convenience sampling in

data collection due to time, accessibility, resource, and cost limitations. For example, only 9.3% of studies published during the period 1990–1998 in the *Journal of Gerontology: Psychological Sciences* and *Psychology and Aging* reported research that used random samples (Hultsch, MacDonald, Hunter, Maitland, & Dixon, 2002). Similarly, in a systematic review of mental and physical health studies published between January 1995 and June 2002 in the *Journal of Advanced Nursing*, only 32% of studies used random samples (Williamson, 2003).

Although the power of random selection is theoretically required to quantifiably ensure statistical likelihood that a large enough sample will be representative of and generalizable to the population of interest, this is not always required in reality. Random sampling is not a perfect guarantee against significant random error or unforeseen systematic bias (Pedhazur & Schmelkin, 1991). On the other hand, non-random convenience samples can be informative of and generalizable to the population under study, when common sense, purposeful sampling, and standard precautions are employed in the research design (Pedhazur & Schmelkin, 1991). Being familiar with the area of study makes it more likely that the researcher will be aware of likely confounders and covariates, and being cautious that the recruitment strategy does not introduce bias, are practical and logical ways to reduce the risk that the sample will be non-representative of the target population. The goal is for the sample selection criteria (including the criteria that make it convenient, such as being close geographically, all in one treatment center, or friends of the researcher) to be unrelated to the variables under study. In the current study, care was taken to obtain samples whose members are unrelated and who vary demographically and geographically, decreasing the likelihood that that they will be

associated in unexpected ways that might confound conclusions based on results from this sample.

Empirical justification for the use of convenience samples has been found in a number of studies that have compared the results of convenience and random samples within the same study, and that have concluded that convenience samples are often an appropriate sampling strategy if used with caution and awareness (Evans, Wiggins, Mercer, Bolding, & Elford, 2007; Hultsch, MacDonald, Hunter, Maitland, & Dixon, 2002; Kelly, Riddell, Gidding, Nolan, & Gilbert, 2002; Nielsen & Einarsen, 2008; Pruchno et al., 2008; Straus, 2009).

An example of a study that used a convenience sample effectively was a self-selected convenience sample of gay men obtained via the internet (n=2065); this sample was found to have social and demographic characteristics that were broadly similar to a national probability sample (Evans, Wiggins, Mercer, Bolding, & Elford, 2007). Similarly, a random cluster survey and a convenience sample gave comparable estimates of immunity to vaccine preventable diseases in children of school age in Victoria, Australia (Kelly, Riddell, Gidding, Nolan, & Gilbert, 2002).

A study of a much smaller sample size found more variation between random (N=55) and convenience sample (N=87) characteristics of caregivers (Pruchno et al., 2008). The samples had similar variances on 68.4% of the examined variables, but had significant mean differences for 63% of the variables examined. The report concluded that researchers should use convenience samples cautiously. It should be noted that absolute values of variables (means) differed more than did relative values (variances),

implying that while the sample may have been off center, the associations among variables were stable.

Stability in variance and associations among variables are more important than absolute values (such as means) for the current study, since we are interested in the degree to which variations in some variables explain variations in others, such as how couple's being more *partnering* and *transforming* explains their being more *successful* in diabetes management. This is typical of social science research, in which absolute magnitudes on psychosocial scales have no intrinsic meaning, but differences among scores are meaningful.

Another study compared two convenience samples (N=61; N=54) and a random sample (N=1278) in measuring the performance of older adults (65–100 years) on demographic and psychological measures (Hultsch, MacDonald, Hunter, Maitland, & Dixon, 2002). Less than half the variables had significant differences, all differences were small to moderate in magnitude, and correlations and between-person variability had minimal differences. Note that again, while absolute values may be centered differently in the convenience sample versus the population under study, the relationships among variables remained essentially the same.

Greater differences between convenience and random samples were found in a study that compared a convenience sample of support-seeking targets of workplace bullying (N=221) with a representative sample of Norwegian targets of bullying (N=4500) (Nielsen & Einarsen, 2008). A far higher percentage of the convenience sample had blown the whistle at their workplace, and they also reported significantly more frequent and more intense exposure to aggression. This seems likely to be because

the selection mechanism of the convenience sample (those who sought help) could be related to the variables of interest, which were being a whistle blower and more severe exposure to aggression. Clearly when the selection criteria of the convenience sample is itself highly related to the variables of interest, that convenience sample is likely to have biased results.

Finally, samples of a large scale were compared in a study that investigated whether results from cross-national studies using convenience samples could provide valid cross-national comparisons (Straus, 2009). Analysis of data from the International Dating Violence Study (IDVS) of university students in 32 nations (N=17,404) found an average correlation of 0.51 between variables measured by the convenience samples and by nationally representative samples. Construct validity was supported by 41 empirical tests. They concluded that convenience samples can provide valid tests of theories. This again shows that relationships among variables tend to hold true in convenience samples, even when sample means are shifted relative to population means.

From these studies we can conclude that, for the current study, convenience sampling is likely to provide a valid test of the study model and hypothesized relationships among variables. To increase validity and generalizability, recommendations from the above studies suggest that convenience samples are more generalizable when the following care is observed: when the selection strategy is not related to variables of interest, when the sample is diverse and varies demographically, when unusual or extreme cases are excluded (as is done in structured samples of convenience, defined below), and when the sample size is sufficiently large. These strategies were employed in the research design of the current study. Additionally, the

current study used a structured sample of convenience, which improves on the simple convenience sample, as described in the following section.

Structured Samples of Convenience

It has been suggested that sampling in psychological research can be grouped into three major categories: random samples, structured samples of convenience, and explicitly biased samples with particular characteristics (Schaie & Hertzog, 1985; Hultsch, MacDonald, Hunter, Maitland, & Dixon, 2002). In structured samples of convenience, participants are not randomly selected, but are generally recruited by solicitation of volunteers via flyers, media, or appeals to community groups (Schaie et al.. 1985; Hultsch et al., 2002). Often an effort is made to achieve a sample that is diverse or has particular quotas for demographic variables such as age, ethnicity, SES, or genders (Schaie; Hultsch). Sometimes individuals with particular characteristics that are likely to skew results are excluded from the sample (Schaie; Hultsch). Face validity is checked by theoretical considerations such as whether the selection process is likely to introduce bias in the variables under study (Schaie; Hultsch).

This dissertation study employed a structured sample of convenience, rather than a truly random sample, due to time and resource constraints. Thus participants were recruited via flyers, appeals to community groups such as diabetes education groups, appeals to on-line website groups for diabetes support, and networking via social media. Individuals with particular characteristics that might skew the results were excluded: exclusion criteria for this study include individuals taking steroid medication, who had major physical co-morbidity (amputations, chronic renal failure, recent myocardial

infarct, cerebrovascular accident), or who were diagnosed with major mental illness (schizophrenia, bipolar disorder, eating disorders, substance abuse). Data were collected from a number of varied settings, with the goal of increasing diversity of respondents in terms of age, religion, ethnicity, SES, and geographical location.

Face validity indicates that those who respond to surveys in general may differ from those who do not, in terms of various personal characteristics. Some bias may occur in that those who would volunteer for such a project might be more motivated for self-care or might have more resources (time, transportation, energy, etc.) that could make them more or less likely to be affected by the study variables than those who do not chose to participate. It could be further noted that those in the general population who tend to seek treatment or therapy, and who thus come to the attention of helping professionals, might similarly fall in this category, making this study's results applicable to treatment populations. In order to minimize this effect, strong efforts were made in the data collection process to recruit outside of diabetes education and treatment centers as well as within them, to offer incentives to promote participation, to travel to participants' homes, and to recruit through a variety of means. It is unlikely that this self-selection bias introduced significant bias to this study of how couples manage diabetes in their lives. It is especially unlikely to have introduced bias to this study's focus on the relationships among variables, and conclusions should be valid since we were able to obtain data across the range of each of the variables studied.

Alpha Level, Power, Effect Size, Sample Size, and Normality of the Sample

For this study the researcher selected the moderate 0.05 level of significance (alpha level), rather than the more stringent 0.01 alpha level, because a false positive (decide the model has explanatory power when it does not) would indicate that further study of this model on a larger scale is warranted, and this would cause less harm than a false negative (decide the model doesn't fit when it does), which might cause a promising model to be prematurely discarded (Pehazur & Schmelkin, 1991). Power was chosen to be the conventional 80% (0.8) (meaning if our model was correct, we had an 80% chance of correctly detecting this). Effect size was chosen to be the moderate level, 0.15. For two predictors (as in the current study) in a multiple regression, the sample size required to achieve these values is 67 cases (Soper, 2010). When four covariates are included in the regression model (demographic covariates of age, gender, race/ethnicity, and SES), the number of predictors increases to 6, and the required sample size becomes 97 cases (Soper). The current study's sample size of N=118 is therefore adequate to the study's goals for regression analysis.

For structure equation modeling (SEM), the sample size required for confidence in results has been much debated, with research suggesting that certain model fit indices are less susceptible to sample size than others (Schumacker & Lomax, 2004). Sample size requirement is related to the number of multiple indicators of the latent variables (Schumacker et al.). SEM is generally understood to be a large-sample technique (Kline, 2005). Only very simple models can be examined for sample sizes under 100; a sample of 100-200 cases could be considered "medium," and 200 or more could be considered

"large" (Kline, p. 15). However, Ken Bollen stated that he does not agree that SEM requires very large sample sizes, and that even small samples can give quite meaningful results in testing model fit (ICPSR Summer Course, 2006).

In order to meet required sample sizes for both multiple regression analysis (required N=96) and SEM (medium sample size N=100 to 200), the sample size for the current study had a goal of at least N=100 cases, and did achieve N=118 cases.

Finally, a main concern in statistical analysis using non-random data is that the requirement for a normal distribution be satisfied. Face validity and previous research comparing random and non-random samples (described above) give a reasonable degree of confidence that using a structured convenience sample in this study was not likely to yield a distribution of data that violated assumptions of normality. Normality checks were performed on the data as part of the screening prior to analysis.

Participants

Inclusion/Exclusion Criteria

Participants were N=118 married or cohabitating couples living in the United States, of adult age defined as 18 years and older, with at least one spouse having diabetes. The age range criterion is based on CDC data on distribution of age at diagnosis of diabetes among adult cases, which reports that in 2007 64% of the adult incident cases of diabetes were diagnosed between the age of 40 and 64 years, about 19% were diagnosed between the age of 18 and 40, and about 17% were diagnosed between the age of 65 and 79 (CDC, 2007). Participants and their spouses were English speaking. Exclusion criteria were individuals taking steroid medication, with major physical co-

morbidity (amputations, chronic renal failure, recent myocardial infarct, or cerebrovascular accident), or diagnosed with major mental illness (schizophrenia, bipolar disorder, eating disorders, or substance abuse). These exclusions were intended to increase generalizability of findings by excluding those whose situations might be expected to obscure the construct relationships under investigation. Participants were screened during the recruitment and consent process. The recruitment flyer is shown in Appendix D. Recruitment was also done via on-line social networking (Facebook.com) and an on-line support group (TuDiabetes.com).

This study looked at people whose initial diagnosis of diabetes occurred at least 6 months prior to participation in the study, so that they had had an initial period of education and adjustment after diagnosis, so that their emotions, attitudes, support roles, and adjustments regarding living with diabetes could be expected to be stable. Thus variations could more likely be ascribed to variations in the constructs of interest, rather than to initial, undeveloped reactions.

Diversity of Sample

The sample included diverse participants, specifically in terms of demographics of age (mean 54.9, standard deviation = 13.2 years), race/ethnicity (diabetic spouse: 56% White, 17% Black, 28% Hispanic, 2% Native American, 9% Asian/Pacific Islander, 2% Iran, 1% West Indian; non- diabetic spouse: 63% White, 15% Black, 24% Hispanic, 7% Asian/Pacific Islander, 1% Arabic, 1% Jewish, 2% Iran), and SES (mean 22,3, standard deviation 6.7, in a range of scores from 7 to 33) and being balanced in gender make-up (diabetic spouse: 41.9% men, 58.1% women).

Cultural beliefs and world-view are likely to be affected by these demographic parameters of age, race, gender, and SES. Since culture seems to have a moderating effect on the relationship among psychosocial variables in general (e.g., Bond & Smith, 1996), and because this effect has specifically been seen on meaning-oriented constructs similar to those of this study (Chesla et al., 2003; Ford, Havstad, Brooks, & Tilley, 2002; O'Connor, Desai, Solberg, Rush, & Bishop, 2003), a diverse sample was more likely to provide data that covered a range of values for the variables under study, and thereby give more confidence about the generalizability of this study's findings regarding relationships among variables, across those ranges. Specifically, African American, Hispanic, American Indian, and Alaska Native adults are twice as likely as white adults to have diabetes (CDC, 2008), thus we made every effort to include respondents from these racial/ethnic backgrounds in order to increase the representativeness of our sample for conclusions about theory.

Procedure

Recruitment

Recruitment included a number of strategies to gather a structured convenience sample. Researchers contacted diabetes education programs, support groups, clinics, churches, and community centers in Southern California in varied settings, with an invitation for diabetic patients and their spouses to participate in our study. Flyers were distributed, and presentations were made. Online recruitment was devised via Facebook social networking and via a site-owners-approved presence on the TuDiabetes online support group. Family, friends, and word-of-mouth contacts were also used. Recruitment

also occurred at diabetes events and fundraisers, such as a 10K run/walk. In order to generate interest in participation, invitations included information about why we expected the study to increase knowledge about effective diabetes treatments. In some cases, incentives, valued at $5 to $20 each, were offered to participants. Recruitment activities including the offering and accepting of incentives were tracked.

Data Collection

Survey questionnaires were distributed over a several-month period in order to reach an adequate sample size. When people expressed interest in participating in the study, the investigator screened them for inclusion/ exclusion criteria and gave them a complete description of the study that includes informed consent for participation. Spouses were asked to separately complete either the diabetic spouse or non-diabetic spouse survey. If one spouse was not initially present, contact information was requested so that the other spouse could be invited to participate. Time and place to complete the surveys were set up in the most convenient way for participants. Questionnaires were hand delivered, mailed, or emailed upon request of the participant, and they were filled out at homes, clinics, and Loma Linda University and returned to the investigator via similar means once completed. The investigator asked participants if they knew anyone else who might be open to participating in the study and if so, obtained their contact information and invited them to participate.

Measures

Measures consisted of items from two previously validated scales, as well as new, pilot-tested items; these were combined to form the surveys for the diabetic and non-diabetic spouses. The previously validated instruments are the Diabetes Care Profile (DCP) (Davis, Hess, & Hiss, 1987) and the Appraisal of Diabetes Scale (ADS) (Carey et al., 1991). The three new scales created for this study were the *Relationship with Diabetes* Scale, the *Partnering Support* Scale, and the *Diabetes Management* Scale. A few demographic questions were also added to the surveys. Details on how the scales were used to operationalize study variables are given in the following paragraphs. Appendix E provides the specific details of how items were combined to create predictor variables and indicators of constructs.

Relationship with Diabetes Scale

The relationship with diabetes is a framing, cohesive set of emotions, meanings, and narratives. It is conceptualized as a level of positive adjustment to living with the illness and its management requirements, having values on a spectrum from least transforming (rejecting), to moderately transforming (accepting), to fully transforming.

Although the concept of a transformational experience with chronic illness is not new, there is not an established, psychometrically validated measure for this construct. Studies that have examined similar narrative constructs have tended to be qualitative. Therefore, we developed a Relationship with Diabetes Scale for this study. It was based on (1) a combination of items taken from validated scales (the DCP (Davis, Hess, & Hiss, 1987) and the ADS (Carey et al., 1991)) and (2) new items developed and pilot tested for

this study (see Appendix C). Both sets of items are described in detail in the following paragraphs and in Appendix G. The goal of this new scale was to capture emotion and meaning dimensions of the *relationship with diabetes* and to quantify the degree to which it is *transforming*.

The *relationship-with-diabetes* construct was conceived as being comprised of emotional and meaning dimensions of how the couple views diabetes in their lives. Thus the scale for this construct incorporated items from empirically validated scales that measure diabetes-related emotions, attitudes, and perceived impacts, and that have been demonstrated to have excellent psychometric properties of reliability and validity. These instruments are the Diabetes Care Profile (DCP) (Davis, Hess, & Hiss, 1987) and the Appraisal of Diabetes Scale (ADS) (Carey et al., 1991); these instruments are described in the Literature Review section and provided in Appendices J and K. The items taken from these scales are detailed in the following paragraphs.

In addition to these items, further questions were developed, pilot tested (see Appendix C), modified to increase face validity, and added to the questionnaire, with a goal of creating a more complete measure (more indicators) of this construct. Including more indicators of the latent variable or construct is in keeping with good practices for Structural Equation Modeling construct operationalization (Bollen, 1989, 1998; Hoyle, 1995), which is one of the analysis techniques used in this study. It is also likely to increase construct validity (Pedhazur & Schmelkin, 1991).

Items from the DCP in the Relationship with Diabetes Scale

The items taken from the DCP (Davis, Hess, & Hiss, 1987) and incorporated into

the new Relationship with Diabetes Scale are shown in Appendix G. These items were taken from two of the 16 scales in the DCP: the Social and Personal Factors Scale and the Attitudes toward Diabetes Scale.

These items included, “How often has your diabetes kept you from doing your normal daily activities during the past year (e.g., couldn't: go to work, work around the house, go to school, visit friends)?” as well as, “Diabetes doesn't affect my life at all,” and “I feel I'm not as good as others because of my diabetes.” Items from the Attitudes Toward Diabetes Scale included, “I am afraid of my diabetes,” “Diabetes doesn't affect my life at all,” “I feel unhappy and depressed because of my diabetes,” and “Things are going very well for me right now.”

Items from the ADS in the Relationship with Diabetes Scale

All seven items that comprise the ADS (Carey et al., 1991) were incorporated into the new Relationship with Diabetes Scale, as shown in Appendix G. These items assessed the couple’s perception of the stressful impact of diabetes. The seven items used a five-point scale, for example, 1=Not at All, 2=Slightly, 3=Moderately, 4=Very, and 5=Extremely. The items measure diabetes control, worry and uncertainty (“How much control over your diabetes do you have?” “Do you believe that achieving good diabetic control is due to your efforts as compared to factors which are beyond your control?” and “How much uncertainty do you currently experience in your life as a result of being diabetic?”), coping (“How effective are you in coping with your diabetes?”), affect of diabetes on life goals (“To what degree does your diabetes get in the way of your developing life goals?”), predictive view of diabetes (“How likely is your diabetes to

worsen over the next several years?"), and the degree of distress caused by diabetes ("How upsetting is having diabetes for you?").

New Items Developed for the Relationship with Diabetes Scale

The new items developed for this scale were based on relevant research literature, narrative and meaning-oriented theory about transformative illness narratives, and grounded theory created by the author and colleague in a previous qualitative study (Houston-Barrett & Wilson, in press). These items were pilot tested (see Appendix C), modified to increase face validity, and added to the instrument, with a goal of creating a more complete measure (more indicators) of this construct that ranged in value from least to most *transforming*.

These new items included questions about emotions regarding diabetes, for the respondent and for their perception of their spouse. From two stems, "I feel…," and "My spouse feels…" the respondent was asked to indicate strength of agreement on a 5-point Likert scale with the endings, "angry," "fearful," "hopeless," "overwhelmed," "hatred," "sad," "hopeful," "embarrassed," "guilt," "sense of loss," and "confident."

Six new double-perspective questions were added with the aim to characterize the couple's relationship with diabetes as being transforming, accepting, or rejecting (with two questions for each type of relationship). The respondent was asked to answer from his or her own perspective, and then from his or her perception of his or her spouse's perspective, whether, "In some ways we are grateful that diabetes has come into our lives," "Accept diabetes matter-of-factly, without a lot of strong emotions," "Worry quite a lot about the diabetes," "Avoid thinking about the diabetes as much as possible," "See

living with diabetes primarily as a practical matter that we deal with," and "Diabetes does not have a major impact on us."

Finally, the new items included questions aimed to further assess areas in which the relationship with diabetes might be transforming. These included two stems, "Having diabetes has made us place more value on…" and "Having diabetes has made us focus more on…" with the same six endings: "the important things in our lives," "our marriage relationship," "our relationship with our children," "our relationships with other family members," "our health," and "how we choose to spend our time." Respondents are directed to answer each of these twice: first as pertaining to him or herself, and then as pertaining to his or her spouse.

The items comprising the couple's Relationship with Diabetes Scale were scored, recoded, and combined to form an emotion-oriented indicator and a meaning-oriented indicator of the *relationship with diabetes* construct. The details of recoding are given in Appendix E. Additionally, exploratory factor analysis was used to discover whether this appeared to be a unidimensional construct or made up of two or more significant, meaningful dimensions.

Partnering Support Scale

The non-diabetic spouse plays a role in managing the diabetes regimen that may be as a partner, a pusher, uninvolved, or a combination of these (Houston-Barrett & Wilson, in press). This variable was conceptualized for the current study as a level of *partnering support* in managing the diabetes regimen, having values on a spectrum from least partnering (avoiding or *uninvolved* with it), to moderately partnering (*pushing* the

other to take care of it), to fully *partnering* (actively learning about, planning, and physically doing the regimen with the diabetic spouse).

Although the concept of support from the non-diabetic spouse was not new, this particular dimension of support had not been operationalized in an established, psychometrically validated measure. Additionally, since research shows that the specific *type* of support greatly matters in determining whether the support is helpful, we did not want to use an omnibus or broadly related measure of support in this study.

This study sought to examine a very specific dimension of support that is conceived as an active role of partnership in managing the diabetes regimen of diet, exercise, glucose testing, and medication testing. Therefore, items were selected specifically from empirically validated scales (from the DCP (Davis, Hess, & Hiss, 1987)), and new items were created to capture further aspects of this construct. Creation of the new items was guided by theory, previous research, and grounded theory developed by the author and colleague (Houston-Barrett & Wilson, in press).

Items from the DCP in the Partnering Support Scale

Items were taken from the Education and Advice Received section of the DCP's Social and Personal Factors Scale (Davis, Hess, & Hiss, 1987) and incorporated into this study's Partnering Support Scale (see Appendix H for the complete Partnering Support Scale). These items included questions about diabetes education of the diabetic and non-diabetic spouses, such as the stem, "How do you rate your understanding of…" with endings, "diet and blood sugar control," "weight management," "exercise," "use of insulin/pills," "sugar testing," "foot care," complications of diabetes," "eye care,"

"combining diabetes medications with other medications," and "alcohol use and diabetes."

The same questions were asked with the stem, "How do you rate your spouse's understanding of…" Originally the scales were used to assess attributions between patient and health care provider; however this study adapted the scales to reflect the attributions made by patient and spouse ("To what extent was the cause controllable by your spouse?").

The item, "Who helps you the most in caring for your diabetes?" was also incorporated from the DCP's Social and Personal Factors Scale (Davis, Hess, & Hiss, 1987), with choices: spouse, other family members, friends, paid helper, doctor, nurse, care manager, other health professional, and no one. This item was recoded as "spouse" and "not spouse."

New Items Developed for the Partnering Support Scale

The new items for this scale were developed based on relevant empirical research and psychosocial theory regarding social support and illness management, as well as grounded theory developed in the preceding qualitative study (Houston-Barrett & Wilson, in press). These items were pilot tested (see Appendix C), modified to increase face validity, and added to the questionnaire, with a goal of creating a more complete measure (more indicators) of this construct, and thus better construct validity (Bollen, 1989).

One set of new questions was aimed to assess the extent to which the couple actively manages the diabetes together as partners: "How often do you and your spouse

do the following diabetes-related activities together?" These inquired for example about, "planning a diabetes-healthy diet," "exercising," attending diabetes classes," and "going to medical appointments."

The other set of new questions were two items included to assess another dimension of partnering, the couple's self-perceived similarity of meanings and feelings regarding diabetes: "My spouse and I feel similarly about having diabetes in our lives," and "My spouse and I think similarly about having diabetes in our lives." The two items were used in the Partnering Support Scale as a direct measure of a thinking/feeling dimension of the partnering support variable.

The items comprising the Partnering Support Scale were scored, recoded and combined to form nine indicators of this construct of *partnering support.* These nine indicators included five indicators regarding doing activities together related to diet, exercise, testing blood sugar, taking medications and attending medical appointments and diabetes education. They also included four indicators that assessed the partnering support cognitively and emotionally: questions of whether the couple members each feel they and their spouse think similarly and feel similarly toward diabetes, each spouse's assessment of the non-diabetic spouse's diabetes education, and a global question asked of the diabetic spouse, "Who helps you the most with your diabetes?" which was recoded to "spouse" or "other."

The details of recoding of items to indicators and predictor variables are given in Appendix E. Additionally, factor analysis examined dimensionality of this construct, to discover whether it appeared to be a unidimensional construct, or whether it was made up of two or more separate and significant, meaningful dimensions.

Diabetes Management Scale

Diabetes management is comprised of adherence to the self-care regimen of diet, exercise, glucose testing, and medication taking, as well as global assessments of blood sugar control and ability to manage diabetes. This was measured by a combination of items that ask the diabetic spouse to report how well they follow their prescribed regimen and manage in general. These items were taken from the DCP scale (Davis, Hess, & Hiss, 1987), with one additional question added, as described below.

Testing/Monitoring Blood Sugar

Three questions in the survey indicated the testing of blood sugar levels; these were taken from the DCP (Davis, Hess, & Hiss, 1987). These items are a yes-no question, "Do you test your blood sugar?" followed by two fill-in-the-blank questions, "How many days a week do you test your blood sugar?" and "On days that you test, how many times per day do you test your blood sugar?"

Taking Medications Correctly

Taking medications correctly was indicated by two items that were taken from the DCP (Davis, Hess, & Hiss, 1987). The first was from an item with the stem, "During the past year**,** how often did your blood sugar become **too high** because:" and the ending, "you took the wrong amount of medicine?" The second was from an item with the stem, "During the past year**,** how often did your blood sugar become **too low** because:" and the ending, "you took the wrong amount of medicine?" Responses for both of these were

indicated on a scale: 1 = Never, 2 = Rarely, 3 = Sometimes, 4 = Often, 5 = Very often, and DK = Don't know.

Diet

Diet management was indicated by four items from the DCP (Davis, Hess, & Hiss, 1987): "How often do you follow a meal plan or diet?", "How often do you follow the schedule for your meals and snacks?", "How often do you weigh or measure your food?", "How often do you (or the person who cooks your food) use the exchange lists or food group lists to plan your meals?" Responses for each of these were indicated on a 5-point scale, from 1 = Never, to 5 = Always.

Exercise

An Exercise Management Practices Scale was added to the questionnaire. It consisted of one stem, "How often do you exercise or do activities that cause:" and three endings: "a light sweat (i.e. light work around the house)?", "a moderate sweat (i.e. walk outside your home or yard such as for fun or exercise, walking the dog)?", a heavy sweat (i.e. recreational activities such as dancing, bicycling or exercise bike, swimming, skating, or stair climbing)?" Responses were indicated on a 5-point scale: 1 = Never, 2 = Once a week, 3 = 2-3 times a week, 4 = 4-5 times a week, and 5 = Almost every day.

Overall Management

Three questions addressed how well the diabetes was managed overall: "I keep my blood sugar in good control," "I keep my weight under control," and "I do the things I

need to do for my diabetes (diet, medicine, exercise, etc.)." Each of these was measured on a scale, 1 = Never, 2 = Rarely, 3 = Sometimes, 4 = Often, 5 = Very often, and DK = Don't know.

These items were recoded and combined to create six indicators for the construct, *diabetes management*. The four areas of diabetes management – testing, taking medications, diet, and exercise – were scored separately in order to examine whether the different components of management work differently in the model. Details of recoding are given in Appendix E.

Reliability and Validity

Reliability and validity concerns are paramount in any study design and implementation. In quantitative research, the issues of validity and reliability are understood in terms of the ways in which error confounds the interpretability of data obtained via measurement. Systematic errors degrade validity, while unsystematic or random errors impact both reliability and validity (Pedhazur & Schmelkin, 1991). Below, reliability and validity are addressed in terms of these sources of error, and in how these apply to the current study.

Assessing Reliability in Quantitative Research

Reliability can be characterized as *theories of error* in that different theories of error lead to different ways to view spurious variation (variation that is not due to variation in the target construct). Different conceptions of error lead to different definitions of reliability (Pedhazur & Schmelkin, 1991. So it is misleading to speak of

the reliability of a measure. Thus it is important that reports of reliability contain sufficient information so that the reader can ascertain what sources of error have been addressed (Pedhazur & Schmelkin, 1991). In the current study, sources of error are explicitly addressed in the Methods sections that address sampling, participants, recruitment, and measurement, and they are further discussed in the Analysis, Results, and Limitations sections.

Reliability is generally assessed across three dimensions: reliability of time, of content, and of scores (Snyder & Rice, 1996). Measures of temporal stability including a *test-retest reliability coefficient* and a *reliable change index* (Snyder & Rice, 1996*).* However, while a coefficient of stability for test-retest reliability is useful, there are problems with the idea of repeated measures in psycho-socio-behavioral sciences (Pedhazur & Schmelkin, 1991). In psycho-socio-behavioral sciences, biases may occur due to carry-over effects, where the very act of measurement changes the people being measured (such as when people remember their answers from the last time they took a survey), and generally these effects lead to overestimates of reliability (Pedhazur & Schmelkin, 1991). This problem may partially explain the fact that "the literature is replete with scales for which only estimates of internal consistency are available, and test-retest reliability coefficients are absent" (Snyder & Rice, 1996, p. 225). Pedhazur and Schmelkin (1991) proposed the solution that a better indication of reliability of measures is the extent to which individuals retain their relative position in a group, rather than their absolute scores. The current study did not calculate test-retest reliability.

A second type of reliability assessment is *content reliability* of a scale, also called *internal consistency.* This reflects the homogeneity of the scale. "To be substantively

meaningful, a composite score has to be based on items [that are each] 'measuring the same phenomena'" (Pedhazur & Schmelkin, 1991, p. 90). However, while increasing the scale's homogeneity also increases internal consistency and content reliability, it decreases the scale's *external validity* and its usefulness in measuring a multidimensional target construct (Snyder & Rice, 1996). The current study used measures that intended to measure the scope of the constructs, while being consistent and focused on the constructs, striking a good balance between these two concerns. This was done by employing previously validated scales, along with new items with good face validity (developed based on previous research and colleague collaboration) and good pilot-test results.

Internal consistency is evaluated by methods such as measuring the correlation across items, or the correlation between items and total scores. Pedhazur and Schmelkin (1991) recommend the use of *Cronbach's alpha coefficient*, which reflects the mean of all split-half coefficients resulting from different splitting of the test. They call this the "method of choice" when measuring constructs (Pedhazur & Schmelkin, p. 104). Both instruments used in the current study's questionnaires have been measured to have acceptable values of Cronbach's alphas in previous studies.

A third type of reliability assessment is *interscorer consistency* (Snyder & Rice, 1996). This includes the scorers' *consistency of interpretation* and *consistency of decisions*. Pedhazur and Schmelkin (1991) point out there is an important distinction between interobserver agreement and interobserver reliability, and there are various methods to assess each. Since the current study used quantitative questionnaires as measures, interscorer consistency was not expected to be a significant source of error.

It is important to note that reliability is a function of both the instrument and the sample on which it is used (Pedhazur & Schmelkin, 1991). A reliability estimate provided with the manual for an instrument is not necessarily the reliability when used for other study samples. The "relevant reliability estimate is the one obtained for the sample used in the study under consideration," and it is this reliability coefficient that must be used to calculate other statistics such as standard errors of measurement and correction for correlation attenuation (Pedhazur & Schmelkin, 1991, p. 86).

The current study employed instruments whose reliability had been measured to be good in previous studies, but it was outside the scope of the current study to measure reliability of the questionnaires in this study. However, given that most of the scales used in this study had good reliability in previous studies, it seems reasonable to expect that they were reliable for this study's sample.

Assessing Validity in Quantitative Research

"*Validity* is concerned with whether a variable measures what it is supposed to measure" (Bollen, 1989, p. 184). We can never prove validity, but we can develop strong support for it (Bollen). There are multiple approaches to assessing validity in quantitative research. Pedhazur and Schmelkin (1991) reject the concept of validity of an instrument, and emphasize that validity refers to the appropriateness, meaningfulness, and usefulness of the specific *inferences* made from the data. Traditionally, validity in measurement has been thought of in three categories – content, criterion, and construct – but it is important to note that these are artificial distinctions, because these three categories are in fact interrelated facets of the same construct (Pedhazur & Schmelkin, 1991). Validity within

the context of research design has commonly been classified into four types: *internal validity, construct validity, external validity,* and *statistical conclusion validity* (Pedhazur & Schmelkin, 1991).

Internal validity is the "*sine qua non* of meaningful research" (Pedhazur & Schmelkin, 1991, p. 224). It refers to the validity of the assertions regarding the effects of the independent variable(s) on the dependent variable(s). It depends on the plausibility of alternate explanations. Therefore, the use of controls on confounding covariates can greatly increase internal validity (Pedhazur & Schmelkin, 1991). The current study examined relationships with and without control of known covariates: the demographic variables of age, race/ethnicity, gender, and SES.

A major area of *internal validity* is *criterion-related validation,* which focuses on the degree of successful prediction or concurrence of a criterion. Its Achilles' heel is the *definition of the criterion*, and if prediction fails, it may be the criterion, rather than the predictors at fault (Pedhazur & Schmelkin, 1991). Different criteria lead to different "validity coefficients" for the same measure, and sometimes there is no criterion available (Bollen, 1989). Difficulties in defining/quantifying criteria often lead to resorting to intermediate criteria that are predictable rather than appropriate. In the social sciences, construct validity is thus often used instead of criterion validity (Bollen, 1989); this is the case with the current study.

Construct validity, another aspect of *internal validity,* describes the extent to which a score can be used to indicate a theoretical construct (Snyder & Rice, 1996); in other words, it "assesses whether a measure relates to other observed variables in a way that is consistent with theoretically derived predictions" (Bollen, 1989, p. 188). Construct

validity exists to the extent that empirical associations parallel theoretically specified associations (Bollen, 1989). In SEM, measured items (questions in the survey) are the indicators; they indicate the latent variables or constructs in the model. How well these items indicate the latent variables is the issue for construct validity.

Note that indicators of constructs may have very different meanings in different times, places, and cultures, so their ability to indicate or predict constructs varies accordingly. If indicators in the current study were selected from instruments validated with samples from multiple racial/ethnic, SES, and cultural characteristics, then confidence would be higher in these indicators for our study. Most of the indicators in the current study were taken from the DCP (Davis, Hess, & Hiss, 1987) which had been validated for specific populations, including among African Americans (Fitzgerald et al., 1998; Fitzgerald, Havstad, Brooks, & Tilley, 2000) and among Hispanic veterans (Cunningham et al., 2005) with type 2 diabetes. Some indicators in the current study were taken from the ADS (Carey et al., 1991), whose reliability and validity were tested with a sample of 200 adult male, primarily Caucasian outpatients, attending a US Veteran's administration medical center diabetes clinic (Carey et al., 1991); this gave somewhat less confidence in the validity of this scale for other samples; however, face validity and concurrence with study variables makes it appeared to be a good choice for the current study.

Additionally, this study used well-constructed multiple indicators, which are greatly superior to single indicators in decreasing measurement error effects (Bollen, 1989). Single indicators of constructs are a generally a bad idea, although they are commonly used in sociobehavioral sciences, and multiple indicators (even two or three)

are far better (Pedhazur & Schmelkin, 1991). Kline (2005) points out that it is preferable to have at least three indicators per factor (construct, or latent variable in SEM) in order to decrease estimation problems, especially with a small sample. Of course, a prerequisite for critically evaluating a measure or set of measures of a latent or observed variable is a thorough knowledge of theories and research findings relevant to the construct (Pedhazur & Schmelkin, 1991). The current study built on the theories and research findings regarding the latent variables in the model, and it employed a number of items to indicate the constructs being measured, all in an effort to increase construct validity.

Construct validation is an ongoing process, as evidence for credibility accumulates. It can be examined in terms of logical analysis, internal-structure analysis, and cross-structure analysis (Pedhazur & Schmelkin, 1991). The major aim of *logical analysis* is to generate alternate hypotheses about what is happening. This includes scrutinizing the definition of the construct, the measurement procedure, and scoring procedures. *Internal-structure analysis* is used to assess the validity of treating a set of indicators as reflecting the same construct. For example, factor analysis can be used to assess unidimensionality vs. multidimensionality of a construct. The current study used factor analysis and structural equation modeling (SEM) to examine the structure and dimensionality of the constructs being measured.

The third type of construct validation, c*ross-structure analysis,* comprises tests of hypotheses about relations among the constructs or variables in a theoretical context. This is also known as nomological validity (Pedhazur & Schmelkin, 1996). Multiple methods allow assessment of *convergent validity* – when multiple methods have

convergent, confirming results – and *discriminant validity* – when measures are able to discriminate between different constructs. Note that the multiple methods should be *maximally different.* However, there are no clear criteria for maximally different. The current study used multiple regression and SEM analysis to test the model and hypotheses about relationships among the study constructs; this model was based on a qualitative study (Houston-Barrett & Wilson, in press). Thus, multiple and different methods were employed in developing and testing the model.

External validity is the next logical area of interest, once internal validity has been established. It refers to generalizability of findings to other populations, settings, times, and so forth (Pedhazur & Schmelkin, 1991). Generalizability depends on how representative the sample is to the larger population, or to other populations. Thus, sampling techniques are very important to external validity. In an experimental design, randomization and sufficient sample sizes are expected to provide equivalent (treatment and control groups) and/or representative (generalizable) samples. In practice, however, it may be very difficult to have truly random selection in large enough numbers, and there may as well be other problems such as ethical issues of withholding treatment, and therefore a quasi-experimental design and/or convenience samples must be used. This of course decreases reliability and validity (both internal and external) of results accordingly. This study used a structured sample of convenience, which provided good confidence for generalizability of results, as described in the Sampling section above.

Statistical content validity refers to the validity of conclusions or inferences based on statistical tests of significance, which includes discussion of effect sizes, Type I and Type II errors, statistical power, and issues around rejecting or accepting an exact null

hypothesis (Pedhazur & Schmelkin, 1991). It is important to avoid the common error of confounding statistical significance with substantive meaningfulness (Pedhazur & Schmelkin, 1991.). Effect size is useful and appropriate for interpreting the strength, importance, and meaningfulness of findings (Pedhazur & Schmelkin, 1991). The current study chose to use an effect size of 0.15, the moderate 0.05 level of significance, and power of 80%, as described in the Sampling section above.

Analysis

This study tested 5 hypotheses and a structural equation model of the relationships among the three study constructs: (1) the degree that *relationship with diabetes* is transforming is positively correlated with diabetes-specific *partnering support* provided by the non-diabetic spouse, (2) the degree that *relationship with diabetes* is transforming is positively correlated with success in *diabetes management*, (3) the degree of diabetes-specific *partnering support* that the non-diabetic spouse provides is positively correlated with success in *diabetes management*, (4) effects of the couple's *relationship with diabetes* and diabetes-specific *partnering support* significantly explain the couple's degree of success in *diabetes management,* and (5) the path and measurement model proposed in this study will have good fit with the data.

Diabetes management is the main outcome (endogenous) variable for this study. *Diabetes management* was measured with items assessing success in the diabetic's regimen of exercise, diet, medication adherence, and glucose monitoring, as well as overall blood sugar control and degree of agreement with the assertion that "I do the

things I need to do for my diabetes." As described below, the *diabetes management* construct was redefined as *diabetes management2,* based on factor and other analysis.

A number of descriptive and analytical statistical techniques were employed in this study to describe the distributions of data for the study variables, to explore the relationships among the study variables, and to explore whether and to what degree exogenous variables –*relationship with diabetes* and *partnering support* – were predictive of the endogenous variable – *diabetes management*.

The software programs used for data analysis was the Statistical Package for the Social Sciences (IBM-SPSS 20), and EQS (6), a program that performs SEM. Prior to analysis, data were screened and cleaned to identify and address outliers, missing values, normality, and homogeneity of variance. The cleaned, raw data were then manipulated to create composite and recoded variables in preparation for analysis. These processes are described in more detail below.

Descriptive Statistics

Univariate descriptive statistics were calculated for all input and output variables. These included frequency distribution, histograms, measures of central tendency, range, and variance. These provided a general overview of the data, prior to further analysis. They were also used to help assess normality and missing data, as described below.

Bivariate Correlations

In order to address the first three hypotheses of this study, bivariate descriptive statistics (correlations) were conducted to assess associations among the study variables:

relationship with diabetes, *partnering support*, and success in *diabetes management*. Table 1 gives the correlations between pairs of predictor variables. Table 2 gives the correlations of the predictor variables with the dependent variable, *diabetes management* success. One-tailed tests of significance were used, since there was an expected direction of relationship (positive) in all cases. A description of the factor analysis that led to the selection of these particular predictor variables is provided below.

Table 1

Correlations between pairs of predictor variables.

	RD Emotion DS	RD Emotion NS	RD Meaning DS	RD Meaning NS	Partnering Support DS	Partnering Support NS
RD Emotion DS	1					
RD Emotion NS	.564**	1				
RD Meaning DS	.448**	.450**	1			
RD Meaning NS	.194*	.372**	.561**	1		
Partnering support DS	.602**	.583**	.446**	.327**	1	
Partnering support NS	.426**	.747**	.408**	.428**	.725**	1

*** Correlation is significant at the 0.01 level (1-tailed).*

** Correlation is significant at the 0.05 level (1-tailed).*

RD: relationship with diabetes, DS: diabetic spouse, NS: non-diabetic spouse

The bivariate correlation values given in Table 1 support the first hypotheses of this study, that *relationship with diabetes* is positively correlated with *partnering support*. The Pearson correlations for all such pairs of variables are positive, substantial (.327 to .747), and highly significant $p < .001$. Additionally, not shown in the table, the

correlation of the couple's overall relationship with diabetes (emotion plus meaning) with the couple's combined assessment of partnering support is very high: the Pearson correlation is .701, $p < .001$. These results strongly support hypothesis 1.

Table 2

Correlations between predictors and dependent variable

	Diabetes Management2 (diet, exercise, control blood sugar, do things needed for diabetes)
Relationship with Diabetes, **Emotion** Diabetic Spouse	.505**
Relationship with Diabetes, **Emotion** Non-diabetic Spouse	.326**
Relationship with Diabetes, **Meaning** Diabetic Spouse	.101 (not sig., p=.137)
Relationship with Diabetes, **Meaning** Non-Diabetic Spouse	.054 (not sig., p=.281)
Partnering **Support**, Diabetic Spouse	.225**
Partnering **Support**, Non-diabetic Spouse	.168*
Relationship with Diabetes, for the Couple	.399**
Partnering Support, for the Couple	.245**

** *Correlation is significant at the 0.01 level (1-tailed).*

* *Correlation is significant at the 0.05 level (1-tailed).*

The bivariate correlations given in Table 2 provide strong support for the 2nd and 3rd hypotheses. For hypothesis 2, that *relationship with diabetes* is positively correlated with success in *diabetes management*, we see that the overall relationship with diabetes for the couple is significantly, positively, and substantively correlated with diabetes

management success (.399, $p < .001$). This provides strong support for hypothesis 2. However, note that when looking at the meaning and emotions indicators separately, only the emotion component of the relationship with diabetes is significantly associated with management success, and also note that the association is stronger for the diabetic (.505) than the non-diabetic (.326) spouse (both $p < .001$).

For hypothesis 3, that *partnering support* is positively correlated with success in *diabetes management*, as expected, management is positively, substantively, and significantly correlated with the couple's combined partnering support (.245, $p < .001$), as well as with both indicators of partnering support, when examined separately: from the perspectives of the diabetic spouse (.225, $p < .001$) and the non-diabetic spouse (.168, $p < .05$). These results provide strong support for hypothesis 3.

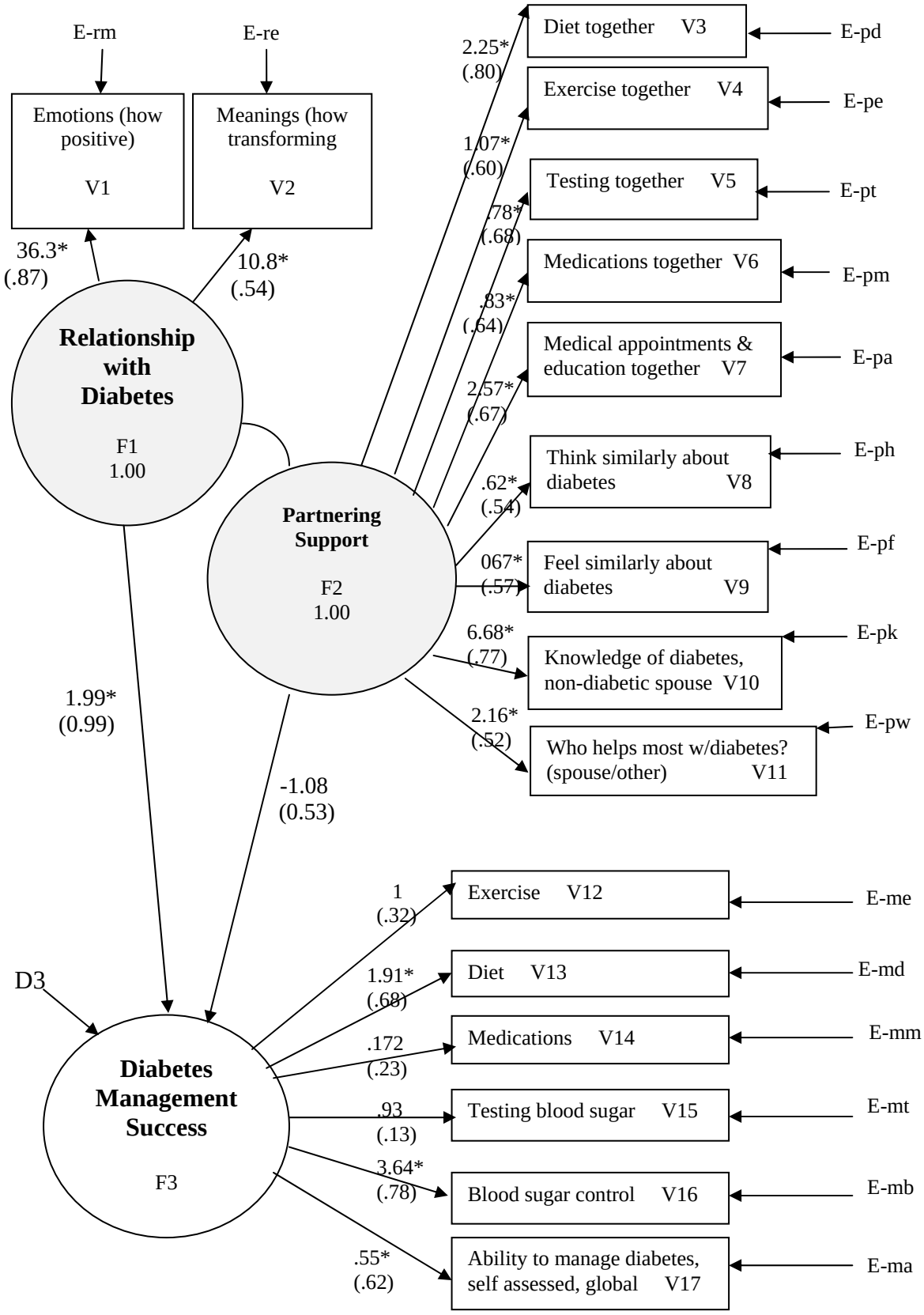
The Hypothesized Model

The hypothesized model is shown in Figure 3. Circles represent latent variables, and rectangles represent measured variables. Absence of a line connecting variables implies lack of hypothesized direct effect. The shaded circles are the independent (exogenous) variables, and the white circle is the dependent (endogenous) variable.

The hypothesized model examined the predictors of *diabetes management success*. *Diabetes management success* was a latent variable with 6 indicators (the diabetic spouse's self-reported success in following the prescribed regimens for diet, exercise, taking medications, testing blood sugar, their self-reported success in controlling blood sugar, and their global assessment that they kept their weight in control and did the things they needed to do for their diabetes). It was hypothesized that

relationship with diabetes (a latent variable with 2 indicators—diabetes related emotion and meaning) and *partnering support* (a latent variable with 9 indicators) directly predicted *diabetes management success*. The latent variable *partnering support* had 9 indicators: these included five indicators regarding doing activities together related to diet, exercise, testing blood sugar, taking medications and attending medical appointments and diabetes education. These also included four indicators that assessed the partnering support cognitively and emotionally: questions of whether the couple members each feel they and their spouse think similarly and feel similarly toward diabetes, each spouse's assessment of the non-diabetic spouse's diabetes education, and a global question asked of the diabetic spouse, "Who helps you the most with your diabetes?" which was recoded to "spouse" or "other."

Figure 3. Structural equation model. (Coefficients are from diabetic spouse data.)



Assumptions & Missing Data

The assumptions were evaluated through SPSS and EQS. The dataset contains responses from 118 couples. Of these, 68 participant couples completed Version 2 of the survey which included additional items developed specifically for the current study. There were complete data for 22 participants (N=22 listwise) on all variables of interest.

Rather than deleting all cases that included any missing values for any item, which is the SPSS default, a missing values analysis was performed using SPSS to determine whether missing data were missing at random or there was a pattern. If missing completely at random, then this helps to justify the use of imputing techniques for the missing data. To assess the randomness of the missingness, SPSS missing values analysis (MVA) was performed on all items.

Little's MCAR test (a test of whether the data is missing completely at random) examines whether there are significant trends in the data such that there is a pattern to the missingness. Results of Little's MCAR test were nonsignificant (chi-square = 8564.260, DF = 16261, sig. = 1.000), indicating that the data were missing completely at random, as hoped and expected (Tabachnick & Fidell, 2007). This means that there was no pattern to the "missingness" in the data, or in other words, there is no significant relationship between the values of the data and the distribution of the missing values in the data. This is of importance to the analyses conducted in this study, because it indicates that it is appropriate to utilize imputation techniques to impute the missing data in this dataset. This means that, rather than discarding all cases with any missing data, which would have reduced the sample size to 22 couples, the data that is present can be used to construct

what is missing. This fully utilizes the information contained in the dataset and results in a sample size of N=118, allowing meaningful analysis to proceed.

Therefore, SPSS multiple imputation was employed, a method currently considered to be one of the most respectable strategies of dealing with missing data (Horton & Lipsitz, 2001; Tabachnick & Fidell, 2007). Imputing data in this way is superior to the strategy of deleting cases with missing data not only because of the preservation of data and power, but also because deleting cases can itself produce bias (Wayman, 2003). Further, it is far superior to more simplistic methods such as replacement with the mean (in which each missing value is replaced with that variables mean), which results in an artificial loss of variance and thus covariance, resulting in the obfuscation of existing relationships among variables. In other words, these more primitive methods actually result in the loss of valuable information that is present in the data collected.

In contrast, the SPSS multiple imputation method employed in this study uses linear regression to predict the missing data in a multi-stage process that is able to use the values that are present in the incomplete dataset (i.e., with some missing values) to construct full datasets (i.e., with no missing values) while preserving the following meaningful aspects of the original data. This approach for imputing missing data maintains *variability* of the missing data, preserves *relationships* among variables, and incorporates appropriate *uncertainty* by observing the variability of the multiple imputed data sets (Tabachnick & Fidell, 2007; Wayman, 2003). A detailed description of the mathematics involved in the software to generate the imputed data is beyond the scope of this dissertation, but the performance of multiple imputation has been well-studied and

well-verified. It has been shown to provide adequate results even in the presence of low sample sizes or high rates of missing data (Graham et al., 1997; Graham & Schafer, 1999; Schafer & Graham, 2002).

To check for normality of distributions, histograms were examined, and values of skewness and kurtosis were obtained using SPSS for all items. Almost all items were found to be normally distributed. The exceptions were those items addressing the diabetic's testing blood sugar levels and taking medications. For testing, these items were DQ4 "Do you test your blood sugar?" (98% responded "yes"); DQ4a "How many days per week do you test your blood sugar?" (72.3% responded 7, among responses of 1 through 7); DQ4b "On days that you test, how many times do you test your blood sugar?" (median was 2, and 88.4% responded that they tested 4 or fewer times per day, but outliers were as high as 15). These items were combined to create DMT, a variable intended to reflect how well the diabetic person managed their diabetes with regards to testing their blood sugars, with the assumption that more frequent testing corresponds to better management (an assumption questioned in the discussion section). This variable was seen to be skewed with three moderate and one large outlier, all on the high end.

The two items addressing the diabetic's taking of medications were (DQ18c) "During the past year, how often did your blood sugar become too high because you took the wrong amount of medication?" (66.9% responded "never") and (DQ19c) "During the past year, how often did your blood sugar become too low because you took the wrong amount of medication?" (63.6% responded "never"). These items were reverse coded and combined to create (DMM), a variable intended to reflect how well the diabetic person managed their diabetes with regards to taking their medications, with the assumption that

fewer episodes of high or low blood sugar ascribed to taking the wrong medication amount corresponds to better management. The resulting variable DMM was highly negatively skewed, i.e., scores were predominantly distributed at the high end (scores ranged from 4 to 10: the majority, 55.1%, scored 10, corresponding to never having a high or low blood sugar incident due to taking the wrong amount of medication. This operationalization of the target construct may have failed to capture adequate variability to show effects of the predictor variables on this area of diabetes management success, pertaining to taking medications.

Structural Equation Modeling

Although the existing research has accounted for some of the variance in explaining diabetes management, there is a need for studies of more complex models to explain how multiple factors influence and are related to diabetes management success (Sperry, 2006, 2008). The current study responds to this need by testing a biopsychosocial, interactional model of the couple's *relationship with diabetes, partnering support*, and success in *diabetes management*.

Structural equation modeling (SEM) was used to test the fit of the proposed model (see Figure 1). This model predicts that the couple's *relationship with diabetes* is related to the *partnering support* provided by the non-diabetic spouse and that both of these interact with each other and ultimately have effects on the couple's degree of *diabetes management* success, that the forward direction is strongest, and that there is also a backward direction of effect. Alternate models were tested and compared via fit indices. The best-fit model(s) is compared to theory, and conclusions are discussed

below. This analysis examines both the measurement model and the path model proposed in this study.

Model Estimation

The hypothesized model was examined with maximum likelihood estimation and tested with the Satorra-Bentler scaled chi square (Satorra & Bentler, 1988). The standard errors also were adjusted to the extent of the nonnormality (Bentler & Dijkstra, 1985). First, the model was examined using data from the surveys completed by the spouses with diabetes (diabetic spouses, DS). Only marginal support (Bentler & Bonnett, 2012) was found for the hypothesized model (Satorra-Bentler x^2 [116, N = 118] = 217.93, p < .05, robust CFI = .813, RMSEA = .091).

Then, the model was slightly adjusted according to theoretical understandings of the variables and according to the modification indexes suggested by the software output, by adding paths between the indicators' measurement errors, to allow the measurement errors to have non-zero covariance. It is reasonable that the variables would share some measurement error, since the variables are themselves correlated. This is a standard procedure in seeking to improve model fit in SEM (Bollen, 1989). After this adjustment, the final model fit the data well (Satorra-Bentler x^2 [111, N =118] = 156.77, $p < .05$ [p= .0028], robust CFI = .916, RMSEA = .062). The final model with standardized and unstandardized coefficients is shown in Figure 3. These results support hypothesis 5 for the diabetic spouse data: the path and measurement model proposed in this study has good fit with the data."

Using data from the surveys completed by the spouses without diabetes (non-diabetic spouses, NS), the proposed measurement model was then examined to see whether it works for the NS data in the same way that it does for the DS data. Again, only marginal support was found for the hypothesized model Satorra-Bentler x^2 (111, N = 118) = 156.77, p < .05, robust CFI = .916, RMSEA = .062. After adjusting by adding a few error covariances, the final model again fit the data well, Satorra-Bentler x^2 (31, N =118) = 44.32, p= .0057, robust CFI = .954, RMSEA = .061. Therefore, the measurement model appears to be very similar for DS and NS data. These results support hypothesis 5 for the non-diabetic spouse data: the path and measurement model proposed in this study has good fit with the data.

Effects in the Model

Based on the final model using diabetic spouse data, increased *diabetes management success* was substantially predicted by improved *relationship with diabetes* (unstandardized coefficient = 1.99, $p < .05$). However, *partnering support* did not significantly predict increased diabetes management success in the model, that is, the coefficient for the path from partnering support to diabetes management was not significant (unstandardized coefficient = -1.08, $p > .05$). Over half (55.7%) of the variance in *diabetes management success* was accounted for by *relationship with diabetes* and *partnering support*. Therefore, based on the SEM analysis of this study's data, only partial support was found for hypothesis 4 that effects of the couple's *relationship with diabetes* and diabetes-specific *partnering support* significantly explain the couple's degree of success in *diabetes management*.

Factor Analysis

Factor analysis provides empirical support for the dimensionality or internal construct validity of an instrument. Factor analysis was performed on the questions comprising each of the new scales – the *relationship with diabetes* scale, the *partnering support* scale, and the success in *diabetes management* scale – to examine associations and structures that underlie total scores. Through factor analysis, it is determined for each scale whether there are meaningful dimensions to the total score, or whether a single global score is more meaningful. For example, previous research indicates that we may find that *partnering support* is comprised of two dimensions: an *instrumental partnering support* dimension and an *emotional/meaning-making partnering support* dimension.

Exploratory factor analysis (EFA) and reliability analyses were conducted for the nine partnering support variables for each group, diabetic spouse (DS) and non-diabetic spouse (NS). Consistent with the results of the SEM analysis, the indicators appeared to fit together as factors of a unidimensional construct, so a single partnering support variable was created for each group (partnering support assessed by the diabetic spouse: PS_DS and partnering support assessed by the non-diabetic spouse: PS_ NS). Repeated measures ANOVA to check for different levels showed a significant but small effect.

Additionally, the final SEM solution for the diabetic spouse group indicated that the management success construct was not holding together as the measurement model indicated it should. To examine the dimensionality of this construct, both three- and two-factor exploratory factor analysis (EFA) solutions were conducted. These clearly suggest that two variables, those indicating success in testing blood sugar (DMT) and taking

medications (DMM), do not belong in that construct. These were targeted for removal by the Wald test.

Due to the SEM and EFA results, multiple regression analyses were performed based on two separate management variables – one called “diabetes medical management" comprised of testing and medications variables, and the other "diabetes lifestyle management” comprised of the other four management variables. These confirmed that the predictor variables did not predict these two dependent variables in the same way, and in fact none of the predictor variables had significant coefficients for “diabetes medical management.” Further, given the possibility that the operationalization of the two variables that comprise “diabetes medical management” appear to have been problematic, as described above, it seems possible that these two variables are not able to well represent the intended constructs. Additionally, a review of research regarding the association of blood testing and diabetes control shows inconsistent findings, indicating the need for more nuanced understandings of this aspect of diabetes management (Allemann, Houriet, Diem, & Stettler, 2009; Blonde & Karter, 2005; Boutati & Raptis, 2009; Davis, Bruce & Davis, 2006; Farmer et al., 2009; Poolsup, Suksomboon, & Rattanasookchit, 2009). Thus, it was decided to base further analysis on the dependent variable with the testing and medications variables removed, and this modified dependent variable is called *diabetes management2*.

Multiple Regression Analyses

Multiple regression analyses were run on *diabetes management2* to determine the equation that expresses the relationship among the variables that indicate the

independent/exogenous variables (*relationship with diabetes* and *partnering support*) and the dependent/endogenous variable (*diabetes management*) of the model. Hierarchical regressions were also run with covariates controlled, to determine whether parceling out individual effects reduces the explanatory power of the model. This is intended to provide a check for spurious variance; that is, variance which is not due to the target construct.

Going forward, a number of multiple regression analyses were performed on *diabetes management2* which includes diet and exercise, but not testing and medications. This dependent variable also includes global indicators of the diabetic person's self-assessment of how well they were able to control their blood sugar and how well they were able to do the things they need to for their diabetes ("diet, medicine, exercise, etc."). The six predictor variables were the two diabetic spouse's relationship with diabetes emotion and meaning variables, the two non-diabetics spouse's relationship with diabetes emotion and meaning variables, and the partnering support variables for the diabetic and non-diabetic spouses.

Results show that the only significant regression coefficient is for the predictor: the emotion aspect of the diabetic spouse's relationship with diabetes (RDE_DS). The unstandardized regression coefficient (*B*) is .227 (95% confidence interval = .121 to .332) and the standardized regression coefficient (β) is 0.528, $p < .0001$. R for regression was significantly different from zero $F(6, 118) = 6.255$, $p < .0001$, with R^2 at .29. The adjusted R^2 value of .24 indicates that about a quarter of the variability in *diabetes management2* is predicted by the independent variables. The size and direction of the relationship suggests that more positive emotions in the diabetic spouse's relationship with diabetes results in substantial benefits for diabetes management success.

Although the bivariate correlations between *diabetes management2* and two other predictors – the non-diabetic spouse's emotions regarding diabetes and the partnering support reported by the diabetic spouse – were statistically different from zero, they did not contribute significantly to regression. One possibility that could explain this is that the relationships between these two predictors and *diabetes management2* may be mediated by the diabetic spouse's emotions regarding diabetes.

To further examine the mediator model a regression analysis was conducted with the possible mediator removed, that is, with the diabetic spouse's *emotions regarding diabetes* not entered into the regression model. If the removed variable is playing a mediating role, then the effects of the other predictors impact the mediator and then the dependent variable, so the mediator in effect hides the contributions of the mediated predictors. Removing the mediator would then allow the effects of the predictors to be seen on the dependent variable. In fact, the other predictors did increase in value and significance when the suspected mediator (emotion component of the diabetic spouse's relationship with diabetes) was removed. Most notably, the standardized coefficient of the non-diabetic spouse's emotion regarding diabetes increased from .235 to .458 and changed from nonsignificant (p = .115) to significant (p = .000). The partnering support variables of the diabetic and spouse improved only slightly as a predictor with the removal of diabetic spouse's *emotions regarding diabetes*: the standardized coefficient increased from -.068 to .178 and significance increased from very nonsignificant (p = .635) to approaching significance (p = .213). This suggests that the non-diabetic spouse's emotions regarding diabetes seem to strongly effect diabetes management indirectly through the diabetic spouse's emotions regarding diabetes.

Demographics as Covariates

Regressions were also run with the demographic variables of age, race (dummy coded as white or non-white), gender, and SES added singly and all together, and in each case the coefficients were very small and nonsignificant. The strongest of these was for gender, in the direction of better diabetes management for men than for women with diabetes (β = -.171, p = .093), which is consistent with previous research (Davis, Fowler, & Costa, 2000). The addition or deletion of the examined covariates did not greatly affect the coefficients of the other predictors, and even with all demographics entered as covariates the standardized coefficient of the diabetic spouse's emotions regarding diabetes only changed slightly from 0.528 to 0.530 and remained highly significant (p < .001).

The literature review in this paper conceptualized that demographic variables would likely be found to be reflected within the relationship with diabetes construct. Regression analyses with and without demographics entered, and with and without predictor variables entered, provided some important observations. For example, if, in fact, demographics are variables that affect the *relationship with diabetes* and thus *diabetes management* mostly indirectly rather than directly, then we would expect a regression analysis with both the demographics and the predictors entered to show small, nonsignificant coefficients for the demographics (as above), while a regression run with just the demographics would arrive at larger coefficients for demographic variables. In fact, when these regressions were conducted, this result was found. Specifically, when SES of the couple and sex, age, and race of the diabetic spouse (dummy coded as white or non-white) were run in a regression analysis as the sole predictors of *diabetes*

management2, their standardized coefficients increased in size and significance. The largest were for SES of the couple β = .206, p = .033; and for sex of the diabetes spouse β = -.162, p = .091. These results provide some support for the conceptualization that the demographic variables that have been seen to affect diabetes management do so in fact *through their effects on the relationship with diabetes*.

In addition, there are some very interesting differences in the distributions of values and in the degrees of the various bivariate correlations, when the person with diabetes is a man or a woman. For example, the mean combined partnering-support score for the diabetic spouse was 27% higher for men than for women, the mean combined relationship-with-diabetes score for the diabetic spouse was 7.3% higher for men, and the diabetes-management-success score was 7.1% higher for men. Future work should explore whether the SEM model might have different path coefficients for men and women. However, the sample size in the current study was not large enough to allow exploration of these differences. This would be a fruitful area to investigate in future research, but would require large enough subsamples to run the analyses separately for men and women as the diabetic spouse.

CHAPTER FIVE

DISCUSSION AND IMPLICATIONS

Couples who live with diabetes face a chronic, incurable disease that has threatening consequences and multiple, challenging limitations on daily life. Achieving successful diabetes management is crucial to avoiding serious outcomes of morbidity and mortality, yet many are unable to meet the demanding and complicated self-management requirements and the many needed accommodations in daily life. The current study provides insight about what helps couples be more successful in diabetes management. Results demonstrated that for married couples who face the challenges of diabetes, their ability to be successful in managing the illness requirements has a great deal to do with the nature of their relationship with diabetes and the partnering support provided by the non-diabetic spouse. It was found that positive relationships with diabetes and active partnering support work together to increase the couple's management success, while negative relationships with diabetes and low levels of partnering support make successful management far more unlikely. In particular, more positive and less negative emotions in the diabetic spouse's relationship with diabetes appear to have especially strong effects on management success.

Specifically, the study's hypotheses were confirmed by the analysis. Regarding hypothesis 1, as expected, bivariate correlational analysis showed that more positive and transforming relationships with diabetes are indeed associated with stronger, more active partnering support from the non-diabetic spouse in managing diabetes. This makes sense in a number of ways. Helpful support from a spouse can be seen as often ameliorating the impact of diabetes, decreasing negative feelings and meanings in the relationship with

diabetes (such as helplessness and fear) and aiding positive emotions and meanings (such as acceptance and confidence). In contrast, a lack of needed support from a spouse can be understood to have the opposite effect, in many cases. On the other hand, a rejecting or negative relationship with diabetes (such as angry, fearful, or refusal to accommodate illness needs) is likely to include rejection of the non-diabetic spouse's attempts to provide support, whereas a more positive relationship with diabetes is likely to include inviting or accepting a spouse's partnering support.

Similarly, hypothesis 2 was supported by bivariate correlational analysis, which showed that more positive and transforming relationships with diabetes are indeed associated with greater diabetes management success, while negative emotions and meanings in the relationship with diabetes are associated with less success in diabetes management. Correlational analysis also provided support for hypothesis 2, that partnering support in which the non-diabetic spouse takes an active role in performing diabetes management tasks together with the diabetic spouse is associated with increased management success. These associations were present for both the diabetic and the non-diabetic spouse. These findings are consistent with this study's hypothesized model and with the grounded theory developed in the preceding qualitative study (Houston-Barrett & Wilson, in press), as well as with theories in the literature that better outcomes are related to positive emotions and meanings about illness from both the diabetic (Williams, McGregor, Zeldman, Freedman, & Deci, 2004) and the non-diabetic spouse (Wearden, Tarrier, & Davies, 2000) and related to collaborative styles of illness-related support (Trief et al., 2003).

Next, this study developed these understandings about couples with diabetes further in two important ways. First, new instruments were developed, through the incorporation of previously validated measures with newly developed items, to measure the three main constructs of this study, which are of substantial importance to couples' lives with diabetes: relationship with diabetes, diabetes-related partnering support, and diabetes management success. The results of this study's exploratory factor analysis (EFA) and SEM analysis provided support for the measurement model of these key constructs, for both the diabetic spouse and non-diabetic spouse. EFA showed that the nine partnering support indicators comprise a unidimensional set indicating the construct of support. The six diabetes management indicators were also found to comprise a unidimensional set of indicators of management success, with the exception of the testing and medications indicators. The relationship with diabetes construct was confirmed to be well-indicated by the emotion component, while the meaning component may need to be better defined. However, taken as a whole, good model fit was achieved. This confirmed measurement model provides a valuable contribution, as we seek to further develop instruments that tap into these important constructs of emotions, meanings, support, and illness management.

Second, by proposing, testing, and demonstrating a structural equation model, this study contributed to understandings about how couples with diabetes are more or less able to manage diabetes well. Analysis results demonstrated support for the study model in which positive relationships with diabetes and active partnering support work together to increase the couple's management success. In particular, more positive and less negative emotions in the diabetic spouse's relationship with diabetes appear to have

especially strong effects on management success. This model provides insight into the important processes that affect illness management.

Additionally, multiple regression analyses were used to examine singly and in groups the ability of different study variables and demographics to predict diabetes management success. One particularly interesting finding was that the emotion component of the diabetic spouse's relationship with diabetes was an especially strong predictor of management success. When that variable was not included in regression analysis, it was found that the non-diabetic spouse's emotions toward diabetes were the most important predictor. Meanings about diabetes and partnering support were much less important in the regression analyses, when emotion predictors were included. However, when meanings or partnering support variables were included without emotion variables, these became stronger predictors. These results suggest that the emotion variables are extremely important to management success, which is certainly consistent with the literature (e.g., Fisher, Thorpe, DeVellis, & DeVellis, 2007). The results also suggest that emotion may play a mediating role between other predictors and management success. Additionally, it may be that the measures of meaning regarding diabetes developed in this study were not adequate to capture the construct. Also, examination of the items that that were used to measure the latent constructs in light of the analysis results, as well as with theoretical considerations, suggest that items may have been better assigned to the variable *meaning* that were assigned to the variable *emotion*. Thus, it is in the careful definition of how the latent variables are tapped into that we can more clearly determine the roles of emotion and meaning in illness

management. Future studies should continue to develop improved instruments to measure important dimensions of meanings about diabetes.

Finally, multiple regression analyses suggested that the effects of demographic variables (such as gender and SES) and partnering support variables on diabetes management may by mediated by the variable *relationship with diabetes*. This makes sense in that the relationship with diabetes is conceptualized as the cohesive, framing set of emotions and meanings regarding diabetes. As such, it makes a great deal of sense that the relationship with diabetes might be the final mediating psychosocial variable between all other predictor variables and the outcome variable of diabetes management. In other words, environmental and demographic factors, the non-diabetic spouse's partnering support and relationship with diabetes, and all other predictor variables may all ultimately and most strongly impact diabetes management indirectly through their effects on the diabetic spouse's relationship with diabetes. This interesting postulation of a modified model would be exciting to explore in future research.

Theory Implications

This study makes a contribution to theory by adding to the growing body of literature and research evidence that supports a biopsychosocial, meaning-oriented perspective of illness management. Additionally, it builds on relational and family research, contributing to explorations of the issue of illness management from the perspective of the couple dyad.

This study specifically examines a biopsychosocial, emotion-and-meaning-oriented model of diabetes management, which represents an integrated response to the

research literature in three major areas. First, it answers the widespread call to employ a biopsychosocial approach in studying diabetes (Brennan, 1996; Fisher, Thorpe, DeVellis & DeVellis, 2007; Gonder-Frederick, Cox & Ritterband, 2002; Sperry, 2008; Walker, Jackson & Littlejohn, 2004). Second, it responds to the evolving evidence that a meaning-and-emotion oriented approach to diabetes self-management is highly useful and helpful (Chesla et al., 2003; Christensen, Moran & Wiebe, 1999; Ford, Havstad, Brooks, & Tilley, 2002; Goldman & Maclean, 1998; Hornsten, Sandstrom & Lundman, 2004; O'Connor, Desai, Solberg, Rush, & Bishop, 2003; Snoek & Skinner, 2002; Sperry, 2006; Talbot, Nouwen, Gingras, Bélanger, & Audet, 1999; Williams, McGregor, Zeldman, Freedman, & Deci, 2004; Yorgason et al., 2010), by employing meaning-and-emotion-oriented constructs in the predictor (endogenous) variables of the model. Third, it responds to the growing promise that a couple-dyad perspective on illness adaptation will lead to important understandings related to diabetes management success (Berg et al., 2008; Berg & Upchurch, 2007; Bodenmann, Pihet & Kayser, 2006; Fisher, La Greca, Greco, Arfken, & Schneiderman, 1997; Gilden, Hendryx, Casia & Singh, 1989; Houston-Barrett & Wilson, in press; Kayser, Watson & Andrade, 2007; Kuijer et al., 2000; Miller & Brown, 2005; Miller Wikoff, Keen, & Norton, 1987; Skerrett, 1998; Trief et al. 2003; Yorgason et al., 2010; Zunkel, 2002).

This study integrates these three areas of theory cohesively in a model that proposes that the meanings and emotions that couples make about living with diabetes, the ways that they partner in managing the diabetes, and their success in managing the diabetes are significantly related, and explained by the proposed path and measurement model. The results provide support for the grounded theory developed in the preceding

study (Houston-Barrett & Wilson, in press), as well as contributing to the growing body of research that indicates the importance of psychosocial variables of meanings, emotions, and support to health behaviors and outcomes.

The new measures developed in this study are unique in their representation of the key constructs examined here. While previous research has indicated that these concepts are important to address, this work represents the first time that instruments have represented these specific concepts fully and together. For the construct, relationship with diabetes, this study created a new measure combining emotion and meaning that goes beyond previous related measures. It combines relevant items from two previously developed instruments with new items intended to get at important pieces of this construct. The measure developed for the partnering support construct is also a new contribution to efforts to operationalize important aspects of helpful support. Additionally the measure of diabetes management success combined new with old items, thereby providing a more detailed assessment of this construct. The findings from this study support the worth of these measures and also provide valuable information that indicate how these measures might be improved in future studies.

As a mixed-methods study, the quantitative findings of the current study Combined with the qualitative findings of the preceding study (Houston-Barrett & Wilson, in press) provide an enriched perspective on what happens with couples who live with diabetes. Consistently both the qualitative and quantitative study found that the relationship with diabetes is an important aspect of managing the illness requirements successfully. However, the high degree of partnering support seen among the most successful in the qualitative study did not appear to play as important a role in the

quantitative study. While correlational analysis supported the positive association of partnering support with diabetes management success, the corresponding path was found to be nonsignificant in the SEM analysis, and as a predictor partnering support was not significant in regression analysis of the full model. This is an interesting finding, worthy of careful interpretation. One explanation may be that the measure of partnering support is not full adequate to capture important dimensions of this construct. Another is that the model might be improved by modifying it such that the relationship with diabetes is a mediator between partnering support and management. Longitudinal studies might also provide a better understanding of how these variables work that would be richer and more informative than the cross-sectional snapshot of a moment in time in the couples' lives with diabetes.

Research Implications

Recommendations for future research have included increasing emphasis on the positive aspects of successful chronic illness self-management (Watkins & Connell, 2004, in a review of current diabetes assessment tools). This study focuses on successful diabetes self-management, in order to increase understanding about what makes couples with diabetes able to be successful in managing the disease. This study builds on previous research that has focused on the importance of narratives and meanings in illness adaptation, by incorporating the construct of the couple's *relationship with diabetes*. This study builds on the literature that has examined couple's dyadic coping and active support, by incorporating the construct of the *partnering support* of the non-diabetic spouse. To the extent that the hypotheses and model tested in this study are supported by

this study's results, it indicates the promise of fruitfulness for continued research focusing on these and other emotion-and-meaning-oriented, couple-dyad constructs. This direction of research may then lead to improved, practical, and meaningful understanding of how couples can attain success in diabetes management, as well as other chronic illnesses and conditions.

Further, this study provides illustration of a progressive, mixed-methods course of research that begins without a priori assumptions, develops grounded theory via qualitative research, and operationalizes and tests the developed model via quantitative research, thereby providing indications of model fit and generalizability to larger populations. It also employs SEM to test a more complex model than other analysis techniques are able to test, illustrating the usefulness of this analysis approach for the field of marriage and family therapy.

Future research may expand on these findings by continuing with further qualitative or quantitative research on this study's model, constructs, and/or measures. For example, future studies may add more depth and nuanced understanding via qualitative research such as focus groups. Other studies may add refinement to the quantitative measures used, improving their ability to represent the constructs of this study. Additionally, future studies may employ further quantitative studies with more diverse and larger samples, increasing the applicability and generalizability of findings.

Clinical Implications

Since the couple's relationship with diabetes seems to have powerful effects on how they experience and interact with diabetes and its management regimen, it is

important to explore how marriage and family therapists might craft interventions to help couples to achieve more *accepting* or even more *transforming* relationships with diabetes. Narrative therapy, collaborative language systems, and other social constructionist approaches seem particularly promising for the work of finding alternate, more helpful narratives for couples and others with diabetes, in order to help to co-construct for each couple a more positive relationship with diabetes. Additionally, approaches that address the emotional aspect of the relationship with diabetes may be particularly beneficial.

The clinician might, therefore, when first meeting with the couple with diabetes, explore with them regarding their current descriptions of the role diabetes plays in their lives and how they feel about that. For example the therapist might ask, "What sorts of emotions do you feel, when you think about diabetes in your life?" To tap into the possibility that a transforming relationship with diabetes may be possible, the clinician could inquire, "Are there ways in which you feel grateful that diabetes has entered your lives? Are there things that you appreciate that might not have happened without it?" In the case that a couple describes a negative relationship with diabetes, the clinician may want to open space to address how the couple has coped with other difficulties, to find areas of resilience that may be applicable to work on shifting the couple's relationship with diabetes to a more positive one. In working to expand more positive meanings and feelings, the therapist can help the couple to benefit from the development of an improved relationship with diabetes.

Another fruitful area of focus for clinical interventions is the non-diabetic spouse's role in helping the couple to achieve the tasks, knowledge, and attitudes that seem to lead to successful diabetes management. Since this study demonstrates that

increased *partnering support* is associated with improved illness management, it seems likely that clinicians may beneficially address with clients how they can create ways to work and learn together to achieve the exercise, diet, medication, testing, and other elements of regimen adherence in their daily lives. The therapist could, for example, ask, "What sorts of things do you enjoy doing together? Are there aspects of the diabetes management that you might enjoy doing together, such as cooking or exercising? What kinds of support do you find most helpful/feel most comfortable providing?" By exploring and expanding options and highlighting successes, the clinician may be able to help the couple to develop better ways of supporting/being supported for the illness management tasks.

Because this study illuminates some of the processes whereby people struggle with diet and exercise, these findings may also be helpful to a broader population who struggle with these same issues. These include couples dealing with obesity, pre-diabetes, cancer, cardiovascular disease, and immune disorders. For those with pre-diabetes, diabetes can be prevented or delayed among persons at risk by increased physical activity and moderate weight loss (Kirtland, Li, Geiss, & Thompson, 2008). Clinically, this study indicates that it may be beneficial to use an approach that helps clients to create more helpful relationships with the requirements for managing a healthy lifestyle. Also, marriage and family therapists might focus on interventions designed to help couples to exercise and diet together in a partnership to achieve weight management goals.

Limitations

A discussion of a study's limitations is a discussion of reliability, validity, and generalizability as it pertains to the current study. This includes a discussion of practical considerations in the study design such as constrained and constraining resources, availability of previously developed relevant instruments, the nature of the study's data which may lead to difficulties in analysis, and ultimately, the validity of interpretation of the study results. In the Methods section, generalizability, validity, and reliability were discussed in detail, along with design considerations and expectations for the current study. The following paragraphs summarize and extend this discussion.

One potential limitation of the current study is its sample. This study employs a structured sample of convenience, which is recognized as a useful and appropriate sample for psychosocial research (Hultsch, MacDonald, Hunter, Maitland, & Dixon, 2002; Schaie & Hertzog, 1985); it also uses a sample size that is considered moderate (Kline, 2005) for SEM analysis. While there is reasonable expectation that this sample will provide generalizable results, there is unavoidable error. Current resources of this study made it unfeasible to use larger samples or random samples, and this limitation does affect generalizability. Additionally, while efforts were made to obtain participants such that the demographics of the sample were varied, providing ample ability to analyze covariant effects, and to cover the range of variability, in order to be able to observe the behavior of constructs across their range of values, the sample would have been improved by greater diversity.

In particular, the SES of the sample was skewed toward the upper-middle class. It is possible that the model holds for moderate SES levels, but break down at the high and

low extremes, where resources for diabetes management are exceptionally rich or scarce (and so *partnering support* and *relationship with diabetes* may have less effect on and relevance for diabetes management. Future research should be conducted for samples that are large enough and diverse enough to better examine this question. However, a sample can never be expected to perfectly represent all persons, and there will be unavoidable differences between sample and population characteristics.

Another limitation of this study is the measures that were employed. Because there were no pre-existing measures which perfectly correspond to the constructs of the current study, new measures were developed, attempting to operationalize the constructs of relationship with diabetes, partnering support, and diabetes management success. This process included incorporating items from previously established measures, the DCP (Davis, Hess, & Hiss, 1987) and the ADS (Carey et al., 1991), which have been shown to have good, but not perfect, reliability and validity parameters, based on previous study samples. While the current study reasonably expected similarly good reliability and validity, these are not guaranteed for the current sample and the current study.

Additionally, the measures in this study include the early development of new items that attempted to measure the target constructs, which have not been previously operationalized and validated. In particular, new items were developed to access the emotion and meaning aspects of the relationship with diabetes and the active partnership of support from the spouse.

While pilot testing of the new items was conducted (see Appendix C), and while face validity appeared to be good, based on the author's familiarity with theories on which the constructs are based, and based on cross-checking with colleagues, these

unproven measures produced resultant uncertainty of construct validity and reliability. In fact, while correlational analysis supported the study hypotheses, regression and SEM analysis provided strong support for only some parts of the model, particularly those regarding the relationship with diabetes and especially the emotion indicator of that construct. They indicated that the meaning and partnering support variables were less important to diabetes management success than hypothesized, and only the emotion variables, which appear to have been well measured, had strong effects on management. It is possible that the constructs do not affect each other in the ways that theory and previous research suggest, but it seems more likely that the newly created items failed to tap into the constructs as well as intended. Specifically, the meaning-related items and the partnering support items may require evaluation and improvement.

The idea that cognitions and meanings, as well as emotions, are important to chronic illness adaptation is well-supported. However, as the results of the current study show, the nuances of measuring meaning are essential to capture. For example, *acceptance* has been found to have either negative or positive effects on chronic illness outcomes, depending on how it is defined and operationalized: studies that have defined *acceptance* to be a kind of resignation have shown negative effects (Greer et al., 1990; Reed et al., 1994), while a study that defined *acceptance* as the perceived ability to live with and master the illness needs found it to have positive effects (Evers et al., 2001). Future studies should re-examine the model proposed in the current study with improved operationalization of the meaning and partnering constructs.

For example, Evers and colleagues (2001) developed a measure of illness cognitions, The Illness Cognition Questionnaire with demonstrated good reliability and

validity, that measures helplessness to assess the aversive meaning of the disease, acceptance as an indication of diminishes aversive meaning, and perceived benefits that add positive meaning to the disease. Their instrument, which is provided in Appendix F, has strong reliability and validity and has shown strong support for the theory that increased positive and reduced negative meanings about the illness improve illness outcomes. Additionally, their questionnaire contains a number of items to assess positive illness meanings, in contrast to the current study which contained very few such items.

All study design and interpretation is based on theory, and thus any study is only as good as the theory that frames it. The current study employs theory that has solid logic and well-founded support in the current literature, and it has reasonable confidence in its theoretical underpinnings. However, all such theory is mutable and under constant reinvestigation, and the current study is not immune from reexamination. With this understanding, every effort has been made to report methodology, analysis, and results in sufficient thoroughness that future reinterpretation could be made usefully.

Another potential source of problems for the current study is that the parameters of data for the diabetic management indicator of taking medications and testing blood sugar were obtained such that analysis and interpretation are difficult. The non-normality of their distributions and lack of meaningful variability of values made analysis difficult, and these important indicators of diabetes management success had to be excluded.

Ultimately, the most important consideration to the study is the interpretation of results that arise from the data and analysis (Pedhazur & Schmelkin, 1991). Particular emphasis has been given in this study to interpretation of results. Confidence has been increased by using multiple indicators to improve construct validity (Bollen, 1989, 1998;

Hoyle, 1995), by the author's thorough understanding of the theories on which the study model is based, which is essential to SEM model fit interpretations (Bollen, 1998), by testing alternate models to compare model fit (Kline, 2005), and by the usefulness of SEM analysis techniques to model and test psychosocial models (Bollen, 1998), as well as the addition of complementary analyses, including bivariate correlational, multiple regression, and exploratory factor analysis. While in each of these areas there is unavoidable bias and error, in this study the methods employed provide good confidence in the validity of the interpretation of results and contributions to the literature.

This study illustrates and provides empirical evidence to support a model that shows how the couple's *relationship with diabetes* and the *partnering support* of the non-diabetic spouse are central to the crucial tasks of *diabetes management*. It is hoped that these findings will enhance our understanding of what it means to live with this difficult illness, and that it will lead to more effective interventions, inform theory development, and inspire further research in these areas.

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APPENDIX A

INSTRUMENTS FOR DIABETES MANAGEMENT AND PSYCHOSOCIAL FACTORS

ASK-20	Adherence Starts with Knowledge	Adherence Barrier Survey to identify actionable risk factors for medication nonadherence Two summary scores – • the sum of all positive barriers or Total Barrier Count (TBC) • the sum of raw item scores, the ASK-20 score	20 items	Hahn, Park et al., 2008
ADS	Appraisal of Diabetes Scale	single scale, stressful impact	7 items	Carey, Jorgensen, Weinstock et al., 1991
ADA-P/-C	Assessment of Diabetes Adherence, Parent and Child	based on DSMP, plus psychosocial measures		Lehmkuhl et al., 2009
ADDQoL	Audit of Diabetes-Dependent Quality of Life	single scale, life without diabetes		Carey et al.
ATT39	Attitudes to Diabetes, Emotional	emotional component of attitudes to diabetes		Dunn et al., 1986
	Barriers to Adherence Questionnaire	frequency of environmental and cognitive events that may be **obstacles to regimen adherence**, for type 1 diabetes	15 items 8 items	Glasgow, McCaul, & Schafer, 1986

BSMBG	Barriers to Self-Monitoring Blood Glucose Scale	circumstances, thoughts, and feelings associated with barriers to testing blood glucose	80 items	Jones, Remley, & Engberg, 1996
BAS PSCL	Barriers to Adherence Scale: Problem Situations Check List Benefits/ Barriers Scale	see PSC (seems to be the same)	see PSC	see PSC
CFI	Camberwell Family Interview	Wearden et al. used this to code spontaneous causal attributions; expressed emotion; laborious to use		
D-39	Diabetes-39 Diabetes Attitude Scale			Anderson et al., 1990
DBRS	Diabetes Behavior Rating Scale			
DCPZ	Diabetes Care Profile	a broad conceptualization of diabetes-specific QOL contains a profile that measures adherence		Hess et al., 1986; Davis, Hess, & Hiss, 1987; Fritzgerald, 1996
DDHS	Diabetic Daily Hassles Scale	Activities of Daily Living, Self Care, Self Management		Carey, Jorgensen, Weinstock et al., 1991
DDS	Diabetes Distress Scale Diabetes Empowerment Scale			

DFBC	Diabetes Family Behavior Checklist			Schafer et al
DFBCII	Diabetes Family Behavior Checklist II	**family interactions** specific to diabetes self-care that may support or interfere in 6 regimen areas (diet, exercise, medication, glucose testing, feet self-exam, doctor visits)		McCaul, Glasgow, & Schafer, 1987
DFCS, revised	Diabetes Family Conflict Scale, revised	diabetes-specific conflict in families with **children and adolescents** with type 1 diabetes		Hood, Butler et al., 2007
DHBQ-R	Diabetes Health Belief Questionnaire-Revised	Health Attitudes, Health Behavior, Sick Role, Treatment Compliance		Brownlee-Duffeck, et al., 1987
DHBS	Diabetes Health Belief Scale			
DHP, DHP-1, DHP-18	Diabetes Health Profile	single scale, focuses on diabetes-related distress, activity and eating behavior (DHP-1 for type 1)		
DIMS	Diabetes Impact Measurement Scales	a broad conceptualization of diabetes-specific QOL		
DMS DMS-A DMS-P	Diabetes Management Scale, A-adolescents P-parents		23-item	Schilling, Grey et al., 2002
DQOL	Diabetes Quality of Life Scale	a broad conceptualization of diabetes-specific QOL		Jacobson et al

DRAQ	Diabetes Regimen Adherence Scale	*Also translated to French, Tubiana-Rufi et al., 1998*		Hanson, Henggeler, Burghen et al., 1987
DRAQ-R	Diabetes Regimen Adherence Questionnaire	Activities of Daily Living, Patient Compliance, Self Care, Self Management, Treatment Compliance	18 items	Brownlee, Peterson, Simonds et al., 1991
DSCBS-OA	Diabetes Self-Care Barriers			
DSMP	Diabetes Self Management Profile	**adherence**, across multiple self-care behaviors	Inter-view	Harris et al., 2000
DSQOL	Diabetes Specific Quality of Life Scale	a broad conceptualization of diabetes-specific QOL, for type 1		
EDBS	Elderly Diabetes Burden Scale			
FES	Family Environment Scale			Moos and Moos
–	Perceived Social Support from Family Scale	Family support		Procidano & Heller's, 1983
–	Hassles and Uplifts Scale	Daily stress		DeLongis, Folkman, & Lazarus, 1988
HPSS	Health Problem-Solving Scale	based on theories of **problem solving** in cognitive psychology, education/ learning theory, and social problem-solving		Hill-Briggs, 2005
HR-QOL	Health-Related QOL			

–	Health Self-Determinism Index	a measure of intrinsic **motivation** in health behavior		Cox, 1985
IDSRQ	Insulin Delivery System Rating Questionnaire		67 items	
–	Irrational Health Belief Scale			Christensen, Moran, & Wiebe, 1999
LOC	Diabetes Locus of Control (LOC) Scale	Generates 3 subscales: Internal (LOC) Others (LOC) Chance (LOC		Ferraro et al., 1987
LQD	Quality of Life with Diabetes Questionnaire			
MISS-21	Medical Interview Satisfaction Scale		50 items	Meakin & Weinman, 2002
SF-36	Medical Outcomes Study Health Survey			Ware & Sherbourne
MHLC	Multidimensional Health Locus of Control scale (& expanded Form C), Multidimensional HLC Scale Multidimensional Diabetes Questionnaire			

–	Perceived Diabetes and Dietary Competence *(dev from DFBCII)*	**social support**, diabetes-specific	28-item	Samuel-Hodge et al., 2002
PAID	Problem Areas in Diabetes Scale	single scale, diabetes-related distress		
PSC *also called BAS-PSCL*	Problem Situations Checklist *revision to Barriers Adherence Questionnaire*	**obstacles to regimen adherence,** for type 2 diabetes: environmental., cognitive, and lifestyle factors thought to interfere with adherence to diabetic regimens – focuses on 4 aspects of regimen: diet, exercise, medication, and glucose testing	31 items	Glasgow, Toobert, Riddle et al. 1987
–	Psychosocial Aspects of Diabetes Schedule			Sensky et al.
QSD-R	Questionnaire on Stress in Diabetic Patients-Revised	single scale, has a primary focus on diabetes-related distress		

SCI-R	Self-Care Inventory-Revised	self-report measure of perceived adherence to diabetes self-care recommendations, among adults with diabetes SCI-R is correlated with diabetes-related distress (r = -0.36), self-esteem (r = 0.25), self-efficacy (r = 0.47), depression (r = -0.22), anxiety (r = -0.24), and HbA(1c) (r = -0.37), supporting construct validity. SCI-R scores improved with diabetes psychoeducation.		Weinger, Butler, et al., 2005
–	Social Support for Diabetes Regimen Adherence in African American Women With NIDDM	social support, family relations, health behavior, treatment compliance adapted from Diabetes Family Behavior Checklist II (DFBCII)	28 items	Samuel-Hodge et al., 2002
SCS	Self Control Schedule			Rosenbaum, 1980
SMBG	Self-Monitoring of Blood Glucose Information Tool	2 factors found in instrument : “Social Influence” – degree to which patients rely on others to help them test "Physical Influence" – degree to which patients use physical symptoms of blood glucose levels to help them test	15 item	Wagner, Schnoll, & Gipson, 1998
–	Socioeconomic Status Measure	Family income, educational level	2 items	Aikens, Wallker, Bell, & Cole (1992)
SDSCA	Summary of Diabetes Self-Care Activities Scale			

SCL-90	Symptom Checklist-90			
–	Ways of Coping Instrument	4 factors: avoidance, effort, advice, and growth; or 2 factors: avoidance and pro-active	68 items	Lazarus & Folkman's (1984)
WED	Well-Being Enquiry for Diabetics	single scale, primarily concerned with perceptions of patients with diabetes in relation to mental health	50 items	
WBQ	Well-Being Questionnaire			Bradley, Brewin, & Moses (1984)

The instruments cover the following general assessment areas:

Psychological adjustment

Various domains of self-determination

Self-management behaviors, for example, foot care, blood glucose testing and lifestyle domains

Diabetes knowledge and understanding

APPENDIX B

PSYCHOSOCIAL PREDICTORS OF DIABETES

MANAGEMENT AND CONTROL

Predictors can be grouped into 4 categories:

- Cognitions (Beliefs, Attitudes, & Expectancies)
- Barriers & Stressors
- Resources, Personal characteristics, & Abilities
- Social, Family, & Relational Influences

Cognitive (Beliefs, Attitudes, & Expectancies):

Health beliefs	(Penick, 1998; Brownlee-Duffeck, et al., 1987)
Locus of control	(O'Hea, 2005; O'Hea, Grothe, 2005; Tillotson, Smith, 1996; (internal, external, chance/other) O'Hea, Moon, et al., 2009)
Outcome expectancy	(O'Hea, 2005; O'Hea, Moon, et al., 2009); Perceived net benefits (Aalto & Uutela, 1997); Expectancies (McCaul, Glasgow, & Schafer, 1987)
Self efficacy	(O'Hea, 2005; Gemmell, 2008; Aalto & Uutela, 1997; French, 1997, O'Hea, Moon, et al., 2009; Elliot, 2003)
Motivation	(Apóstolo et al., 2008), Intrinsic Motivation (Walker, 1988); Motivation (Autonomy, Competency, Health care provider relationship) (Butler, 2003); Motivational variables (readiness, importance, self-efficacy) (Gemmell, 2008)
Morale	(Connell, O'Sullivan et al., 1988)
Coping with stressful diabetes event	(Frenzel et al., 1988)
Proactive capacity	Capacity to take up the challenges posed by diabetes (Lo, 1999)

Barriers & Stressors:	
Barriers	(Glasgow, McCaul, & Schafer, 1986; Tu, 1996); Associated: circumstances, thoughts, feelings (Jones, Remley, et al., 1996); barriers & benefits (Connell et al., 1988)
Stress	Chronic Stress (Lo, 1999); Daily Stress (Aikens et al., 1992); Perceived stress associated, Daily Hassles, not associated (Frenzel et al., 1988)
Depression	(Elliot, 2003)
Resources & Abilities:	
Diabetes Knowledge	(McCaul, Glasgow, & Schafer, 1987; Tu, 1996; Butler, 2003; Hill-Briggs, 2003)
Skills	(McCaul, Glasgow, & Schafer, 1987)
Problem solving ability	Problem solving skill and orientation, disease-specific knowledge, transfer of past experience (Hill-Briggs, 2003)
Adlerian scales	Predicted different adherence behaviors, but not overall (Penick, 1998)
Social, Family, & Relational Influences	
Environmental support	(McCaul, Glasgow, & Schafer, 1987)
Family support	(Lo, 1999)
Partner's Expressed Emotion & Attributions	(Wearden et al., 2000, 2006, 2006)
Family system variables	(Trief, Grant et al., 1998)
Social support	(Tillotson, Smith, 1996; Aalto & Uutela, 1997; Butler, 2003; Connell, et al., 1988)
Perception of significant other's belief	(Miller et al., 1997)
Good rapport with Health Professionals	(Lo, 1999); Health care provider relationship (Butler, 2003); Collaborative Model of care emphasizing patient autonomy & choice (Delamater, 2006)

APPENDIX C

PILOT TEST QUESTIONS AND RESULTS

Pilot Test Questions, Version 1:

Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree	Does Not Apply

When my spouse and I think about the diabetes, the main thing we feel is that we hate it.

1 2 3 4 5 N/A

Most of all, what my spouse and I would tell you about living with diabetes is that it is just something that we accept and deal with.

1 2 3 4 5 N/A

There are important, positive effects that diabetes has brought to my life (or my spouse's life) for which we are grateful.

1 2 3 4 5 N/A

Overall, my spouse's and my relationship with diabetes is more positive than negative.

1 2 3 4 5 N/A

Pilot Test Questions, Version 2:

Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree	Does Not Apply

When my spouse and I think about the diabetes, the main thing we feel is that we hate it. *The strongest emotion I feel is hatred.*

1 2 3 4 5 N/A

Most of all, what my spouse and I would tell you about living with diabetes is that it is just something that we accept and deal with.

1 2 3 4 5 N/A

There are important, positive effects that diabetes has brought to my life (or my spouse's life) for which we are grateful.

1 2 3 4 5 N/A

Overall, my spouse's and my relationship with diabetes is more positive than negative.

1 2 3 4 5 N/A

Pilot Test Questions, Version 3:

Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree	Does Not Apply

RELATIONSHIP WITH DIABETES – "ACCEPTING"

My spouse and I mostly see living with diabetes as a practical matter that we must deal with.

1 2 3 4 5 N/A

Diabetes is not something that makes us feel very strong emotions – we accept it matter-of-factly.

1 2 3 4 5 N/A

We would rather not have diabetes in our lives, but it does not really have a major impact on us.

1 2 3 4 5 N/A

RELATIONSHIP WITH DIABETES – "TRANSFORMING"

Diabetes has made us value or focus more on the important things in life.

1 2 3 4 5 N/A

We believe that because diabetes has come into our lives, we have experienced certain things for which we are profoundly grateful.

1 2 3 4 5 N/A

If diabetes had not come into our lives, we believe that we would have experienced certain very negative things.

1 2 3 4 5 N/A

RELATIONSHIP WITH DIABETES – "REJECTING"

When my spouse and I think about the diabetes, the strongest emotion we usually feel is hatred, anger, hopelessness, or fear.

1 2 3 4 5 N/A

We worry quite a lot about the diabetes.

1 2 3 4 5 N/A

We avoid thinking about the diabetes as much as possible.

1 2 3 4 5 N/A

GENERAL

We manage the diabetes well in our life.

1 2 3 4 5 N/A

Overall, my spouse's and my relationship with diabetes is more positive than negative.

1 2 3 4 5 N/A

Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree	Does Not Apply

PARTNERING

My spouse and I *think* very similarly about having diabetes in our lives.

1 2 3 4 5 N/A

My spouse and I *feel* very similarly about having diabetes in our lives.

1 2 3 4 5 N/A

We exercise together (or coordinate our work-outs) most of the time.

1 2 3 4 5 N/A

We are partners in planning, preparing, and eating a diabetes-healthful diet.

1 2 3 4 5 N/A

We work together to make sure that testing and medications occur as they have been prescribed.

1 2 3 4 5 N/A

We do diabetes related activities together, such as attending classes, going to medical appointments, reading about diabetes, researching diabetes online, or participating in support groups.

1 2 3 4 5 N/A

We are both experts in diabetes care.

1 2 3 4 5 N/A

REGIMEN ADHERENCE

The diabetic person is consistent in taking medications as prescribed, in dosage and timing.

1 2 3 4 5 N/A

The diabetic person is consistent in testing when they should, as prescribed.

1 2 3 4 5 N/A

The diabetic person is consistent in following a diabetes-healthful diet.

1 2 3 4 5 N/A

The diabetic person is consistent in following a program of exercise most days of the week.

1 2 3 4 5 N/A

Pilot Test Questions, Version 4:

Pilot Study, Relationship-with-Diabetes Instrument

____I have diabetes ____My spouse has diabetes

____Female ____Male

Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree	Does Not Apply

RELATIONSHIP WITH DIABETES – "ACCEPTING"

My spouse and I mostly see living with diabetes as a practical matter that we must deal with.

1 2 3 4 5 N/A

Diabetes is not something that makes us feel very strong emotions – we accept it matter-of-factly.

1 2 3 4 5 N/A

We would rather not have diabetes in our lives, but it does not really have a major impact on us.

1 2 3 4 5 N/A

RELATIONSHIP WITH DIABETES – "TRANSFORMING"

Diabetes has made us value or focus more on the important things in life.

1 2 3 4 5 N/A

We believe that because diabetes has come into our lives, we have experienced certain things for which we are profoundly grateful.

1 2 3 4 5 N/A

If diabetes had not come into our lives, we believe that we would have experienced certain very negative things.

1 2 3 4 5 N/A

RELATIONSHIP WITH DIABETES – "REJECTING"

When my spouse and I think about the diabetes, the strongest emotion we usually feel is hatred, anger, hopelessness, or fear.

1 2 3 4 5 N/A

We worry quite a lot about the diabetes.

1 2 3 4 5 N/A

We avoid thinking about the diabetes as much as possible.

1 2 3 4 5 N/A

Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree	Does Not Apply

GENERAL

We manage the diabetes well in our life.

1 2 3 4 5 N/A

Overall, my spouse's and my relationship with diabetes is more positive than negative.

1 2 3 4 5 N/A

PARTNERING

My spouse and I *think* very similarly about having diabetes in our lives.

1 2 3 4 5 N/A

My spouse and I *feel* very similarly about having diabetes in our lives.

1 2 3 4 5 N/A

We exercise together (or coordinate our work-outs) most of the time.

1 2 3 4 5 N/A

We are partners in planning, preparing, and eating a diabetes-healthful diet.

1 2 3 4 5 N/A

We work together to make sure that testing and medications occur as they have been prescribed.

1 2 3 4 5 N/A

We do diabetes related activities together, such as attending classes, going to medical appointments, reading about diabetes, researching diabetes online, or participating in support groups.

1 2 3 4 5 N/A

We are both experts in diabetes care.

1 2 3 4 5 N/A

REGIMEN ADHERENCE

The diabetic person is consistent in taking medications as prescribed, in dosage and timing.

1 2 3 4 5 N/A

The diabetic person is consistent in testing when they should, as prescribed.

1 2 3 4 5 N/A

The diabetic person is consistent in following a diabetes-healthful diet.

1 2 3 4 5 N/A

The diabetic person is consistent in following a program of exercise most days of the week.

1 2 3 4 5 N/A

APPENDIX D: Recruitment Flyer

A Request for Survey Participants

Married Couples with Diabetes

Hello and Good Day! My name is Ruth Houston Barrett. I am a Ph.D. student at Loma Linda University doing **dissertation research on diabetes and married couples**: learning about how couples live with diabetes and what helps in managing nutrition, exercise, medical regimens, issues, and feelings about it. Although I am not able to provide incentives for completing the surveys I would be very glad to share current and future results of this research!!

Your participation in this study would provide a wealth of valuable information. In turn, the results will inform health care providers and educators who seek to improve the life quality and management success of those with diabetes. In addition to completing the survey, all thoughts or reflections about the survey or about living with diabetes are highly welcome.

The survey for the diabetic spouse may take about 40 minutes to complete, and the one for the non-diabetic spouse may take about 20 minutes. Confidentiality is maintained for all participants.

Please email me at rbarrett@llu.edu or call (310) 995-9356 if you and your spouse are interested in participating. Thank you for your time and the very valuable expertise your participation will share.

APPENDIX E

SURVEY ITEMS RECODING TO INDICATORS OF CONSTRUCTS

Constructs: Relationship with Diabetes, Partnering Support, and Diabetes Management

RELATIONSHIP WITH DIABETES: RD

Diabetic spouse

RDD ➔ RDED (emotion) and RDMD (meaning),

where:

RDED = + DQ8(a+b+c+d+e+f+g+h+i+j)	+ Confidence in own diabetes education
+ DQ9(a+b+c+d+e+f+g+h+i+j)	+ Confidence in spouse's diabetes education
– DQ20–DQ21(a+b+c+d+e+f+g+h+i+j)–DQ22–DQ23	– Problems from diabetes
+ DQ24(–a–b–c+d–e+f–g+h+i+j)–DQ30+DQ31	+ Positive attitudes toward diabetes
+ DQ49(–a+b–c–d–e+f–g)	+ Positive expressed emotion about diabetes
+ DQ32 left (-a-b-c-d-e-f +g -h-i-j +k)	+ New- I feel
+ DQ32 right (-a-b-c-d-e-f +g -h-i-j +k)	+ New- my spouse feels
RDMD = + DQ26(a+b+c+d)	+ Meaning- important to manage diabetes
+ DQ35 (a*2 +b-c-d+e+f)	+ New- direct RD items (gratitude, etc.)
+ DQ37(a+b+c+d+e+f)	+ New- direct RD items (value)
+ DQ38(a+b+c+d+e+f)	+ New- direct RD items (focus)

Non-diabetic spouse

RDN ➔ RDEN (emotion) and RDMN (meaning),

where:

RDEN = + NQ3(a+b+c+d+e+f+g+h+i+j)	+ Confidence in own diabetes education
+ NQ4(a+b+c+d+e+f+g+h+i+j)	+ Confidence in spouse's diabetes education

+ NQ9 left (-a-b-c-d-e-f +g -h-i-j +k)	+ New- I feel
+ NQ9 right (-a-b-c-d-e-f +g -h-i-j +k)	+ New- my spouse feels
RDMN = + NQ11(a*2 +b-c-d+e+f)	+ New- direct RD items (gratitude, etc.)
+ NQ12(a+b+c+d+e+f)	+ New- direct RD items (value)
+ NQ13(a+b+c+d+e+f)	+ New- direct RD items (focus)

Couple

RDC ➔ RDED, RDEN, RDMD, and RDMN

PARTNERING SUPPORT IN DIABETES MANAGEMENT: PS

Diabetic spouse

PSD ➔ PSDD, PSED, PSTD, PSMD, PSAD, PSHD, PSFD, PSKD, and PSWD,

where:

PSDD = + DQ10(a+b+c)	+ New: Diet together
PSED = + DQ10(d+e)	+ New: Exercise together
PSTD = + DQ10(f)	+ New: Testing together
PSMD = + DQ10(g)	+ New: Medications together
PSAD = + DQ10(h+i+j+k)	+ New: Medical appoints/education together
PSHD = + DQ34(a)	+ New: We think similarly
PSFD = + DQ34(b)	+ New: We feel similarly
PSKD = + DQ9(a+b+c+d+e+f+g+h+i+j)	+ Rating of spouse's diabetes education
PSWD = + Q14 (10 if spouse, 1 else)	+ Spouse is who helps with diabetes the most

Note that the first 5 indicators might combine into one: "Doing diabetes-related activities together" = DQ10(a thru k)

Non-diabetic spouse

PSN ➔ PSDN, PSEN, PSTN, PSMN, PSAN, PSHN, PSFN, and PSKN,

where:

PSDN + NQ5(a+b+c)	+ New: Diet together

PSEN =	+NQ5(d+e)	+ New: Exercise together
PSTN =	+NQ5(f)	+ New: Testing together
PSMN =	+NQ5(g)	+ New: Medications together
PSAN =	+NQ5(h+i+j+k)	+ New: Medical appoints/education together
PSHN =	+ NQ10(a)	+ New: We think similarly
PSFN =	+ NQ10(b)	+ New: We feel similarly
PSKN =	+ NQ3(a+b+c+d+e+f+g+h+i+j)	+Rating of own diabetes education

Note that the first 5 indicators might combine into one: "Doing diabetes-related activities together" = NQ5(a thru k)

Couple

PSC ➔ the 18 PS__ indicators above

DIABETES MANAGEMENT SUCCESS: DM

Diabetic spouse

DM ➔ DME, DMD, DMM, DMT, DMB, and DMA,

where:

DME =	+ DQ47(a+b*2+c*3)–DQ18(f)–DQ19(f)	+ Exercise success
DMD =	+ DQ40+DQ44+DQ45+DQ46–DQ18(d+e) – DQ19(d+e+g)	+ Diet success
DMM =	– DQ18(c)–DQ19(c)	+ Medication success
DMT =	+ DQ4[no=1, yes =(DQ4a*DQ4b)]	+ Test and record blood sugar
DMB =	– DQ18(a+b+c+d+e+f+g)–DQ19(a+b+c+d+e+f+g+h) + DQ27	+ BS is well-controlled
DMA =	+ DQ28 + DQ29	+ Ability to manage diabetes, self-assessed

Non-diabetic spouse and couple diabetes management variables are indicated by the diabetic spouse indicators.

APPENDIX F

THE ILLNESS COGNITION QUESTIONNAIRE FOR CHRONIC DISEASES

(Evers et al., 2001)

Helplessness:

15. My illness frequently makes me feel helpless.

12. My illness limits me in everything that is important to me.

5. My illness controls my life.

1. Because of my illness, I miss the things I like to do most.

9. My illness prevents me from doing what I would really like to do.

7. My illness makes me feel useless at times.

Acceptance:

10. I have learned to accept the limitations imposed by my illness.

3. I have learned to live with my illness.

13. I can accept my illness well.

17. I can cope effectively with my illness.

2. I can handle the problems related to my illness.

14. I think I can handle the problems related to my illness, even if the illness gets worse.

Perceived Benefits:

4. Dealing with my illness has made me a stronger person.

6. I have learned a great deal from my illness.

18. My illness has taught me to enjoy the moment more.

8. My illness has made life more precious to me.

16. My illness has helped me realize what's important in life.

11. Looking back, I can see that my illness has also brought about some positive changes in my life.

Note: Cronbach's alpha for the scale in Ever and colleagues' (2001) study was .96 and .92 in Rheumatoid Arthritis and Multiple Sclerosis patients, respectively.

Evers, A.W.M., Kraaimaat, F. W., van Lankveld, W., Jongen, P. J. H., Jacobs, J. W. G., & Bijlsma, J. W. (2001). Beyond unfavorable thinking: The Illness Cognition Questionnaire for chronic diseases. *Journal of Consulting and Clinical Psychology,* Vol. 69, No. 6, 1026-1036.

APPENDIX G

RELATIONSHIP WITH DIABETES SCALE

The following are items from the Diabetes Care Profile (DCP) that are part of the measure of **RELATIONSHIP WITH DIABETES.**

From Section VI - Social and Personal Factors Scale of the DCP

		Never	Rarely	Sometimes	Often	Very Often	Don't Know
Q20.	How often has your diabetes kept you from doing your normal daily activities during the past **year** (e.g., couldn't: go to work, work around the house, go to school, visit friends)?	1	2	3	4	5	DK

Q21.	My diabetes and its treatment keep me from: (circle one answer for each line)	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
	a) having enough money.	1	2	3	4	5
	b) meeting school, work, household, and other responsibilities.	1	2	3	4	5
	c) going out or traveling as much as I want.	1	2	3	4	5
	d) being as active as I want.	1	2	3	4	5
	e) eating foods that I like.	1	2	3	4	5
	f) eating as much as I want.	1	2	3	4	5

	g) having good relationships with people.	1	2	3	4	5
	h) keeping a schedule I like (e.g., eating or sleeping late).	1	2	3	4	5
	i) spending time with my friends.	1	2	3	4	5
	j) having enough time alone.	1	2	3	4	5

		Strongly Disagree	**Disagree**	**Neutral**	**Agree**	**Strongly Agree**
Q22.	Paying for my diabetes treatment and supplies is a problem.	1	2	3	4	5
Q23.	Having diabetes makes my life difficult.	1	2	3	4	5

From Section VII - Attitudes toward Diabetes Scales of the DCP

Q24.		**Strongly Disagree**	**Disagree**	**Neutral**	**Agree**	**Strongly Agree**
a)	I am afraid of my diabetes.	1	2	3	4	5
b)	I find it hard to believe that I really have diabetes.	1	2	3	4	5
c)	I feel unhappy and depressed because of my diabetes.	1	2	3	4	5
d)	I feel satisfied with my life.	1	2	3	4	5
e)	I feel I'm not as good as others because of my diabetes.	1	2	3	4	5

f)	I can do just about anything I set out to do.	1	2	3	4	5
g)	I find it hard to do all the things I have to do for my diabetes.	1	2	3	4	5
h)	Diabetes doesn't affect my life at all.	1	2	3	4	5
i)	I am pretty well off, all things considered.	1	2	3	4	5
j)	Things are going very well for me right now.	1	2	3	4	5

Q25.	I am **able** to: (circle one answer for each line)	**Strongly Disagree**	**Disagree**	**Neutral**	**Agree**	**Strongly Agree**
	d) handle my feelings (fear, worry, anger) about my diabetes.	1	2	3	4	5

		Never	**Rarely**	**Sometimes**	**Often**	**Always**
Q30.	I feel dissatisfied with life because of my diabetes.	1	2	3	4	5
Q31.	I handle the feelings (fear, worry, anger) about my diabetes fairly well.	1	2	3	4	5

The following are items from the Appraisal of Diabetes (ADS) scale that are part of the measure of **RELATIONSHIP WITH DIABETES.**

Please circle <u>one</u> answer for each line						
Q49a	How upsetting is having diabetes for you?	Not At All	Slightly Upsetting	Moderately Upsetting	Very Upsetting	Extremely Upsetting
		1	2	3	4	5
Q49b	How much control over your diabetes do you have?	None At All	Slight Amount	Moderate Amount	Large Amount	Total Amount
		1	2	3	4	5
Q49c	How much uncertainty do you currently experience in your life as a result of being diabetic?	None at All	Slight Amount	Moderate Amount	Large Amount	Extremely Large Amount
		1	2	3	4	5
Q49d	How likely is your diabetes to worsen over the next several years?	Not Likely At All	Slightly Likely	Moderately Likely	Very Likely	Extremely Likely
		1	2	3	4	5
Q49e	Do you believe that achieving good diabetic control is due to your efforts as compared to factors which are beyond your control?	Totally Because of Me	Mostly Because of Me	Partly Because of Me And Partly Because of Other Factors	Mostly Because of Other Factors	Totally Because of Other Factors
Q49f	How effective are you in coping with your diabetes?	Not At All	Slightly Effective	Moderately Effective	Very Effective	Extremely Effective
Q49g	To what degree does your diabetes get in the way of your developing life goals?	Not At All	Slight Amount	Moderate Amount	Large Amount	Extremely Large Amount

The following are new items developed for this study that are part of the measure of **RELATIONSHIP WITH DIABETES.**

Thinking about yourself, and then your spouse, how strongly would you agree/disagree with the following statements? (circle one answer for each line)			
1 = Strongly Disagree 2 = Disagree **3 = Neutral** 4 = Agree **5 = Strongly Agree**			
Q32.		**I feel**	**My spouse feels**
a.	Angry	1 2 3 4 5	1 2 3 4 5
b.	Fearful	1 2 3 4 5	1 2 3 4 5
c.	Hopeless	1 2 3 4 5	1 2 3 4 5
d.	Overwhelmed	1 2 3 4 5	1 2 3 4 5
e.	Hatred	1 2 3 4 5	1 2 3 4 5
f.	Sad	1 2 3 4 5	1 2 3 4 5
g.	Hopeful	1 2 3 4 5	1 2 3 4 5
h.	Embarrassed	1 2 3 4 5	1 2 3 4 5
i.	Guilt	1 2 3 4 5	1 2 3 4 5
j.	Sense of loss	1 2 3 4 5	1 2 3 4 5
k.	Confident	1 2 3 4 5	1 2 3 4 5

Some couples think or feel very similarly toward diabetes, while others do not. Regarding yourself and your spouse, how strongly do you agree/disagree with the following statements? (circle one answer for each line)						
Q34.		**Strongly Disagree**	**Disagree**	**Neutral**	**Agree**	**Strongly Agree**
	a) My spouse and I **<u>feel</u>** similarly about having diabetes in our lives.	1	2	3	4	5
	b) My spouse and I **<u>think</u>** similarly about having diabetes in our lives.	1	2	3	4	5

Thinking about yourself, and then your spouse, how strongly would you agree/disagree with the following statements? (circle one answer for each line)			
1 = Strongly Disagree 2 = Disagree **3 = Neutral** 4 = Agree **5 = Strongly Agree**			
Q35.		**You**	**Your Spouse**
a.	In some ways are grateful that diabetes has come into our lives	1 2 3 4 5	1 2 3 4 5
b.	Accept diabetes matter-of-factly, without a lot of strong emotions	1 2 3 4 5	1 2 3 4 5
c.	Worry quite a lot about the diabetes	1 2 3 4 5	1 2 3 4 5
d.	Avoid thinking about the diabetes as much as possible	1 2 3 4 5	1 2 3 4 5
e.	See living with diabetes primarily as a practical matter that we deal with	1 2 3 4 5	1 2 3 4 5
f.	Diabetes does not have a major impact on us	1 2 3 4 5	1 2 3 4 5

Some people find that having diabetes causes them to place more value on certain things in their lives. Thinking about yourself, and then your spouse, please circle the answer on each line that best represents how much each of you would agree/disagree with the following statements.			
1 = Strongly Disagree 2 = Disagree **3 = Neutral** 4 = Agree **5 = Strongly Agree**			
Having diabetes has made us <u>place more value</u> on…			
Q37.		**You**	**Your Spouse**
a.	the important things in our lives	1 2 3 4 5	1 2 3 4 5
b.	our marriage relationship	1 2 3 4 5	1 2 3 4 5
c.	our relationship with our children	1 2 3 4 5	1 2 3 4 5
d.	our relationships with other family members	1 2 3 4 5	1 2 3 4 5
e.	our health	1 2 3 4 5	1 2 3 4 5
f.	How we choose to spend our time	1 2 3 4 5	1 2 3 4 5

Some people find that having diabetes causes them to place more value on certain things in their lives. Thinking about yourself, and then your spouse, please circle the answer on each line that best represents how much each of you would agree/disagree with the following statements.			
1 = Strongly Disagree 2 = Disagree **3 = Neutral** 4 = Agree **5 = Strongly Agree**			
Having diabetes has made us <u>focus more</u> on…			
Q38.		**You**	**Your Spouse**
a.	the important things in our lives	1 2 3 4 5	1 2 3 4 5
b.	our marriage relationship	1 2 3 4 5	1 2 3 4 5
c.	our relationship with our children	1 2 3 4 5	1 2 3 4 5
d.	our relationships with other family members	1 2 3 4 5	1 2 3 4 5
e.	our health	1 2 3 4 5	1 2 3 4 5
f.	How we choose to spend our time	1 2 3 4 5	1 2 3 4 5

APPENDIX H

PARTNERING SUPPORT SCALE

The following are items from the Diabetes Care Profile (DCP) that are part of the measure of **PARTNERING SUPPORT**.

From Section III – Education / Advice Received

Q7. Have you ever received diabetes education? (for example: attended a series of classes or series of meetings with a diabetes educator) (check one box)

☐1 No ☐2 Yes ☐3 Not Sure

Q8.	How do you rate **YOUR** understanding of: (circle one answer for each line)	**Poor**		**Good**	**Excellent**	
	a) diet and blood sugar control	1	2	3	4	5
	b) weight management	1	2	3	4	5
	c) exercise	1	2	3	4	5
	d) use of insulin/pills	1	2	3	4	5
	e) sugar testing	1	2	3	4	5
	f) foot care	1	2	3	4	5
	g) complications of diabetes	1	2	3	4	5
	h) eye care	1	2	3	4	5
	i) combining diabetes medication with other medications	1	2	3	4	5
	j) alcohol use and diabetes	1	2	3	4	5

Q9.	How do you rate your **SPOUSE'S** understanding of: (circle one answer for each line)	**Poor**		**Good**	**Excellent**	
	a) diet and blood sugar control	1	2	3	4	5

	b) weight management	1	2	3	4	5
	c) exercise	1	2	3	4	5
	d) use of insulin/pills	1	2	3	4	5
	e) sugar testing	1	2	3	4	5
	f) foot care	1	2	3	4	5
	g) complications of diabetes	1	2	3	4	5
	h) eye care	1	2	3	4	5
	i) combining diabetes medication with other medications	1	2	3	4	5
	j) alcohol use and diabetes	1	2	3	4	5

Q14. Who helps you the **most** in caring for your diabetes? (check only one box)

- ☐ 1 Spouse
- ☐ 2 Other family members
- ☐ 3 Friends
- ☐ 4 Paid helper
- ☐ 5 Doctor
- ☐ 6 Nurse
- ☐ 7 Case manager
- ☐ 8 Other health care professional
- ☐ 9 No one

The following are new items developed for this study that are part of the measure of **PARTNERING SUPPORT**.

Q10. How often do you and your spouse do the following diabetes-related activities **together**?

(circle one answer for each line)

	None of the Time	**Little of the Time**	**Some of the Time**	**Most of the Time**	**All of the Time**
a) planning a diabetes-healthy diet	1	2	3	4	5

b) preparing a diabetes-healthy diet	1	2	3	4	5
c) eating a diabetes-healthy diet	1	2	3	4	5
d) exercising	1	2	3	4	5
e) coordinating our workouts	1	2	3	4	5
f) ensuring that testing is done as prescribed	1	2	3	4	5
g) ensuring that medications are taken as prescribed	1	2	3	4	5
h) attending diabetes classes	1	2	3	4	5
i) reading about diabetes	1	2	3	4	5
j) going to medical appointments	1	2	3	4	5
k) participating in diabetes groups	1	2	3	4	5

Some couples think or feel very similarly toward diabetes, while others do not. Regarding yourself and your spouse, how strongly do you agree/disagree with the following statements? (circle one answer for each line)

Q34.		**Strongly Disagree**	**Disagree**	**Neutral**	**Agree**	**Strongly Agree**
	b) My spouse and I **feel** similarly about having diabetes in our lives.	1	2	3	4	5
	b) My spouse and I **think** similarly about having diabetes in our lives.	1	2	3	4	5

APPENDIX I

DIABETES MANAGEMENT SUCCESS SCALE

The following are items from the Diabetes Care Profile (DCP) that are part of the measure of **DIABETES MANAGEMENT SUCCESS**.

From Section I - Demographics

Q4. Do you test your blood sugar? (check one box)

☐1 No ☐2 Yes ⟶ Q4a. How many days a week do you test your blood sugar? _____ (days / week)

Q4b. On days that you test, how many times do you test your blood sugar? _____ (times / day)

Q4c. Do you keep a record of your blood sugar test results? (check one box)

☐1 No ☐2 Yes ☐3 Only Unusual Values

Section V - Control Problems

Q18.	During the past year, how often did your blood sugar become **too high** because: (circle one answer for each line)	**Never**	**Rarely**	**Sometimes**	**Often**	**Very Often**	**Don't Know**
	c) you took the wrong amount of medicine?	1	2	3	4	5	DK
	d) you ate the wrong types of food?	1	2	3	4	5	DK
	e) you ate too much food?	1	2	3	4	5	DK
	f) you had less physical activity than usual?	1	2	3	4	5	DK

Q19.	During the past year, how often did your blood sugar become **too low** because: (circle one answer for each line)	**Never**	**Rarely**	**Some-times**	**Often**	**Very Often**	**Don't Know**
	c) you took the wrong amount of medicine?	1	2	3	4	5	DK
	d) you ate the wrong types of food?	1	2	3	4	5	DK
	e) you ate too little food?	1	2	3	4	5	DK
	f) you had more physical activity than usual?	1	2	3	4	5	DK
	g) you waited too long to eat or skipped a meal?	1	2	3	4	5	DK

Section VII - Attitudes toward Diabetes Scales

Q25.	I am **able** to: (circle one answer for each line)	**Strongly Disagree**	**Disagree**	**Neutral**	**Agree**	**Strongly Agree**
	a) keep my blood sugar in good control.	1	2	3	4	5
	b) keep my weight under control.	1	2	3	4	5
	c) do the things I need to do for my diabetes (diet, medicine, exercise, etc.).	1	2	3	4	5

		Never	**Rarely**	**Sometimes**	**Often**	**Always**	**Don't Know**
Q27.	I keep my blood sugar in good control.	1	2	3	4	5	DK

		Never	**Rarely**	**Sometimes**	**Often**	**Always**
Q28.	I keep my weight under control.	1	2	3	4	5

Q29.	I do the things I need to do for my diabetes (diet, medicine, exercise, etc.).	1	2	3	4	5

Section VIII - Diet Adherence Scale

Q39. Has any health care provider or nurse told you to follow a meal plan or diet? ☐ 1 No ☐ 2 Yes ☐ 3 Not sure

		Never		Sometimes		Always
Q40.	How often do you follow a meal plan or diet?	1	2	3	4	5

Q41. Have you been told to follow a schedule for your meals and snacks? ☐ 1 No ☐ 2 Yes

Q42. Have you been told to weigh or measure your food? ☐ 1 No ☐ 2 Yes

Q43. Have you been told to use exchange lists or food group lists to plan your meals? ☐ 1 No ☐ 2 Yes

		Never		**Sometimes**		**Always**
Q44.	How often do you follow the schedule for your meals and snacks?	1	2	3	4	5
Q45.	How often do you weigh or measure your food?	1	2	3	4	5
Q46.	How often do you (or the person who cooks your food) use the exchange lists or food group lists to plan your meals?	1	2	3	4	5

Section XII - Exercise Management Practice Scales

Q47	How often do you exercise or do activities that cause:	**Never**	**Once a week**	**2-3 times a week**	**4-5 times a week**	**Almost everyday**
	a) a light sweat (e.g., light work around the house)?	1	2	3	4	5
	b) a moderate sweat (e.g., walk outside your home or yard such as for fun or exercise, walking the dog) ?	1	2	3	4	5
	c) a heavy sweat (e.g., recreational activities such as dancing, bicycling or exercise bike, swimming, skating, or stair climbing)?	1	2	3	4	5

APPENDIX J

APPRAISAL OF DIABETES SCALE (ADS)

As in the Diabetic Spouse Questionnaire: Section IX – Expressed Emotion

People differ in their thoughts and feelings about having diabetes. We would like to know how you feel about having diabetes.

For the following questions, please circle the answer to each question which is closest to the way *you* feel. Please give your honest feelings- we are interested in how you feel, not what your doctor or family may think.

Please circle one answer for each line:						
Q49a	How upsetting is having diabetes for you?	Not At All	Slightly Upsetting	Moderately Upsetting	Very Upsetting	Extremely Upsetting
		1	2	3	4	5
Q49b	How much control over your diabetes do you have?	None At All	Slight Amount	Moderate Amount	Large Amount	Total Amount
		1	2	3	4	5
Q49c	How much uncertainty do you currently experience in your life as a result of being diabetic?	None at All	Slight Amount	Moderate Amount	Large Amount	Extremely Large Amount
		1	2	3	4	5
Q49d	How likely is your diabetes to worsen over the next several years?	Not Likely At All	Slightly Likely	Moderately Likely	Very Likely	Extremely Likely
		1	2	3	4	5
Q49e	Do you believe that achieving good diabetic control is due to your efforts as compared to factors which are beyond your control?	Totally Because Of Me	Mostly Because Of Me	Partly Because Of Me And Partly Because Of Other Factors	Mostly Because Of Other Factors	Totally Because Of Other Factors

		1	2	3	4	5
Q49f	How effective are you in coping with your diabetes?	Not At All	Slightly Effective	Moderately Effective	Very Effective	Extremely Effective
		1	2	3	4	5
Q49g	To what degree does your diabetes get in the way of your developing life goals?	Not At All	Slight Amount	Moderate Amount	Large Amount	Extremely Large Amount
		1	2	3	4	5

APPENDIX K

DIABETES CARE PROFILE (DCP)

ID# _____

Name _____

Today's Date _____

Diabetes Care Profile

Michigan Diabetes
Research and Training Center
DCP2.0

Section I - Demographics

Please answer each of the following questions by filling in the blanks with the correct answers or by choosing the single best answer.

Note: For this survey, a Health Care Provider refers to a doctor, nurse practitioner, or physician assistant.

Q1. Age: __ __ years old

Q2. Birth date: __ __ /__ __ /__ __
(Month / Day / Year)

Q3. Zip Code: __ __ __ __ __

Q4. Sex: ☐1 Male ☐2 Female

Q5. What year were you first told you had diabetes? (Please enter the year) __ __ __ __

Q6. What is your marital status? (check one box)

- ☐1 Never married
- ☐2 Married
- ☐3 Separated/Divorced
- ☐4 Widowed

Q7. What is your ethnic origin/race? (check one box)

- ☐1 White
- ☐2 Black
- ☐3 Hispanic
- ☐4 Native American
- ☐5 Asian or Pacific Islander
- ☐6 Arabic
- ☐7 Other _____

Q8. Where do you live most of the year? (check one box)

- ☐1 Your home, apartment or condo
- ☐2 Senior citizen apartment/condo
- ☐3 Home of a relative/friend
- ☐4 Retirement home
- ☐5 Adult foster care
- ☐6 Nursing home
- ☐7 Other _____

Q9. How many people live with you? (check one box)

- ☐0 I live alone
- ☐1 1 person
- ☐2 2 people
- ☐3 3 people
- ☐4 4 people
- ☐5 5 or more

Q10. How much schooling have you had? (Years of formal schooling completed) (check one box)

- ☐1 8 grades or less
- ☐2 Some high school
- ☐3 High school graduate or GED
- ☐4 Some college or technical school
- ☐5 College graduate (bachelor's degree)
- ☐6 Graduate degree

Q11. Which of the following best describes your current employment status? (check one box)

- ☐ 1 Working full-time, 35 hours or more a week
- ☐ 2 Working part-time, less than 35 hours a week
- ☐ 3 Unemployed or laid off and looking for work
- ☐ 4 Unemployed and not looking for work
- ☐ 5 Homemaker
- ☐ 6 In school
- ☐ 7 Retired
- ☐ 8 Disabled, not able to work
- ☐ 9 Something else? (Please specify): _____

Q12. How would you describe the insurance plan(s) you have had in the past 12 months?
(check all that apply)

- ☐ 1 An individual plan – the member pays for the plan premium
- ☐ 2 A group plan through an employer, union, etc. – the employer pays all or part of the plan premium
- ☐ 3 U.S. Governmental Health Plan (e.g., Military, CHAMPUS, VA)
- ☐ 4 Medicaid
- ☐ 5 Medicare
- ☐ 6 I have not had an insurance plan in the past 12 months

Q13. What type(s) of insurance plans have you had in the past 12 months? (check all that apply)

- ☐ 1 Indemnity or fee-for-service plan (i.e., you choose which health care provider you see for care without financial penalty)
- ☐ 2 Health Maintenance Organization (HMO) (i.e., you must have a primary care provider who must refer you to specialty care if needed)
- ☐ 3 Preferred Provider Organization (PPO) (i.e., you have lower co-payments when you see a preferred provider within the network, but you can see a provider out-of-network for a higher co-payment)
- ☐ 4 Point of Service (POS) (i.e., you must have a primary care provider; you have the option to self-refer to an in-network specialist, or you can see an out-of-network specialist with a higher co-payment)
- ☐ 5 Other (please specify): _____
- ☐ 6 I have not had an insurance plan in the past 12 months.

Q14. Do you test your blood sugar? (check one box)

☐1 No ☐2 Yes → Q14a. How many days a week do you test your blood sugar?

_____ (days / week)

↓

Q14b. On days that you test, how many times do you test your blood sugar?

_____ (times / day)

↓

Q14c. Do you keep a record of your blood sugar test results? (check one box)

☐1 No ☐2 Yes ☐3 Only Unusual Values

Section II – Health Status

Q1. In general, would you say your health is: (check one box)

☐1	☐2	☐3	☐4	☐5
Excellent	Very Good	Good	Fair	Poor

Q2. These questions ask about how you feel and how things have been with you **during the past 4 weeks**. For each question, please give the one answer that comes closest to the way you have been feeling.

How much of the time **during the past 4 weeks**:
(circle one answer for each line)

	All of the Time	**Most of the Time**	**A Good Bit of the Time**	**Some of the Time**	**A Little of the Time**	**None of the Time**
A. Have you felt **calm and peaceful**?	1	2	3	4	5	6
B. Did you have a **lot of energy**?	1	2	3	4	5	6
C. Have you felt **downhearted and blue**?	1	2	3	4	5	6

Section III – Education / Advice Received

Q1. Has your health care provider or nurse ever told you to take special care of your feet?

(check one box)

☐1 No ☐2 Yes ☐3 Not Sure

Q2. Has your health care provider or nurse ever told you to follow an exercise program?
(check one box)

☐1 No ☐2 Yes ☐3 Not Sure

Q3. Has your health care provider or nurse ever told you to follow a meal plan or diet?
(check one box)

☐1 No ☐2 Yes ☐3 Not Sure

Q4. Have you ever received diabetes education? (for example: attended a series of classes or series of meetings with a diabetes educator) (check one box)

☐1 No ☐2 Yes ☐3 Not Sure

Section IV - Understanding

Q1. How do you rate your understanding of: (circle one answer for each line)	**Poor**		**Good**		**Excellent**
a) overall diabetes care	1	2	3	4	5
b) coping with stress	1	2	3	4	5
c) diet for blood sugar control	1	2	3	4	5
d) the role of exercise in diabetes care	1	2	3	4	5
e) medications you are taking	1	2	3	4	5
f) how to use the results of blood sugar monitoring	1	2	3	4	5
g) how diet, exercise, and medicines affect blood sugar levels	1	2	3	4	5
h) prevention and treatment of high blood sugar	1	2	3	4	5
i) prevention and treatment of low blood sugar	1	2	3	4	5
j) prevention of long-term complications of diabetes	1	2	3	4	5
k) foot care	1	2	3	4	5
l) benefits of improving blood sugar control	1	2	3	4	5
m) pregnancy and diabetes	1	2	3	4	5

Section V – Support

Q1. I **want** a lot of help and support from my family or friends in:
(circle one answer for each line)

	Strongly Disagree	**Somewhat Disagree**	**Neutral**	**Somewhat Agree**	**Strongly Agree**	**Does Not Apply**
a) following my meal plan.	1	2	3	4	5	N/A
b) taking my medicine.	1	2	3	4	5	N/A
c) taking care of my feet.	1	2	3	4	5	N/A
d) getting enough physical activity.	1	2	3	4	5	N/A
e) testing my sugar.	1	2	3	4	5	N/A
f) handling my feelings about diabetes.	1	2	3	4	5	N/A

Q2. My family or friends help and support me a lot to:
(circle one answer for each line)

	Strongly Disagree	**Somewhat Disagree**	**Neutral**	**Somewhat Agree**	**Strongly Agree**	**Does Not Apply**
a) follow my meal plan.	1	2	3	4	5	N/A
b) take my medicine.	1	2	3	4	5	N/A
c) take care of my feet.	1	2	3	4	5	N/A
d) get enough physical activity.	1	2	3	4	5	N/A
e) test my sugar.	1	2	3	4	5	N/A
f) handle my feelings about diabetes.	1	2	3	4	5	N/A

Q3.My family or friends: (circle one answer for each line)

	Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree
a) accept me and my diabetes.	1	2	3	4	5
b) feel uncomfortable about me because of my diabetes.	1	2	3	4	5
c) encourage or reassure me about my diabetes.	1	2	3	4	5
d) discourage or upset me about my diabetes.	1	2	3	4	5
e) listen to me when I want to talk about my diabetes.	1	2	3	4	5
f) nag me about diabetes.	1	2	3	4	5

Q4. Who helps you the **most** in caring for your diabetes? (check only one box)

- ☐$_1$ Spouse
- ☐$_2$ Other family members
- ☐$_3$ Friends
- ☐$_4$ Paid helper
- ☐$_5$ Doctor
- ☐$_6$ Nurse
- ☐$_7$ Case manager
- ☐$_8$ Other health care professional
- ☐$_9$ No one

Section VI - Control Problems Scale

For the following questions, please check the appropriate response.

Q1.How many **times** in the last **month** have you had a **low blood sugar** (glucose) reaction with symptoms such as sweating, weakness, anxiety, trembling, hunger or headache?

- ☐ 1 0 times
- ☐ 2 1-3 times
- ☐ 3 4-6 times
- ☐ 4 7-12 times
- ☐ 5 More than 12 times
- ☐ 6 Don't know

Q2.How many **times** in the last **year** have you had **severe low blood sugar** reactions such as passing out or needing help to treat the reaction?

- ☐ 1 0 times
- ☐ 2 1-3 times
- ☐ 3 4-6 times
- ☐ 4 7-12 times
- ☐ 5 More than 12 times
- ☐ 6 Don't know

Q3.How many **days** in the last **month** have you had **high blood sugar** with symptoms such as thirst, dry mouth and skin, increased sugar in the urine, less appetite, nausea, or fatigue?

☐$_1$ 0 days
☐$_2$ 1-3 days
☐$_3$ 4-6 days
☐$_4$ 7-12 days
☐$_5$ More than 12 days
☐$_6$ Don’t know

Q4.How many **days** in the last **month** have you had **ketones** in your urine?

☐$_1$ 0 days
☐$_2$ 1-3 days
☐$_3$ 4-6 days
☐$_4$ 7-12 days
☐$_5$ More than 12 days
☐$_6$ Don’t test

Q5. During the past year, how often did your blood sugar become **too high** because: (circle one answer for each line)	**Never**		**Sometimes**		**Often**	**Don't Know**
a) you were sick or had an infection?	1	2	3	4	5	DK
b) you were upset or angry?	1	2	3	4	5	DK
c) you took the wrong amount of medicine?	1	2	3	4	5	DK
d) you ate the wrong types of food?	1	2	3	4	5	DK
e) you ate too much food?	1	2	3	4	5	DK
f) you had less physical activity than usual?	1	2	3	4	5	DK
g) you were feeling stressed?	1	2	3	4	5	DK

Q6. During the past year, how often did your blood sugar become **too low** because: (circle one answer for each line)	**Never**		**Sometimes**		**Often**	**Don't Know**
a) you were sick or had an infection?	1	2	3	4	5	DK
b) you were upset or angry?	1	2	3	4	5	DK
c) you took the wrong amount of medicine?	1	2	3	4	5	DK
d) you ate the wrong types of food?	1	2	3	4	5	DK
e) you ate too little food?	1	2	3	4	5	DK
f) you had more physical activity than usual?	1	2	3	4	5	DK
g) you waited too long to eat or skipped a meal?	1	2	3	4	5	DK
h) you were feeling stressed?	1	2	3	4	5	DK

Section VII - Social and Personal Factors Scale

For the following questions, please circle the appropriate response.

	Never		Some times		Often	Don't Know
Q1. How often has your diabetes kept you from doing your normal daily activities during the past **year** (e.g., couldn't: go to work, work around the house, go to school, visit friends)?	1	2	3	4	5	DK

Q2. My diabetes and its treatment keep me from: (circle one answer for each line)	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
a) having enough money.	1	2	3	4	5
b) meeting school, work, household, and other responsibilities.	1	2	3	4	5
c) going out or traveling as much as I want.	1	2	3	4	5
d) being as active as I want.	1	2	3	4	5
e) eating foods that I like.	1	2	3	4	5
f) eating as much as I want.	1	2	3	4	5
g) having good relationships with people.	1	2	3	4	5
h) keeping a schedule I like (e.g., eating or sleeping late).	1	2	3	4	5
i) spending time with my friends.	1	2	3	4	5
j) having enough time alone.	1	2	3	4	5

		Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
Q3.	Paying for my diabetes treatment and supplies is a problem.	1	2	3	4	5

		Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
Q4.	Having diabetes makes my life difficult.	1	2	3	4	5

Section VIII - Attitudes Toward Diabetes Scales

(Positive Attitude, Negative Attitude, Care Ability, Importance of Care, and Self-Care Adherence)

For the following questions, please circle the appropriate response.
(circle one answer for each line)

		Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
Q1.	I am afraid of my diabetes.	1	2	3	4	5
Q2.	I find it hard to believe that I really have diabetes.	1	2	3	4	5
Q3.	I feel unhappy and depressed because of my diabetes.	1	2	3	4	5
Q4.	I feel satisfied with my life.	1	2	3	4	5
Q5.	I feel I'm not as good as others because of my diabetes.	1	2	3	4	5
Q6.	I can do just about anything I set out to do.	1	2	3	4	5
Q7.	I find it hard to do all the things I have to do for my diabetes.	1	2	3	4	5
Q8.	Diabetes doesn't affect my life at all.	1	2	3	4	5
Q9.	I am pretty well off, all things considered.	1	2	3	4	5
Q10.	Things are going very well for me right now.	1	2	3	4	5

Q11.	I am **able** to: (circle one answer for each line)	**Strongly Disagree**	**Disagree**	**Neutral**	**Agree**	**Strongly Agree**
	c) keep my blood sugar in good control.	1	2	3	4	5
	d) keep my weight under control.	1	2	3	4	5
	c) do the things I need to do for my diabetes (diet, medicine, exercise, etc.).	1	2	3	4	5
	d) handle my feelings (fear, worry, anger) about my diabetes.	1	2	3	4	5

Q12.	I think it is **important** for me to: (circle one answer for each line)	**Strongly Disagree**	**Disagree**	**Neutral**	**Agree**	**Strongly Agree**
	c) keep my blood sugar in good control.	1	2	3	4	5
	b) keep my weight under control.	1	2	3	4	5
	c) do the things I need to do for my diabetes (diet, medicine, exercise, etc.).	1	2	3	4	5
	d) handle my feelings (fear, worry, anger) about my diabetes.	1	2	3	4	5

		Never		**Sometimes**		**Always**	**Don't Know**
Q13.	I keep my blood sugar in good control.	1	2	3	4	5	DK

		Never		Sometimes		Always
Q14.	I keep my weight under control.	1	2	3	4	5
Q15.	I do the things I need to do for my diabetes (diet, medicine, exercise, etc.).	1	2	3	4	5
Q16.	I feel dissatisfied with life because of my diabetes.	1	2	3	4	5
Q17.	I handle the feelings (fear, worry, anger) about my diabetes fairly well.	1	2	3	4	5

Section IX - Diet Adherence Scale

Q1. Has any health care provider or nurse told you to follow a meal plan or diet? ☐ 1 No ☐ 2 Yes ☐ 3 Not sure

		Never		Sometimes		Always
Q2.	How often do you follow a meal plan or diet?	1	2	3	4	5

Q3. Have you been told to follow a schedule for your meals and snacks? ☐ 1 No ☐ 2 Yes

Q4. Have you been told to weigh or measure your food? ☐ 1 No ☐ 2 Yes

Q5. Have you been told to use exchange lists or food group lists to plan your meals? ☐ 1 No ☐ 2 Yes

		Never		**Sometimes**		**Always**
Q6.	How often do you follow the schedule for your meals and snacks?	1	2	3	4	5
Q7.	How often do you weigh or measure your food?	1	2	3	4	5
Q8.	How often do you (or the person who cooks your food) use the exchange lists or food group lists to plan your meals?	1	2	3	4	5

Section X - Long-Term Care Benefits Scale

For the following questions, please circle the appropriate response.
(circle one answer for each line)

Q1.	Taking the best possible care of diabetes will delay or prevent:	**Strongly Disagree**	**Disagree**	**Neutral**	**Agree**	**Strongly Agree**
	a) eye problems	1	2	3	4	5
	b) kidney problems	1	2	3	4	5
	c) foot problems	1	2	3	4	5
	d) hardening of the arteries	1	2	3	4	5
	e) heart disease	1	2	3	4	5

Section XI - Exercise Barriers Scale

For the following questions, please circle the appropriate response.
(circle one answer for each line)

Q1.	How often do you have trouble getting enough exercise because:	**Rarely**		**Sometimes**		**Often**
	a) it takes too much effort?	1	2	3	4	5
	b) you don't believe it is useful?	1	2	3	4	5
	c) you don't like to do it?	1	2	3	4	5
	d) you have a health problem?	1	2	3	4	5
	e) it makes your diabetes more difficult to control?	1	2	3	4	5

Section XII - Monitoring Barriers and Understanding Management Practice Scales

Q1. How many days a week have you been told to test:

a) urine sugar? _____ (days per week) ☐ 9 Not told to test

b) blood sugar? _____ (days per week) ☐ 9 Not told to test

If you **do not** test for sugar, skip Question No. 2.

For the following questions, please circle the appropriate response.
(circle one answer for each line)

Q2. When you **don't** test for sugar as often as you have been told, how often is it because:	**Rarely**		**Sometimes**		**Often**
a) you forgot?	1	2	3	4	5
b) you don't believe it is useful?	1	2	3	4	5
c) the time or place wasn't right?	1	2	3	4	5
d) you don't like to do it?	1	2	3	4	5
e) you ran out of test materials?	1	2	3	4	5
f) it costs too much?	1	2	3	4	5
g) it's too much trouble?	1	2	3	4	5
h) it's hard to read the test results?	1	2	3	4	5
i) you can't do it by yourself?	1	2	3	4	5
j) your levels don’t change very often?	1	2	3	4	5
k) it hurts to prick your finger?	1	2	3	4	5

Q3. Have you ever received diabetes education? ☐ 1 No ☐ 2 Yes

If No, skip Question No. 4

For the following questions, please circle the appropriate response.
(circle one answer for each line)

Q4.	How do you rate your understanding of:	Poor		Good		Excellent
	a) diet and blood sugar control	1	2	3	4	5
	b) weight management	1	2	3	4	5
	c) exercise	1	2	3	4	5
	d) use of insulin/pills	1	2	3	4	5
	e) sugar testing	1	2	3	4	5
	f) foot care	1	2	3	4	5
	g) complications of diabetes	1	2	3	4	5
	h) eye care	1	2	3	4	5
	i) combining diabetes medication with other medications	1	2	3	4	5
	j) alcohol use and diabetes	1	2	3	4	5

Addition to Section I (Demographics) - Income Question

Q5. Which of the categories best describes your total annual <u>combined</u> household income from <u>all</u> sources? (check one box)

- ☐ 01 Less than $5,000
- ☐ 02 $5,000 to $9,999
- ☐ 03 $10,000 to $14,999
- ☐ 04 $15,000 to $19,999
- ☐ 05 $20,000 to $29,999
- ☐ 06 $30,000 to $39,999
- ☐ 07 $40,000 to $49,999
- ☐ 08 $50,000 to $59,999
- ☐ 09 $60,000 to $69,999
- ☐ 10 $70,000 and over

Addition to Section I (Demographics) - Occupation Question (from NHANES III)

Q15/Q16. During the past 2 weeks, did you work at any time at a job or business, not counting work around the house?

☐1 No ☐2 Yes

Q15a/Q16a. What kind of work were you doing?
(For example: electrical engineer, stock clerk, typist, farmer.)

☐01 Executive, administrators, and managers	☐21 Miscellaneous food preparation and service occupations
☐02 Management related occupations	☐22 Health service occupations
☐03 Engineers and scientists	☐23 Cleaning and building service occupations
☐04 Health diagnosing, assessment, and treating occupations	☐24 Personal service occupations
☐05 Teachers	☐25 Farm operators, managers, and supervisors
☐06 Writers, artists, entertainers, and athletes	☐26 Farm and nursery workers
☐07 Other professional specialty occupations	☐27 Related agricultural, forestry, and fishing occupations
☐08 Technicians and related support occupations	☐28 Vehicle and mobile equipment mechanics and repairers
☐09 Supervisors and proprietors, sales occupations	☐29 Other mechanics and repairers
☐10 Sales representatives, finance, business, and commodities except retail	☐30 Construction trades
☐11 Sales workers, retail and personal business	☐31 Extractive and precision production occupations
☐12 Secretaries, stenographers, and typists	☐32 Textile, apparel, and furnishings machine operators
☐13 Information clerks	☐33 Machine operators, assorted materials
☐14 Records processing occupations	☐34 Fabricators, assemblers, inspectors, and samplers
☐15 Material recording, scheduling, and distributing clerks	☐35 Motor vehicle operators
☐16 Miscellaneous administrative support occupations	☐36 Other transportation and material moving occupations
☐17 Private household occupations	☐37 Construction laborers
☐18 Protective service occupations	☐38 Laborers, except construction
☐19 Waiters and waitresses	☐39 Freight, stock, and material movers

☐ 20 Cooks	☐ 40 Other handlers, equipment cleaners, and handlers
	☐ 41 Don’t Know

Replace Section II (Health Status) with SF-12

Q1. In general, would you say your health is: (check one box)

☐1	☐2	☐3	☐4	☐5
Excellent	Very Good	Good	Fair	Poor

The following items are about activities you might do during a typical day. **Does your health now limit you** in these activities? If so, how much? (check one box for each line)

		Yes, Limited a Lot	Yes, Limited a Little	No, Not limited at all
Q2.	**Moderate activities**, such as moving a table, pushing a, vacuum cleaner bowling, or playing golf	☐1	☐2	☐3
Q3.	Climbing **several** flights of stairs	☐1	☐2	☐3

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities **as a result of your physical health**? (check one box for each line)

		No	Yes
Q4.	**Accomplished less** than you would like	☐1	☐2
Q5.	Were limited in the **kind** of work or other activities	☐1	☐2

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities **as a result of any emotional problems** (such as feeling depressed or anxious)? (check one box for each line)

		No	Yes
Q6.	**Accomplished less** than you would like	☐1	☐2
Q7.	Didn't do work or other activities as **carefully** as usual	☐1	☐2

Q8. During the **past 4 weeks**, how much did **pain** interfere with your normal work (including both work outside the home and housework)? (check one box)

☐1	☐2	☐3	☐4	☐5
Not at all	A little bit	Moderately	Quite a bit	Extremely

These questions are about how you feel and how things have been with you **during the past 4 weeks**. For each question please give the one answer that comes closest to the way you have been feeling.

How much of the time **during the past 4 weeks:** (circle one answer for each line)

	All of the Time	Most of the Time	A Good Bit of the Time	Some of the Time	A Little of the Time	None of the Time
Q9. Have you felt **calm and peaceful**?	1	2	3	4	5	6
Q10. Did you have a **lot of energy**?	1	2	3	4	5	6
Q11. Have you felt **downhearted and blue**?	1	2	3	4	5	6

Q12. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)? (check one box)

☐1	☐2	☐3	☐4	☐5
All of the time	Most of the time	Some of the time	A little of time	None of the time

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Replace Section II (Health Status) with SF-36

Q1. In general, would you say your health is: (check one box)

☐1	☐2	☐3	☐4	☐5
Excellent	Very Good	Good	Fair	Poor

Q2. Compared to one year ago, how would you rate your health in general now? (check one box)

- ☐1 Much better now than 1 year ago
- ☐2 Somewhat better now than 1 year ago
- ☐3 About the same
- ☐4 Somewhat worse now than 1 year ago
- ☐5 Much worse now than 1 year ago

Q3. The following questions are about activities you might do during a typical day. Does **your health now limit you** in these activities? If so, how much? (circle one answer on each line)

		Yes, Limited A Lot	Yes, Limited A Little	No, Not Limited At All
A.	Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports?	1	2	3
B.	Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf?	1	2	3
C.	Lifting or carrying groceries?	1	2	3
D.	Climbing several flights of stairs?	1	2	3
E.	Climbing one flight of stairs?	1	2	3
F.	Bending, kneeling, or stooping?	1	2	3
G.	Walking more than a mile?	1	2	3
H.	Walking several blocks?	1	2	3
I.	Walking one block?	1	2	3
J.	Bathing or dressing yourself?	1	2	3

Q4. During the **past 4 weeks**, have you had any of the following problems with your work or other regular daily activities **as a result of your physical health**?
(circle one answer on each line)

	Yes	**No**
A. Cut down the amount of time you spent on work or other activities	1	2
B. Accomplished less than you would like	1	2
C. Were limited in the kind of work or other activities	1	2
D. Had difficulty performing the work or other activities (for example, it took extra effort)	1	2

Q5. During the **past 4 weeks**, have you had any of the following problems with your work or other regular daily activities **as a result of any emotional problems** (such as feeling depressed or anxious)? (circle one answer on each line)

		Yes	No
A.	Cut down the <u>amount of time</u> you spent on work or other activities	1	2
B.	<u>Accomplished less</u> than you would like	1	2
C.	Didn't do work or other activities as <u>carefully</u> as usual	1	2

Q6. During the **past 4 weeks**, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?

(check one box)

☐1 Not at all ☐2 Slightly ☐3 Moderately ☐4 Quite a bit ☐5 Extremely

Q7. How much **bodily** pain have you had during the **past 4 weeks**? (check one box)

☐1 None ☐2 Very Mild ☐3 Mild ☐4 Moderate ☐5 Severe ☐6 Very Severe

Q8. During the **past 4 weeks**, how much did **pain** interfere with your normal work (including both work outside the home and housework)? (check one box)

☐1 Not at all ☐2 A little bit ☐3 Moderately ☐4 Quite a bit ☐5 Extremely

Q9. These questions are about how you feel and how things have been with you **during the past 4 weeks**. For each question please give the one answer that comes closest to the way you have been feeling.

How much of the time **during the past 4 weeks**: (circle one answer on each line)

		All of the Time	**Most of the Time**	**A Good Bit of the Time**	**Some of the Time**	**A Little of the Time**	**None of the Time**
A.	Did you feel full of pep?	1	2	3	4	5	6
B.	Have you been a very nervous person?	1	2	3	4	5	6
C.	Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5	6
D.	Have you felt calm and peaceful?	1	2	3	4	5	6
E.	Did you have a lot of energy?	1	2	3	4	5	6
F.	Have you felt downhearted and blue?	1	2	3	4	5	6
G.	Did you feel worn out?	1	2	3	4	5	6
H.	Have you been a happy person?	1	2	3	4	5	6
I.	Did you feel tired?	1	2	3	4	5	6

Q10. During the **past 4 weeks**, how much of the time has your **physical health or emotional problems** interfered with your social activities (like visiting with friends, relatives, etc.)?
(check one box)

☐1 All of the time
☐2 Most of the time
☐3 Some of the time
☐4 A little of the time
☐5 None of the time

Q11. Please choose the answer that best describes how **true** or **false** each of the following statements is for you. (circle one answer on each line)

	Definitely True	**Mostly True**	**Not Sure**	**Mostly False**	**Definitely False**
A. I seem to get sick a little easier than other people.	1	2	3	4	5
B. I am as healthy as anybody I know.	1	2	3	4	5
C. I expect my health to get worse.	1	2	3	4	5
D. My health is excellent.	1	2	3	4	5

Q12a. Which are you? (check one box)

☐1 Male
☐2 Female

Q12b. How old were you on your last birthday? (check one box)

☐1 Less than 35
☐2 35-44
☐3 45-54
☐4 55-64
☐5 65-74
☐6 75-84
☐7 85 and older

Q13. Have you ever filled out this form before? (check one box)

☐1 Yes
☐2 No
☐3 Don’t remember

DCP Questions Needed for Cost Effectiveness Analysis

Essential:

1. Employment Question (Section I - Q11)
2. Age, Date of DM Diagnosis, and Race Questions (Section I - Q1, Q5, Q7)

Often Needed:

1. Occupation Question (appendix)
2. Health Insurance Questions (Section I - Q12 and Q13)
3. Income Question (appendix)

DCP Summary

Core Questions:
Section I – Demographics (Q1 – Q14)
Section II – Health Status (Q1 – Q2)
Section III – Education / Advice Received (Q1 – Q4)
Section IV – Understanding (Q1)

Section V – Support (Q1 – Q4)

Appendices:
Section VI – Control Problems Scale
Section VII – Social and Personal Factors Scale
Section VIII – Attitudes Toward Diabetes Scales
Section IX – Diet Adherence Scales
Section X – Long-term care benefits Scale
Section XI – Exercise Barriers Scale
Section XII – Monitoring Barriers and Understanding Management Practice Subscales
(add understanding subscale to the end of Section IV)

Addition to Section I (Demographics) – Income Question (Q15)

Addition to Section I (Demographics) – Occupation Question (Q15 or Q16)

Replace Section II (Health Status) with SF-12
Replace Section II (Health Status) with SF-36

APPENDIX L

INFORMED CONSENT FORM

LOMA LINDA UNIVERSITY

School of Science and Technology
Department of Counseling and Family Sciences

Loma Linda, California 92350
(909) 558-4547
FAX: (909) 558-0447

INFORMED CONSENT
Diabetes Couples Study

Purpose and Procedures
Today many couples face the challenge of managing relationships when illness is present. You are invited to participate in a study about the real-life experiences of couples when one spouse has diabetes. Our aim is to understand how the presence of diabetes affects your relationship and how emotions may affect diabetes control and management. Your experiences will provide valuable information that can be accessed for scholarly study regarding families who face this illness.

To participate in this study partners must be married. Your participation will involve a questionnaire that takes approximately 30-45 min for the spouse with diabetes and 15-25 min for the non-diabetic spouse. The questionnaire will have questions about various aspects of diabetes, your relationship together, and other general questions. The purpose of the questionnaire is for us to learn through the eyes of you and your spouse. If you are the diabetic spouse your most recent blood glucose score will also be requested from your medical record. Please note that no other information will be requested, released, or required. The blood glucose score will let us know how well the diabetes is controlled. No assessment regarding the quality of your relationship will be made and no advice or suggestions will be offered. If your spouse is unavailable at the time you complete the questionnaire, we will request their contact information to invite them to participate in the study and set up a time for them to complete the questionnaire. Each spouse will be introduced to the study and asked to provide individual written consent before participation in this study.

Risks
There may be minimal risks to those who participate in this study. The risks to you are the possibility that some issues may be raised that make you or your partner uncomfortable or that you do not want to answer. If this occurs, you can decide whether you wish to answer the question, continue or terminate the survey. Further, there is a potential risk of breached confidentiality when (1) matching surveys of two spouses and (2) retrieving your HbA1c score. In order to minimize the first risk, data collectors will differ from data entry individuals so that only the researcher who administered the questionnaire will have any identifying information. Regarding the second risk, all medical information in this clinic is protected under the health information act HIPPA. Only with your permission will the clinical staff give the researchers in this project your HbA1c level which tells us how well your diabetes is controlled. If you sign this medical release form we will be able to use this information in our study. The adherence to this protection will be reinforced during the retrieving of your HbA1c score to ensure your information is handled with the strictest confidence and integrity.

Initial ____
Date ____

Benefits

While participation in this study may be of no direct personal benefit to you, the potential benefit to society is great. What we learn from you will help other couples living with diabetes enhance their relationships and better solve problems. However, completing the questionnaire may also stimulate helpful discussions with your spouse.

Participants Rights

Your participation in this study is completely voluntary. You are free to choose what information you reveal. You may decline to answer a question or terminate the questionnaire at any time. Stopping the questionnaire will in no way affect any relationship you have with the research assistant, Loma Linda University Department of Counseling and Family Sciences, Loma Linda University, Loma Linda Medical Center or any other health care services you may or may not receive from Loma Linda University schools or health care facilities.

Confidentiality

All personal information revealed in the questionnaire will be held in strict confidence. You will only be identified by an ID number on the questionnaire. Your name will not be recorded on the questionnaire. Information received to retrieve blood glucose score will be kept separate from questionnaires and will only be accessible to the primary and senior investigator. After glucose score is received all identifying information will be destroyed. No identifying material will be used in the presentation or publication of study results.

Costs

There is no cost to you for participating in the study.

Reimbursement

You may receive a book on health or gift card valued at $20.00.

Impartial Third Party Contact

If you wish to contact an impartial third party not associated with this study regarding any question or complaint you may have about the study, you may contact the Office of Patient Relations, Loma Linda Medical Center, Loma Linda, CA 92354, phone (909)558-4647 for information and assistance.

Informed Consent Statement

I have read the contents of the consent form and have listened to the verbal explanation given by investigator. My questions have been answered to my satisfaction. I hereby give voluntary consent to participate in this study. Signing this consent document does not waive my rights nor does it release the investigators, institution or sponsors from their responsibilities. I may call Zephon Lister, MS or Colwick Wilson, PhD, at 909-558-4547 if I have additional questions or concerns.

I have been given a copy of this consent form.

_____ _____

Signature of Participant Date

I have reviewed the consent form with the person signing above. I have explained potential risks and benefits of the study.

_____ _____ _____

Signature of Investigator Phone Number Date

APPENDIX M

DIABETIC SPOUSE QUESTIONNAIRE

ID# _____D-_____

Today's Date _____

Loma Linda University
Department Of Counseling and Family Sciences
Diabetes Care Study-**Diabetic** Spouse Questionnaire

Please answer each of the following questions by filling in the blanks with the correct answers or by choosing the single best answer.

Note: For this survey, a Health Care Provider refers to a doctor, nurse practitioner, or physician assistant.

Section I - Demographics

Q1. Sex: ☐1 Male ☐2 Female

Q2. How many years have you had diabetes? __ __

Q3. Did you have diabetes before you married your spouse? (check one box)

☐1 Yes ☐2 No → Q3a. How long were you married before you Were diagnosed with diabetes?

_____ (enter number of years)

Q4. Do you test your blood sugar? (check one box)

☐1 No ☐2 Yes → Q4a. How many days a week do you test your blood sugar?

_____ (days / week)

Q4b. On days that you test, how many times do you test your blood sugar?

_____ (times / day)

Q4c. Do you keep a record of your blood sugar test results? (check one box)

☐1 No ☐2 Yes ☐3 Only Unusual Values

Section II- Health Status

Q5. In general, would you say your health is: (check one box)

☐1 Excellent ☐2 Very Good ☐3 Good ☐4 Fair ☐5 Poor

For the following questions, please circle the appropriate response. (circle one answer for each line)					
Q6a.	**Been feeling well and in good health?**	Better Than Usual	Same As Usual	Worse Than Usual	Much Worse Than Usual
		1	2	3	4
Q6b.	**Been feeling in need of a good tonic?**	Not At All	No More Than Usual	Rather More Than Usual	Much More Than Usual
		1	2	3	4
Q6c.	**Been feeling run down and out of sorts?**	Not At All	No More Than Usual	Rather More Than Usual	Much More Than Usual
		1	2	3	4
Q6d.	**Felt that you are ill?**	Not At All	No More Than Usual	Rather More Than Usual	Much More Than Usual
		1	2	3	4
Q6e.	**Been getting pains in your head?**	Not At All	No More Than Usual	Rather More Than Usual	Much More Than Usual
		1	2	3	4
Q6f.	**Been getting a feeling of tightness or pressure in the head?**	Not At All	No More Than Usual	Rather More Than Usual	Much More Than Usual
		1	2	3	4
Q6g.	**Been having hot or cold spells?**	Not At All	No More Than Usual	Rather More Than Usual	Much More Than Usual
		1	2	3	4

Q6h.	**Lost much sleep over worry?**	Not At All	No More Than Usual	Rather More Than Usual	Much More Than Usual
		1	2	3	4
Q6i.	**Having difficulty staying asleep once you are off?**	Not At All	No More Than Usual	Rather More Than Usual	Much More Than Usual
		1	2	3	4
Q6j.	**Felt constantly under strain?**	Not At All	No More Than Usual	Rather More Than Usual	Much More Than Usual
		1	2	3	4
Q6k.	**Been edgy and bad tempered?**	Not At All	No More Than Usual	Rather More Than Usual	Much More Than Usual
		1	2	3	4
Q6l.	**Been getting scared and panicky for no good reason ?**	Not At All	No More Than Usual	Rather More Than Usual	Much More Than Usual
		1	2	3	4
Q6m.	**Found everything getting on top of you ?**	Not At All	No More Than Usual	Rather More Than Usual	Much More Than Usual
		1	2	3	4
Q6n.	**Been feeling nervous and strung-up all the time?**	Not At All	No More Than Usual	Rather More Than Usual	Much More Than Usual
		1	2	3	4
Q6o.	**Been managing to keep yourself busy and occupied?**	More So Than Usual	Same As Usual	Rather Less Than Usual	Much Less Than Usual
		1	2	3	4
Q6p.	**Been taking longer over things you do?**	Quicker Than Usual	Same As Usual	Longer Than Usual	Much Longer Than Usual
		1	2	3	4

Q6q.	**Felt on the whole you were doing things well?**	Better Than Usual	About The Same	Less Well Than Usual	Much Less Well
		1	2	3	4
Q6r.	**Been satisfied with the way you carry out a task?**	More Satisfied	About The Same As Usual	Less Satisfied As Usual	Much Less Capable
		1	2	3	4
Q6s.	**Felt that you are playing a useful part in things?**	More So Than Usual	Same As Usual	Less So Than Usual	Much Less Useful
		1	2	3	4
Q6t.	**Felt capable of making decisions about things?**	More So Than Usual	Same As Usual	Less So Than Usual	Much Less Capable
		1	2	3	4
Q6u.	**Been able to enjoy your normal day-to-day activities?**	More So Than Usual	Same As Usual	Less So Than Usual	Much Less Than Usual
		1	2	3	4
Q6v.	**Been thinking of yourself as a worthless person?**	Not At All	No More Than Usual	Rather More Than Usual	Much More Than Usual
		1	2	3	4
Q6w.	**Felt that life is entirely hopeless?**	Not At All	No More Than Usual	Rather More Than Usual	Much More Than Usual
		1	2	3	4
Q6x.	**Felt that life is not worth living?**	Not At All	No More Than Usual	Rather More Than Usual	Much More Than Usual
		1	2	3	4
Q6y.	**Thought of the possibility that you might make away with yourself?**	Definitely Not	I Don't Think So	Has Crossed My Mind	Definitely Have
		1	2	3	4

Q6z.	**Found at times you couldn't do anything because your nerves were so bad?**	Not At All	No More Than Usual	Rather More Than Usual	Much More Than Usual
		1	2	3	4
Q6a1	**Found yourself wishing you were dead and away from it all?**	Not At All	No More Than Usual	Rather More Than Usual	Much More Than Usual
		1	2	3	4
Q6b1	**Found that the idea of taking your own life kept coming into your mind?**	Definitely Not	I Don't Think So	Has Crossed My Mind	Definitely Has
		1	2	3	4

We Would Now Like To Ask You Some Questions About How You Manage Your Diabetes

Section III – Education / Advice Received

Q7. Have you ever received diabetes education? (for example: attended a series of classes or series of meetings with a diabetes educator) (check one box)

☐1 No ☐2 Yes ☐3 Not Sure

Q8.	How do you rate **YOUR** understanding of: (circle one answer for each line)	Poor		Good	**Excellent**	
	a) diet and blood sugar control	1	2	3	4	5
	b) weight management	1	2	3	4	5
	c) exercise	1	2	3	4	5
	d) use of insulin/pills	1	2	3	4	5
	e) sugar testing	1	2	3	4	5
	f) foot care	1	2	3	4	5
	g) complications of diabetes	1	2	3	4	5
	h) eye care	1	2	3	4	5
	i) combining diabetes medication with other medications	1	2	3	4	5
	j) alcohol use and diabetes	1	2	3	4	5

Q9.	How do you rate your **SPOUSE'S** understanding of: (circle one answer for each line)	Poor		Good	**Excellent**	
	a) diet and blood sugar control	1	2	3	4	5
	b) weight management	1	2	3	4	5
	c) exercise	1	2	3	4	5
	d) use of insulin/pills	1	2	3	4	5
	e) sugar testing	1	2	3	4	5

	f) foot care	1	2	3	4	5
	g) complications of diabetes	1	2	3	4	5
	h) eye care	1	2	3	4	5
	i) combining diabetes medication with other medications	1	2	3	4	5
	j) alcohol use and diabetes	1	2	3	4	5

Q10. How often do you and your spouse do the following diabetes-related activities **together**?

(circle one answer for each line)

	None of the Time	**Little of the Time**	**Some of the Time**	**Most of the Time**	**All of the Time**
a) planning a diabetes-healthy diet	1	2	3	4	5
b) preparing a diabetes- healthy diet	1	2	3	4	5
c) eating a diabetes-healthy diet	1	2	3	4	5
d) exercising	1	2	3	4	5
e) coordinating our workouts	1	2	3	4	5
f) ensuring that testing is done as prescribed	1	2	3	4	5
g) ensuring that medications are taken as prescribed	1	2	3	4	5
h) attending diabetes classes	1	2	3	4	5
i) reading about diabetes	1	2	3	4	5
j) going to medical appointments	1	2	3	4	5
k) participating in diabetes groups	1	2	3	4	5

Section IV – Support

Q11. I **want** a lot of help and support from my family or friends in:
(circle one answer for each line)

	Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree	Does Not Apply
a) following my meal plan.	1	2	3	4	5	N/A
b) taking my medicine.	1	2	3	4	5	N/A
c) taking care of my feet.	1	2	3	4	5	N/A
d) getting enough physical activity.	1	2	3	4	5	N/A
e) testing my sugar.	1	2	3	4	5	N/A
f) handling my feelings about diabetes.	1	2	3	4	5	N/A

Q12. My family or friends help and support me a lot to:
(circle one answer for each line)

	Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree	Does Not Apply
a) follow my meal plan.	1	2	3	4	5	N/A
b) take my medicine.	1	2	3	4	5	N/A
c) take care of my feet.	1	2	3	4	5	N/A
d) get enough physical activity.	1	2	3	4	5	N/A
e) test my sugar.	1	2	3	4	5	N/A
f) handle my feelings about diabetes.	1	2	3	4	5	N/A

Q13. My family or friends: (circle one answer for each line)

	Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree
a) accept me and my diabetes.	1	2	3	4	5
b) feel uncomfortable about me because of my diabetes.	1	2	3	4	5
c) encourage or reassure me about my diabetes.	1	2	3	4	5
d) discourage or upset me about my diabetes.	1	2	3	4	5
e) listen to me when I want to talk about my diabetes.	1	2	3	4	5
f) nag me about diabetes.	1	2	3	4	5

Q14. Who helps you the **most** in caring for your diabetes? (check only one box)

- ☐ 1 Spouse
- ☐ 2 Other family members
- ☐ 3 Friends
- ☐ 4 Paid helper
- ☐ 5 Doctor
- ☐ 6 Nurse
- ☐ 7 Case manager
- ☐ 8 Other health care professional
- ☐ 9 No one

Section V - Control Problems

For the following questions, please <u>check</u> the appropriate response.

Q15. How many **times** in the last **month** have you had a **low blood sugar** (glucose) reaction with symptoms such as sweating, weakness, anxiety, trembling, hunger or headache?

- ☐ 1 0 times
- ☐ 2 1-3 times
- ☐ 3 4-6 times
- ☐ 4 7-12 times
- ☐ 5 More than 12 times
- ☐ 6 Don't know

Q16. How many **times** in the last **year** have you had **severe low blood sugar** reactions such as passing out or needing help to treat the reaction?

- ☐ 1 0 times
- ☐ 2 1-3 times
- ☐ 3 4-6 times
- ☐ 4 7-12 times
- ☐ 5 More than 12 times
- ☐ 6 Don't know

Q17. How many **days** in the last **month** have you had **high blood sugar** with symptoms such as thirst, dry mouth and skin, increased sugar in the urine, less appetite, nausea, or fatigue?

- ☐ 1 0 days
- ☐ 2 1-3 days
- ☐ 3 4-6 days
- ☐ 4 7-12 days
- ☐ 5 More than 12 days
- ☐ 6 Don't know

Q18.	During the past year, how often did your blood sugar become **too high** because: (circle one answer for each line)	**Never**	**Rarely**	**Some-times**	**Often**	**Very Often**	**Don't Know**
	a) you were sick or had an infection?	1	2	3	4	5	DK
	b) you were upset or angry?	1	2	3	4	5	DK
	c) you took the wrong amount of medicine?	1	2	3	4	5	DK
	d) you ate the wrong types of food?	1	2	3	4	5	DK
	e) you ate too much food?	1	2	3	4	5	DK
	f) you had less physical activity than usual?	1	2	3	4	5	DK
	g) you were feeling stressed?	1	2	3	4	5	DK

Q19.	During the past year, how often did your blood sugar become **too low** because: (circle one answer for each line)	**Never**	**Rarely**	**Some-times**	**Often**	**Very Often**	**Don't Know**
	a) you were sick or had an infection?	1	2	3	4	5	DK
	b) you were upset or angry?	1	2	3	4	5	DK
	c) you took the wrong amount of medicine?	1	2	3	4	5	DK
	d) you ate the wrong types of food?	1	2	3	4	5	DK
	e) you ate too little food?	1	2	3	4	5	DK
	f) you had more physical activity than usual?	1	2	3	4	5	DK
	g) you waited too long to eat or skipped a meal?	1	2	3	4	5	DK
	h) you were feeling stressed?	1	2	3	4	5	DK

Section VI - Social and Personal Factors Scale

For the following questions, please <u>circle</u> the appropriate response.

		Never	Rarely	Sometimes	Often	Very Often	Don't Know
Q20.	How often has your diabetes kept you from doing your normal daily activities during the past **year** (e.g., couldn't: go to work, work around the house, go to school, visit friends)?	1	2	3	4	5	DK

Q21.	My diabetes and its treatment keep me from: (circle <u>one</u> answer for each line)	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
	a) having enough money.	1	2	3	4	5
	b) meeting school, work, household, and other responsibilities.	1	2	3	4	5
	c) going out or traveling as much as I want.	1	2	3	4	5
	d) being as active as I want.	1	2	3	4	5
	e) eating foods that I like.	1	2	3	4	5
	f) eating as much as I want.	1	2	3	4	5
	g) having good relationships with people.	1	2	3	4	5

	h) keeping a schedule I like (e.g., eating or sleeping late).	1	2	3	4	5
	i) spending time with my friends.	1	2	3	4	5
	j) having enough time alone.	1	2	3	4	5

		Strongly Disagree	**Disagree**	**Neutral**	**Agree**	**Strongly Agree**
Q22.	Paying for my diabetes treatment and supplies is a problem.	1	2	3	4	5
		Strongly Disagree	**Disagree**	**Neutral**	**Agree**	**Strongly Agree**
Q23.	Having diabetes makes my life difficult.	1	2	3	4	5

Section VII - Attitudes Toward Diabetes Scales

For the following questions, please <u>circle</u> the appropriate response.
(circle <u>one</u> answer for each line)

Q24.		**Strongly Disagree**	**Disagree**	**Neutral**	**Agree**	**Strongly Agree**
a)	I am afraid of my diabetes.	1	2	3	4	5
b)	I find it hard to believe that I really have diabetes.	1	2	3	4	5
c)	I feel unhappy and depressed because of my diabetes.	1	2	3	4	5
d)	I feel satisfied with my life.	1	2	3	4	5
e)	I feel I'm not as good as others because of my diabetes.	1	2	3	4	5
f)	I can do just about anything I set out to do.	1	2	3	4	5
g)	I find it hard to do all the things I have to do for my diabetes.	1	2	3	4	5
h)	Diabetes doesn't affect my life at all.	1	2	3	4	5
i)	I am pretty well off, all things considered.	1	2	3	4	5
j)	Things are going very well for me right now.	1	2	3	4	5

Q25.	I am **able** to: (circle one answer for each line)	**Strongly Disagree**	**Disagree**	**Neutral**	**Agree**	**Strongly Agree**
	e) keep my blood sugar in good control.	1	2	3	4	5
	f) keep my weight under control.	1	2	3	4	5
	c) do the things I need to do for my diabetes (diet, medicine, exercise, etc.).	1	2	3	4	5
	d) handle my feelings (fear, worry, anger) about my diabetes.	1	2	3	4	5

Q26.	I think it is **important** for me to: (circle one answer for each line)	**Strongly Disagree**	**Disagree**	**Neutral**	**Agree**	**Strongly Agree**
	d) keep my blood sugar in good control.	1	2	3	4	5
	b) keep my weight under control.	1	2	3	4	5
	c) do the things I need to do for my diabetes (diet, medicine, exercise, etc.).	1	2	3	4	5
	d) handle my feelings (fear, worry, anger) about my diabetes.	1	2	3	4	5

		Never	Rarely	Some-times	Often	Always	Don't Know
Q27.	I keep my blood sugar in good control.	1	2	3	4	5	DK

		Never	Rarely	Some-times	Often	Always
Q28.	I keep my weight under control.	1	2	3	4	5
Q29.	I do the things I need to do for my diabetes (diet, medicine, exercise, etc.).	1	2	3	4	5
Q30.	I feel dissatisfied with life because of my diabetes.	1	2	3	4	5
Q31.	I handle the feelings (fear, worry, anger) about my diabetes fairly well.	1	2	3	4	5

Thinking about yourself, and then your spouse, how strongly would you agree/disagree with the following statements about your feelings toward diabetes? (circle one answer for each line)

1 = Strongly Disagree 2 = Disagree **3 = Neutral** 4 = Agree **5 = Strongly Agree**

Q32.		I feel	My spouse feels
a.	Angry	1 2 3 4 5	1 2 3 4 5
b.	Fearful	1 2 3 4 5	1 2 3 4 5
c.	Hopeless	1 2 3 4 5	1 2 3 4 5
d.	Overwhelmed	1 2 3 4 5	1 2 3 4 5
e.	Hatred	1 2 3 4 5	1 2 3 4 5
f.	Sad	1 2 3 4 5	1 2 3 4 5
g.	Hopeful	1 2 3 4 5	1 2 3 4 5
h.	Embarrassed	1 2 3 4 5	1 2 3 4 5
i.	Guilt	1 2 3 4 5	1 2 3 4 5
j.	Sense of loss	1 2 3 4 5	1 2 3 4 5
k.	Confident	1 2 3 4 5	1 2 3 4 5

We are interested in what you consider may have been the cause of your diabetes. As people are very different, there is no correct answer for this question. We are most interested in your own views about the factors that caused your diabetes rather than what others including doctors or family may have suggested to you. Below is a list of possible causes for your diabetes. Please indicate how much you agree or disagree that they were causes for you by circling the appropriate box. (circle only one response per line)

Q33.		**Strongly Disagree**	**Disagree**	**Neither Agree Nor Disagree**	**Agree**	**Strongly Agree**
a).	Stress or Worry	1	2	3	4	5
b).	Hereditary - it runs in my family.	1	2	3	4	5
c).	A Germ or virus	1	2	3	4	5
d).	Diet or eating habits	1	2	3	4	5
e).	Chance or bad luck	1	2	3	4	5
f).	Poor medical care in my past	1	2	3	4	5
g).	Pollution in the environment	1	2	3	4	5
h).	My own behavior	1	2	3	4	5
i).	My mental attitude e.g. thinking about life negatively	1	2	3	4	5
j).	Family problems or worries	1	2	3	4	5
k).	Overwork	1	2	3	4	5
l).	My emotional state, e.g., feeling down, lonely, anxious, empty	1	2	3	4	5
m)	Ageing	1	2	3	4	5

n).	Alcohol	1	2	3	4	5
o).	Smoking	1	2	3	4	5
p).	Accident or injury	1	2	3	4	5
q)	My personality	1	2	3	4	5
r)	Altered immunity	1	2	3	4	5

In the space below, please list in rank-order the three most important factors that you now believe caused YOUR diabetes. You may use any of the items from the box above, or you may have additional ideas of your own.

The most important causes for me:

1. _____
2. _____
3. _____

Some couples think or feel very similarly toward diabetes, while others do not. Regarding yourself and your spouse, how strongly do you agree/disagree with the following statements? (circle one answer for each line)

Q34.		**Strongly Disagree**	**Disagree**	**Neutral**	**Agree**	**Strongly Agree**
	e) My spouse and I **feel** similarly about having diabetes in our lives.	1	2	3	4	5
	b) My spouse and I **think** similarly about having diabetes in our lives.	1	2	3	4	5

Thinking about yourself, and then your spouse, how strongly would you agree/disagree with the following statements? (circle one answer for each line)

1 = Strongly Disagree 2 = Disagree **3 = Neutral** 4 = Agree **5 = Strongly Agree**

Q35.		**You**	**Your Spouse**
a.	In some ways are grateful that diabetes has come into our lives	1 2 3 4 5	1 2 3 4 5
b.	Accept diabetes matter-of-factly, without a lot of strong emotions	1 2 3 4 5	1 2 3 4 5
c.	Worry quite a lot about the diabetes	1 2 3 4 5	1 2 3 4 5
d.	Avoid thinking about the diabetes as much as possible	1 2 3 4 5	1 2 3 4 5
e.	See living with diabetes primarily as a practical matter that we deal with	1 2 3 4 5	1 2 3 4 5
f.	Diabetes does not have a major impact on us	1 2 3 4 5	1 2 3 4 5

For the following questions imagine the last time you had low blood sugar, please circle the appropriate response.(circle one answer for each line)

Q36a	To what extent was the cause due to something about the patient (you)?	Totally Due To The Patient				Not At All Due To The Patient		
		6	5	4	3	2	1	0
Q36b	To what extent was the cause due to the treatment recommendation by the doctor?	Totally due to treatment recommended				Not at all due to treatment recommended		
		6	5	4	3	2	1	0
Q36c	To what extent was the cause something to do with other people or circumstances?	Totally due to other people or circumstances				Not at all due to other people or circumstances		
		6	5	4	3	2	1	0
Q36d	To what extent was the cause due to chance?	Totally due to chance					Not at all due to chance	
		6	5	4	3	2	1	0

Q36e	To what extent was the cause controllable by the patient (you)?	Totally controllable by the patient				Totally uncontrollable by the patient		
		6	5	4	3	2	1	0
Q36f.	To what extent was the cause controllable by the doctor?	Totally controllable by the doctor				Totally uncontrollable by the doctor		
		6	5	4	3	2	1	0
Q36g	To what extent do you think the patient (you) could have foreseen the cause of the hypoglycemic episode?	Totally foreseeable by the patient				Totally unforeseeable by the patient		
		6	5	4	3	2	1	0
For the following questions imagine the last time you had low blood sugar, please circle the appropriate response.(circle one answer for each line)								
Q36a.	To what extent was the cause due to something about the patient (you)?	Totally Due To The Patient				Not At All Due To The Patient		
		6	5	4	3	2	1	0
Q36b	To what extent was the cause due to the treatment recommendation by the doctor?	Totally due to treatment recommended				Not at all due to treatment recommended		
		6	5	4	3	2	1	0
Q36c	To what extent was the cause something to do with other people or circumstances?	Totally due to other people or circumstances				Not at all due to other people or circumstances		
		6	5	4	3	2	1	0
Q36d	To what extent was the cause due to chance?	Totally due to chance					Not at all due to chance	
		6	5	4	3	2	1	0

Q36e	To what extent was the cause controllable by the patient (you)?	Totally controllable by the patient				Totally uncontrollable by the patient		
		6	5	4	3	2	1	0
Q36f.	To what extent was the cause controllable by the doctor?	Totally controllable by the doctor				Totally uncontrollable by the doctor		
		6	5	4	3	2	1	0
Q36g	To what extent do you think the patient (you) could have foreseen the cause of the hypoglycemic episode?	Totally foreseeable by the patient				Totally unforeseeable by the patient		
		6	5	4	3	2	1	0

Some people find that having diabetes causes them to place more value on certain things in their lives. Thinking about yourself, and then your spouse, please circle the answer on each line that best represents how much each of you would agree/disagree with the following statements.

1 = Strongly Disagree 2 = Disagree **3 = Neutral** 4 = Agree **5 = Strongly Agree**

	Having diabetes has made us <u>place more value</u> on…		
Q37.		**You**	**Your Spouse**
a.	the important things in our lives	1 2 3 4 5	1 2 3 4 5
b.	our marriage relationship	1 2 3 4 5	1 2 3 4 5
c.	our relationship with our children	1 2 3 4 5	1 2 3 4 5
d.	our relationships with other family members	1 2 3 4 5	1 2 3 4 5
e.	our health	1 2 3 4 5	1 2 3 4 5
f.	How we choose to spend our time	1 2 3 4 5	1 2 3 4 5

Some people find that having diabetes causes them to place focus more on certain things in their lives. Thinking about yourself, and then your spouse, please circle the answer on each line that best represents how much each of you would agree/disagree with the following statements.

1 = Strongly Disagree 2 = Disagree **3 = Neutral** 4 = Agree **5 = Strongly Agree**

	Having diabetes has made us <u>focus more</u> on…		
Q38.		**You**	**Your Spouse**
a.	the important things in our lives	1 2 3 4 5	1 2 3 4 5
b.	our marriage relationship	1 2 3 4 5	1 2 3 4 5
c.	our relationship with our children	1 2 3 4 5	1 2 3 4 5
d.	our relationships with other family members	1 2 3 4 5	1 2 3 4 5
e.	our health	1 2 3 4 5	1 2 3 4 5
f.	How we choose to spend our time	1 2 3 4 5	1 2 3 4 5

Section VIII - Diet Adherence Scale

Q39. Has any health care provider or nurse told you to follow a meal plan or diet? ☐ 1 No ☐ 2 Yes ☐ 3 Not sure

		Never		Sometimes		Always
Q40.	How often do you follow a meal plan or diet?	1	2	3	4	5

Q41. Have you been told to follow a schedule for your meals and snacks? ☐ 1 No ☐ 2 Yes

Q42. Have you been told to weigh or measure your food? ☐ 1 No ☐ 2 Yes

Q43. Have you been told to use exchange lists or food group lists to plan your meals? ☐ 1 No ☐ 2 Yes

		Never		**Sometimes**		**Always**
Q44.	How often do you follow the schedule for your meals and snacks?	1	2	3	4	5
Q45.	How often do you weigh or measure your food?	1	2	3	4	5
Q46.	How often do you (or the person who cooks your food) use the exchange lists or food group lists to plan your meals?	1	2	3	4	5

Section XII - Exercise Management Practice Scales

Q47	How often do you exercise or do activities that cause:	**Never**	**Once a week**	**2-3 times a week**	**4-5 times a week**	**Almost everyday**
	a) a light sweat (i.e. light work around the house)?	1	2	3	4	5
	b) a moderate sweat (i.e. walk outside your home or yard such as for fun or exercise, walking the dog) ?	1	2	3	4	5
	c) a heavy sweat (i.e. recreational activities such as dancing, bicycling or exercise bike, swimming, skating, or stair climbing)?	1	2	3	4	5

For the following questions, please <u>circle</u> the appropriate response.
(circle <u>one</u> answer for each line)

Q48.	How often do you have trouble getting enough exercise because:	**Rarely**		**Sometimes**		**Often**
	a) it takes too much effort?	1	2	3	4	5
	b) you don't believe it is useful?	1	2	3	4	5
	c) you don't like to do it?	1	2	3	4	5
	d) you have a health problem?	1	2	3	4	5
	e) it makes your diabetes more difficult to control?	1	2	3	4	5

We Would Now Like To Ask You Some Questions On Your Feelings About Diabetes And Living With Your Spouse

Section IX – Expressed Emotion

People differ in their thoughts and feelings about having diabetes. We would like to know how you feel about having diabetes.

For the following questions, please circle the answer to each question which is closest to the way *you* feel. Please give your honest feelings- we are interested in how you feel, not what your doctor or family may think.

Please circle one answer for each line						
Q49a	How upsetting is having diabetes for you?	Not At All	Slightly Upsetting	Moderately Upsetting	Very Upsetting	Extremely Upsetting
		1	2	3	4	5
Q49b	How much control over your diabetes do you have?	None At All	Slight Amount	Moderate Amount	Large Amount	Total Amount
		1	2	3	4	5
Q49c	How much uncertainty do you currently experience in your life as a result of being diabetic?	None at All	Slight Amount	Moderate Amount	Large Amount	Extremely Large Amount
		1	2	3	4	5
Q49d	How likely is your diabetes to worsen over the next several years?	Not Likely At All	Slightly Likely	Moderately Likely	Very Likely	Extremely Likely
		1	2	3	4	5
Q49e	Do you believe that achieving good diabetic control is due to your efforts as compared to factors which are beyond your control?	Totally Because Of Me	Mostly Because Of Me	Partly Because Of Me And Partly Because Of Other Factors	Mostly Because Of Other Factors	Totally Because Of Other Factors
		1	2	3	4	5
Q49f	How effective are you in coping with your diabetes?	Not At All	Slightly Effective	Moderately Effective	Very Effective	Extremely Effective
		1	2	3	4	5

Q49g	To what degree does your diabetes get in the way of your developing life goals?	Not At All	Slight Amount	Moderate Amount	Large Amount	Extremely Large Amount
		1	2	3	4	5

For the following questions, please <u>circle</u> the appropriate response.
(circle <u>one</u> answer for each line)

Q50.		Never	Very Rarely	Some Days	Most Days	Every Day
a).	It is good to have my spouse around	0	1	2	3	4
b).	My spouse makes me feel drained	0	1	2	3	4
c).	My spouse ignores my advice	0	1	2	3	4
d).	My spouse is really hard to take	0	1	2	3	4
e).	I shout at my spouse	0	1	2	3	4
f).	I wish my spouse were not here	0	1	2	3	4
g).	I feel that my spouse is driving me crazy	0	1	2	3	4
h).	I lose my temper with my spouse	0	1	2	3	4
i).	My spouse is easy to get along with	0	1	2	3	4
j).	I am sick of having to look after my spouse	0	1	2	3	4
k).	My spouse deliberately causes me problems	0	1	2	3	4
l).	I enjoy being with my spouse	0	1	2	3	4
m).	My spouse is a real burden	0	1	2	3	4
n).	I argue with my spouse	0	1	2	3	4
o).	I feel very close to my spouse	0	1	2	3	4

p)	I can cope with my spouse	0	1	2	3	4
q).	Living with my spouse is too much for me	0	1	2	3	4
r)	My spouse is infuriating	0	1	2	3	4
s)	I find myself saying nasty or sarcastic things to my spouse	0	1	2	3	4
t)	My spouse appreciates what I do for them	0	1	2	3	4
u)	I feel that my spouse is becoming easier to live with	0	1	2	3	4
v)	I wish my spouse would leave me alone	0	1	2	3	4
w)	My spouse takes me for granted	0	1	2	3	4
x)	My spouse can control himself /herself	0	1	2	3	4
y)	My spouse is hard to get close to	0	1	2	3	4
z)	I feel that my spouse is becoming harder to live with	0	1	2	3	4
a1)	I feel very frustrated with my spouse	0	1	2	3	4
b1)	My spouse makes a lot of sense	0	1	2	3	4
c1)	I feel disappointed with my spouse	0	1	2	3	4
d1)	My spouse tries to get along with me	0	1	2	3	4

Rate you and your spouse in the following two questions with 1 being the least and 10 being the most (circle <u>one</u> answer for each line)											
Q51a	How critical are you of your spouse?	1	2	3	4	5	6	7	8	9	10
Q51b	How critical is your spouse of you?	1	2	3	4	5	6	7	8	9	10

How often during the previous month has your spouse (circle one answer for each line)								
		Never	Almost Never	Rarely	Sometimes	Often	Almost Always	Always
Q52a	Asked for your opinion	1	2	3	4	5	6	7
Q52b	Listen to your point of view	1	2	3	4	5	6	7
Q52c	Let you know that he or she cares	1	2	3	4	5	6	7
Q52d	Acted in a loving and affectionate manner	1	2	3	4	5	6	7
Q52e	Let you know that you are appreciated	1	2	3	4	5	6	7
Q52f	Help you do something	1	2	3	4	5	6	7
Q52g	Let you know your important to him or her	1	2	3	4	5	6	7
Q52h	Had a good laugh with you	1	2	3	4	5	6	7
Q52i	Acted supportive and understanding	1	2	3	4	5	6	7

We Would Now Like To Ask You About Your Relationship With Your Spouse

SECTION X – Marriage Relationship

Most people have disagreements in their relationships. Please indicate below the approximate level of agreement or disagreement between you and your partner for each item on the following list. (circle one answer for each line)							
		Always Agree	Almost Always Agree	Occasionally Agree	Frequently Disagree	Almost Always Disagree	Always Disagree
Q53 a	Religious matters	5	4	3	2	1	0
Q53 b	Demonstration of affection	5	4	3	2	1	0
Q53 c	Making major decisions	5	4	3	2	1	0
Q53 d	Sex relations	5	4	3	2	1	0
Q53 e.	Conventionality (correct or proper behavior)	5	4	3	2	1	0
Q53 f.	Career decisions	5	4	3	2	1	0
Section 2 (circle one answer for each line)		All The Time	Most Of The Time	More Often Than Not	Occa-sionally	Rarely	Never
Q53 g.	How often do you discuss or have you considered divorce, separation, or terminating your relationship?	0	1	2	3	4	5
Q53 h.	How often do you and your partner quarrel?	0	1	2	3	4	5
Q53 i.	Do you ever regret that you married?	0	1	2	3	4	5
Q53 j.	How often do you and your mate “get on each other’s nerves”?	0	1	2	3	4	5
Section 3 (circle one answer for each line)		Everyday		Almost Everyday	Occasiona lly	Rarely	Never
Q53 k.	Do you and your mate engage in	4		3	2	1	0

	outside interests together?					

Section 4 How often would you say the following events occur between you and your mate?
(circle one answer for each line)

		Never	Less Than Once A Month	Once Or Twice A Month	Once Or Twice A Week	Once A Day	More often
Q53 l.	Have stimulating exchange of ideas	0	1	2	3	4	5
Q53 m	Work together on a project	0	1	2	3	4	5
Q53 n.	Calmly discuss something	0	1	2	3	4	5

Please answer the following questions about your marriage. (circle one answer for each line)

		Extremely Dissatisfied	Very Dissatisfied	Somewhat Dissatisfied	Mixed	Somewhat Satisfied	Very Satisfied	Extremely Satisfied
Q54 a.	How satisfied are you with your marriage?	1	2	3	4	5	6	7
Q54 b.	How satisfied are you with your spouse?	1	2	3	4	5	6	7
Q54 c.	How satisfied are you with your relationship with your spouse	1	2	3	4	5	6	7

We Would Now Like To Ask You About Some Of Your Religious Beliefs And Practices

SECTION XI – Religious Coping

Complete the following statement with each of the responses below. (circle <u>one</u> answer for each line)

Since I was diagnosed with diabetes I have….

Q55		**Not At All**	**Very Little**	**Some-what**	**A Great Deal**
a)	Looked for a stronger connection with God	0	1	2	3
b)	Sought God's love and care	0	1	2	3
c)	Sought help from God in letting go of my anger	0	1	2	3
d)	Tried to put my plans into action together with God	0	1	2	3
e)	Tried to see how God might be trying to strengthen me in this situation	0	1	2	3
f)	Asked forgiveness for my sins	0	1	2	3
g)	Focused on religion to stop worrying about my problems	0	1	2	3
h)	Wondered whether God had abandoned me	0	1	2	3
i)	Felt punished by God for my lack of devotion	0	1	2	3
j)	Wondered what I did for God to punish me	0	1	2	3
k)	Questioned God's love for me		1	2	3
l)	Wondered whether my church had abandoned me	0	1	2	3
m)	Decided the Devil made this happen	0	1	2	3
n)	Questioned the power of God	0	1	2	3

This section contains statements about religious beliefs and practices. Please respond according to how each item describes you. (circle <u>one</u> answer for each line)						
Q56a	How often do you attend services at church?	Less than once a month	Once a month	Two to three times a month	At least once a week	More than once a week
		1	2	3	4	5
Q56b	How much time do you spend in meditation or prayer?	Less than once a week	Once a week	Two to three times a week	At least once a day	More than once a day
		1	2	3	4	5
Q56c	How much time do you spend in Bible study	Less than once a week	Once a week	Two to three times a week	At least once a day	More than once a day
		1	2	3	4	5
Q56d	Aside from attendance at religious services, do you consider yourself to be?	Deeply religious	Fairly religious	Only slightly religious	Not religious at all	
		1	2	3	4	
Q56e	How much is religion a source of strength and comfort for you?	None	A little	A great deal		
		1	2	3		

Hold On, You're Almost To The Finish Line.

Demographics Section I Cont.

Q57. Age: __ __ years old

Q58. Birth date: __ __ /__ __ /__ __
(Month / Day / Year)

Q59. How many years have you been married? : __ __

Q60. What is your race/ethnic origin? (check one box)

- ☐1 White
- ☐2 Black
- ☐3 Hispanic
- ☐4 Native American
- ☐5 Asian or Pacific Islander
- ☐6 Arabic
- ☐7 Other _____

Q61. How much schooling have you had? (Years of formal schooling completed) (check one box)

- ☐1 8 grades or less
- ☐2 Some high school
- ☐3 High school graduate or GED
- ☐4 Some college or technical school
- ☐5 College graduate (bachelor's degree)
- ☐6 Graduate degree

Q62. Which of the following best describes your current employment status? (check one box)

- ☐1 Working full-time, 35 hours or more a week
- ☐2 Working part-time, less than 35 hours a week
- ☐3 Unemployed or laid off and looking for work
- ☐4 Unemployed and not looking for work
- ☐5 Homemaker

☐6 In school

☐7 Retired

☐8 Disabled, not able to work

☐9 Something else? (Please specify): _____

Q63. Did you mark **working full or part time** in the previous question (Q62.) (check one box)

☐1 Yes ☐2 No → **SKIP TO QUESTION Q65**

Q64. Which of the categories below most closely represents the category of your occupation (check one box)

☐01 Arts, Design, Entertainment, Sports, and Media

☐02 Education, Training, and Library

☐03 Office and Administrative Support

☐04 Building and Grounds Cleaning and Maintenance

☐04 Financial

☐06 Sales and Related

☐07 Legal

☐08 Transportation and Material Moving

☐09 Mathematical and Computer Scientists

☐10 Production

☐11 Management

☐12 Farming, Fishing, and Forestry

☐13 Protective Service

☐14 Construction and Extraction

☐15 Installation, Maintenance, and Repair

☐16 Life, Physical, and Social Science

☐17 Engineering, Architecture, and Surveyors

Q65. Which of the categories best describes your total annual <u>combined</u> household income from <u>all</u> sources? (check <u>one</u> box)

☐02 $10,000 or less

☐03 $10,001 to $14,999

☐04 $15,000 to $19,999

☐05 $20,000 to $29,999

☐06 $30,000 to $39,999

☐07 $40,000 to $49,999

☐08 $50,000 to $59,999

☐09 $60,000 to $69,999

☐10 $70,000 to $79.999

☐10 $80,000 to $89,999

☐10 $90,000 and over

Thank You for Your Participation

APPENDIX N

NON-DIABETIC SPOUSE QUESTIONNAIRE

ID# _____N-_____

Today's Date _____

Loma Linda University
Department Of Counseling and Family Sciences

Diabetes Care Study- **Non-Diabetic** Spouse Questionnaire

Please answer each of the following questions by filling in the blanks with the correct answers or by choosing the single best answer.

Note: For this survey, a Health Care Provider refers to a doctor, nurse practitioner, or physician assistant.

Section I - Demographics

Q1. Sex: ☐ 1 Male ☐ 2 Female

Section II – Education & Management

Q2. Have you ever received diabetes education? ☐ 1 No ☐ 2 Yes

Q3.	How do you rate **YOUR** understanding of: (circle one answer for each line)	Poor		Good		Excellent
	a) diet and blood sugar control	1	2	3	4	5
	b) weight management	1	2	3	4	5
	c) exercise	1	2	3	4	5
	d) use of insulin/pills	1	2	3	4	5
	e) sugar testing	1	2	3	4	5
	f) foot care	1	2	3	4	5
	g) complications of diabetes	1	2	3	4	5
	h) eye care	1	2	3	4	5
	i) combining diabetes medication with other medications	1	2	3	4	5
	j) alcohol use and diabetes	1	2	3	4	5

Q4. How do you rate your **SPOUSE'S** understanding of: (circle one answer for each line)	Poor		Good		Excellent
a) diet and blood sugar control	1	2	3	4	5
b) weight management	1	2	3	4	5
c) exercise	1	2	3	4	5
d) use of insulin/pills	1	2	3	4	5
e) sugar testing	1	2	3	4	5
f) foot care	1	2	3	4	5
g) complications of diabetes	1	2	3	4	5
h) eye care	1	2	3	4	5
i) combining diabetes medication with other medications	1	2	3	4	5
j) alcohol use and diabetes	1	2	3	4	5

Q5. How often do you and your spouse do the following diabetes-related activities **<u>together</u>**?

(circle one answer for each line)

	None of the Time	**Little of the Time**	**Some of the Time**	**Most of the Time**	**All of the Time**
a) planning a diabetes-healthy diet	1	2	3	4	5
b) preparing a diabetes- healthy diet	1	2	3	4	5
c) eating a diabetes-healthy diet	1	2	3	4	5
d) exercising	1	2	3	4	5
e) coordinating our workouts	1	2	3	4	5
f) ensuring that testing is done as prescribed	1	2	3	4	5
g) ensuring that medications are taken as prescribed	1	2	3	4	5

h) attending diabetes classes	1	2	3	4	5
i) reading about diabetes	1	2	3	4	5
j) going to medical appointments	1	2	3	4	5
k) participating in diabetes groups	1	2	3	4	5

We would now like to ask you some general questions about your health

Section III - Health Status

Q6. In general, would you say your health is: (check one box)

☐1	☐2	☐3	☐4	☐5
Excellent	Very Good	Good	Fair	Poor

For the following questions, please circle the appropriate response. (circle one answer for each line)					
Q7a.	**Been feeling well and in good health?**	Better Than Usual	Same As Usual	Worse Than Usual	Much Worse Than Usual
		1	2	3	4
Q7b.	**Been feeling in need of a good tonic?**	Not At All	No More Than Usual	Rather More Than Usual	Much More Than Usual
		1	2	3	4
Q7c.	**Been feeling run down and out of sorts?**	Not At All	No More Than Usual	Rather More Than Usual	Much More Than Usual
		1	2	3	4
Q7d.	**Felt that you are ill?**	Not At All	No More Than Usual	Rather More Than Usual	Much More Than Usual
		1	2	3	4
Q7e.	**Been getting pains in your head?**	Not At All	No More Than Usual	Rather More Than Usual	Much More Than Usual
		1	2	3	4
Q7f.	**Been getting a feeling of tightness or pressure in the head?**	Not At All	No More Than Usual	Rather More Than Usual	Much More Than Usual
		1	2	3	4
Q7g.	**Been having hot or cold spells?**	Not At All	No More Than Usual	Rather More Than Usual	Much More Than Usual
		1	2	3	4
Q7h.	**Lost much sleep over worry?**	Not At All	No More Than Usual	Rather More Than Usual	Much More Than Usual
		1	2	3	4

Q7i.	**Having difficulty staying asleep once you are off?**	Not At All	No More Than Usual	Rather More Than Usual	Much More Than Usual
		1	2	3	4
Q7j.	**Felt constantly under strain?**	Not At All	No More Than Usual	Rather More Than Usual	Much More Than Usual
		1	2	3	4
Q7k.	**Been edgy and bad tempered?**	Not At All	No More Than Usual	Rather More Than Usual	Much More Than Usual
		1	2	3	4
Q7l.	**Been getting scared and panicky for no good reason?**	Not At All	No More Than Usual	Rather More Than Usual	Much More Than Usual
		1	2	3	4
Q7m.	**Found everything getting on top of you?**	Not At All	No More Than Usual	Rather More Than Usual	Much More Than Usual
		1	2	3	4
Q7n.	**Been feeling nervous and strung-up all the time?**	Not At All	No More Than Usual	Rather More Than Usual	Much More Than Usual
		1	2	3	4
Q7o.	**Been managing to keep yourself busy and occupied?**	More So Than Usual	Same As Usual	Rather Less Than Usual	Much Less Than Usual
		1	2	3	4
Q7p.	**Been taking longer over things you do?**	Quicker Than Usual	Same As Usual	Longer Than Usual	Much Longer Than Usual
		1	2	3	4
Q7q.	**Felt on the whole you were doing things well?**	Better Than Usual	About The Same	Less Well Than Usual	Much Less Well
		1	2	3	4

Q7r.	**Been satisfied with the way you carry out a task?**	More Satisfied	About The Same As Usual	Less Satisfied As Usual	Much Less Capable
		1	2	3	4
Q7s.	**Felt that you are playing a useful part in things?**	More So Than Usual	Same As Usual	Less So Than Usual	Much Less Useful
		1	2	3	4
Q7t.	**Felt capable of making decisions about things?**	More So Than Usual	Same As Usual	Less So Than Usual	Much Less Capable
		1	2	3	4
Q7u.	**Been able to enjoy your normal day-to -day activities?**	More So Than Usual	Same As Usual	Less So Than Usual	Much Less Than Usual
		1	2	3	4
Q7v.	**Been thinking of yourself as a worthless person?**	Not At All	No More Than Usual	Rather More Than Usual	Much More Than Usual
		1	2	3	4
Q7w.	**Felt that life is entirely hopeless?**	Not At All	No More Than Usual	Rather More Than Usual	Much More Than Usual
		1	2	3	4
Q7x.	**Felt that life is not worth living?**	Not At All	No More Than Usual	Rather More Than Usual	Much More Than Usual
		1	2	3	4
Q7y.	**Thought of the possibility that you might make away with yourself?**	Definitely Not	I Don't Think So	Has Crossed My Mind	Definitely Have
		1	2	3	4
Q7z.	**Found at times you couldn't do anything because your nerves were so bad?**	Not At All	No More Than Usual	Rather More Than Usual	Much More Than Usual
		1	2	3	4

Q7a1	**Found yourself wishing you were dead and away from it all?**	Not At All	No More Than Usual	Rather More Than Usual	Much More Than Usual
		1	2	3	4
Q7b1	**Found that the idea of taking your own life kept coming into your mind?**	Definitely Not	I Don't Think So	Has Crossed My Mind	Definitely Has
		1	2	3	4

We Would Now Like To Ask You Some Questions On Your Feelings About Diabetes And Living With Your Diabetic Spouse

Section IV - Attitudes Toward Diabetes

We are interested in what you consider may have been the cause of your spouse's diabetes. As people are very different, there is no correct answer for this question. We are most interested in your own views about the factors that caused your spouse's diabetes rather than what others including doctors or family may have suggested to you. Below is a list of possible causes for your spouse's diabetes. Please indicate how much you agree or disagree that they were causes for your spouse by circling the appropriate box. (circle only one response)

		Strongly Disagree	**Disagree**	**Neither Agree Nor Disagree**	**Agree**	**Strongly Agree**
Q8a.	Stress or Worry	1	2	3	4	5
Q8b.	Hereditary - it runs in his/her family.	1	2	3	4	5
Q8c.	A Germ or virus	1	2	3	4	5
Q8d.	Diet or eating habits	1	2	3	4	5
Q8e.	Chance or bad luck	1	2	3	4	5
Q8f.	Poor medical care in his/her past	1	2	3	4	5
Q8g.	Pollution in the environment	1	2	3	4	5
Q8h.	His/her own behavior	1	2	3	4	5
Q8i.	His/her mental attitude e.g. thinking about life negatively	1	2	3	4	5
Q8j.	Family problems or worries	1	2	3	4	5
Q8k.	Overwork	1	2	3	4	5
Q8l.	My emotional state e.g. feeling down, lonely, anxious, empty	1	2	3	4	5
Q8m.	Ageing	1	2	3	4	5
Q8n.	Alcohol	1	2	3	4	5

Q8o.	Smoking	1	2	3	4	5
Q8p.	Accident or injury	1	2	3	4	5
Q8q.	My personality	1	2	3	4	5
Q8r.	Altered immunity	1	2	3	4	5

In the table below, please list in rank-order the three most important factors that you now believe caused your spouse's diabetes. You may use any of the items from the box above, or you may have additional ideas of your own.

The most important causes for me:

1. _____

2. _____

3. _____

Thinking about yourself, and then your spouse, how strongly would you agree/disagree with the following statements about your feelings toward diabetes?

(circle one answer for each line)

1 = Strongly Disagree 2 = Disagree **3 = Neutral** 4 = Agree **5 = Strongly Agree**

Q9.		**I feel**	**My spouse feels**
a.	Angry	1 2 3 4 5	1 2 3 4 5
b.	Fearful	1 2 3 4 5	1 2 3 4 5
c.	Hopeless	1 2 3 4 5	1 2 3 4 5
d.	Overwhelmed	1 2 3 4 5	1 2 3 4 5
e.	Hatred	1 2 3 4 5	1 2 3 4 5
f.	Sad	1 2 3 4 5	1 2 3 4 5
g.	Hopeful	1 2 3 4 5	1 2 3 4 5
h.	Embarrassed	1 2 3 4 5	1 2 3 4 5
i.	Guilt	1 2 3 4 5	1 2 3 4 5
j.	Sense of loss	1 2 3 4 5	1 2 3 4 5
k.	Confident	1 2 3 4 5	1 2 3 4 5

Some couples think or feel very similarly toward diabetes, while others do not. Regarding yourself and your spouse, how strongly do you agree/disagree with the following statements?

(circle one answer for each line)

Q10.		**Strongly Disagree**	**Disagree**	**Neutral**	**Agree**	**Strongly Agree**
	f) My spouse and I **feel** similarly about having diabetes in our lives.	1	2	3	4	5
	b) My spouse and I **think** similarly about having diabetes in our lives.	1	2	3	4	5

Thinking about yourself, and then your spouse, how strongly would you agree/disagree with the following statements?

(circle one answer for each line)

1 = Strongly Disagree 2 = Disagree **3 = Neutral** 4 = Agree **5 = Strongly Agree**

Q11.		**You**	**Your Spouse**
a.	In some ways are grateful that diabetes has come into our lives	1 2 3 4 5	1 2 3 4 5
b.	Accept diabetes matter-of-factly, without a lot of strong emotions	1 2 3 4 5	1 2 3 4 5
c.	Worry quite a lot about the diabetes	1 2 3 4 5	1 2 3 4 5
d.	Avoid thinking about the diabetes as much as possible	1 2 3 4 5	1 2 3 4 5
e.	See living with diabetes primarily as a practical matter that we deal with	1 2 3 4 5	1 2 3 4 5
f.	Diabetes does not have a major impact on us	1 2 3 4 5	1 2 3 4 5

Some people find that having diabetes causes them to place more value on certain things in their lives. Thinking about yourself, and then your spouse, please circle the answer on each line that best represents how much each of you would agree/disagree with the following statements.

1 = Strongly Disagree 2 = Disagree **3 = Neutral** 4 = Agree **5 = Strongly Agree**

	Having diabetes has made us <u>place more value</u> on…		
Q12.		**You**	**Your Spouse**
a.	the important things in our lives	1 2 3 4 5	1 2 3 4 5
b.	our marriage relationship	1 2 3 4 5	1 2 3 4 5
c.	our relationship with our children	1 2 3 4 5	1 2 3 4 5
d.	our relationships with other family members	1 2 3 4 5	1 2 3 4 5
e.	our health	1 2 3 4 5	1 2 3 4 5
f.	How we choose to spend our time	1 2 3 4 5	1 2 3 4 5

Some people find that having diabetes causes them to place more value on certain things in their lives. Thinking about yourself, and then your spouse, please circle the answer on each line that best represents how much each of you would agree/disagree with the following statements.

1 = Strongly Disagree 2 = Disagree **3 = Neutral** 4 = Agree **5 = Strongly Agree**

	Having diabetes has made us <u>focus more</u> on…		
Q13.		**You**	**Your Spouse**
a.	the important things in our lives	1 2 3 4 5	1 2 3 4 5
b.	our marriage relationship	1 2 3 4 5	1 2 3 4 5
c.	our relationship with our children	1 2 3 4 5	1 2 3 4 5
d.	our relationships with other family members	1 2 3 4 5	1 2 3 4 5
e.	our health	1 2 3 4 5	1 2 3 4 5
f.	How we choose to spend our time	1 2 3 4 5	1 2 3 4 5

Imagine that your partner (a diabetic patient) had recently experienced a hypoglycemic episode (low blood sugar). Write down the single most likely cause of the hypoglycemic episode in the space below.

_____

For the following questions, please <u>circle</u> the appropriate response. (Circle <u>one</u> answer for each line.)

Q14a	To what extent was the cause due to something about the patient?	Totally Due To The Patient								Not At All Due To The Patient	
		6	5	4	3	2	1	0			
Q14b	To what extent was the cause due to the treatment recommendation by the doctor?	Totally due to treatment recommended								Not at all due to treatment recommended	
		6	5	4	3	2	1	0			
Q14c	To what extent was the cause something to do with other people or circumstances? (e.g. yourself)	Totally due to other people or circumstances								Not at all due to other people or circumstances	
		6	5	4	3	2	1	0			
Q14d	To what extent was the cause due to chance?	Totally due to chance								Not at all ue to chance	
		6	5	4	3	2	1	0			
Q14e	To what extent was the cause controllable by the patient?	Totally controllable by the patient								Totally uncontrollable by the patient	
		6	5	4	3	2	1	0			
Q14f	To what extent was the cause controllable by the doctor?	Totally controllable by the doctor								Totally uncontrollable by the doctor	
		6	5	4	3	2	1	0			
Q14g	To what extent do you think the patient could have foreseen the cause of the hypoglycemic episode?	Totally foreseeable by the patient								Totally unforeseeable by the patient	
		6	5	4	3	2	1	0			

Section V – Expressed Emotion

For the following questions, please <u>circle</u> the appropriate response. (circle <u>one</u> answer for each line)						
		Never	**Very Rarely**	**Some Days**	**Most Days**	**Every Day**
Q15a.	It is good to have my spouse around	0	1	2	3	4
Q15b.	My spouse makes me feel drained	0	1	2	3	4
Q15c.	My spouse ignores my advice	0	1	2	3	4
Q15d.	My spouse is really hard to take	0	1	2	3	4
Q15e.	I shout at my spouse	0	1	2	3	4
Q15f.	I wish my spouse were not here	0	1	2	3	4
Q15g.	I feel that my spouse is driving me crazy	0	1	2	3	4
Q15h.	I lose my temper with my spouse	0	1	2	3	4
Q15i.	My spouse is easy to get along with	0	1	2	3	4
Q15j.	I am sick of having to look after my spouse	0	1	2	3	4
Q15k.	My spouse deliberately causes me problems	0	1	2	3	4
Q15l.	I enjoy being with my spouse	0	1	2	3	4
Q15m.	My spouse is a real burden	0	1	2	3	4
Q15n.	I argue with my spouse	0	1	2	3	4
Q15o.	I feel very close to my spouse	0	1	2	3	4
Q15p.	I can cope with my spouse	0	1	2	3	4
Q15q.	Living with my spouse is too much for me	0	1	2	3	4
Q15r.	My spouse is infuriating	0	1	2	3	4

Q15s.	I find myself saying nasty or sarcastic things to my spouse	0	1	2	3	4
Q15t.	My spouse appreciates what I do for them	0	1	2	3	4
Q15u.	I feel that my spouse is becoming easier to live with	0	1	2	3	4
Q15v.	I wish my spouse would leave me alone	0	1	2	3	4
Q15w.	My spouse takes me for granted	0	1	2	3	4
Q15x.	My spouse can control himself/herself	0	1	2	3	4
Q15y.	My spouse is hard to get close to	0	1	2	3	4
Q15z.	I feel that my spouse is becoming harder to live with	0	1	2	3	4
Q15a1	I feel very frustrated with my spouse	0	1	2	3	4
Q15b1	My spouse makes a lot of sense	0	1	2	3	4
Q15c1	I feel disappointed with my spouse	0	1	2	3	4
Q15d1	My spouse tries to get along with me	0	1	2	3	4

Rate you and your spouse in the following two questions with 1 being the least and 10 being the most (circle <u>one</u> answer for each line)											
Q15a.	How critical are you of your spouse?	1	2	3	4	5	6	7	8	9	10
Q16b.	How critical is your spouse of you?	1	2	3	4	5	6	7	8	9	10

How often during the previous month has your spouse (circle <u>one</u> answer for each line)								
		Never	Almost Never	Rarely	Sometimes	Often	Almost Always	Always
Q17a.	Asked for your opinion	1	2	3	4	5	6	7
Q17b.	Listen to your point of view	1	2	3	4	5	6	7
Q17c.	Let you know that he or she cares	1	2	3	4	5	6	7
Q17d.	Acted in a loving and affectionate manner	1	2	3	4	5	6	7
Q17e.	Let you know that you are appreciated	1	2	3	4	5	6	7
Q17f.	Help you do something	1	2	3	4	5	6	7
Q17g.	Let you know your important to him or her	1	2	3	4	5	6	7
Q17h.	Had a good laugh with you	1	2	3	4	5	6	7
Q17i.	Acted supportive and understanding	1	2	3	4	5	6	7

This questionnaire lists different ways in which families try to cope with everyday problems.

For each item please indicate how often you have reacted to the patient in this way. Please respond to each question, and mark only one response per question.

		Never	**Rarely**	**Often**	**Very Often**
Q18a.	I tend to neglect myself because of my spouse	1	2	3	4
Q18b.	I have to keep asking my spouse to do things	1	2	3	4
Q18c.	I often think about what is to become of my spouse	1	2	3	4
Q18d.	My spouse irritates me	1	2	3	4

		Never	Rarely	Often	Very Often
Q18e.	I keep thinking about the reasons for my spouses' illness	1	2	3	4
Q18f.	I have to try not to criticize my spouse	1	2	3	4
Q18g.	I can't sleep because of my spouse	1	2	3	4
Q18h.	It's hard for us to agree on things	1	2	3	4
Q18i.	When something about my spouse bothers me, I keep it to myself	1	2	3	4
Q18j.	My spouse does not appreciate what I do for him/ her	1	2	3	4
Q18k.	I regard my own needs as less important	1	2	3	4
Q18l.	My spouse sometimes gets on my nerves	1	2	3	4
Q18m.	I'm very worried about my spouse	1	2	3	4
Q18n.	My spouse does some things out of spite	1	2	3	4
Q18o.	I think I will become ill myself	1	2	3	4
Q18p	When my spouse constantly wants something from me, it annoys me	1	2	3	4
Q18q.	My spouse is an important part of my life	1	2	3	4
Q18r.	I have to insist that my spouse behave differently	1	2	3	4
Q18s.	I have given up important things in order to be able to help my spouse	1	2	3	4
Q18t.	I'm often angry with my spouse	1	2	3	4

We Would Now Like To Ask You About Your Relationship With Your Spouse

SECTION VI – Marriage Relationship

Most people have disagreements in their relationships. Please indicate below the approximate level of agreement or disagreement between you and your partner for each item on the following list. (circle <u>one</u> answer for each line)							
		Always Agree	Almost Always Agree	Occasionally Agree	Frequently Disagree	Almost Always Disagree	Always Disagree
Q19a.	Religious matters	5	4	3	2	1	0
Q19b	Demonstration of affection	5	4	3	2	1	0
Q19c.	Making major decisions	5	4	3	2	1	0
Q19d	Sex relations	5	4	3	2	1	0
Q19e.	Conventionality (correct or proper behavior)	5	4	3	2	1	0
Q19f.	Career decisions	5	4	3	2	1	0
Section 2 (circle <u>one</u> answer for each line)		All The Time	Most Of The Time	More Often Than Not	Occasionally	Rarely	Never
Q19g	How often do you discuss or have you considered divorce, separation, or terminating your relationship?	0	1	2	3	4	5
Q19h	How often do you and your partner quarrel?	0	1	2	3	4	5
Q19i.	Do you ever regret that you married?	0	1	2	3	4	5
Q19j.	How often do you and your mate “get on each other’s nerves”?	0	1	2	3	4	5

Section 3 (circle <u>one</u> answer for each line)		Every Day	Almost Every Day	Occasionally	Rarely	Never
Q19k.	Do you and your mate engage in outside interests together?	4	3	2	1	0

Section 4 How often would you say the following events occur between you and your mate?
(circle <u>one</u> answer for each line)

		Never	Less Than Once A Month	Once Or Twice A Month	Once Or Twice A Week	Once A Day	More often
Q19l.	Have stimulating exchange of ideas	0	1	2	3	4	5
Q19m	Work together on a project	0	1	2	3	4	5
Q19n.	Calmly discuss something	0	1	2	3	4	5

Please answer the following questions about your marriage. (circle <u>one</u> answer for each line)

		Extremely Dissatisfied	Very Dissatisfied	Somewhat Dissatisfied	Mixed	Somewhat Satisfied	Very Satisfied	Extremely Satisfied
Q20 a.	How satisfied are you with your marriage?	1	2	3	4	5	6	7
Q20 b.	How satisfied are you with your spouse?	1	2	3	4	5	6	7
Q20 c.	How satisfied are you with your relationship with your spouse	1	2	3	4	5	6	7

We Would Now Like To Ask You About
Some Of Your Religious Beliefs And Practices

SECTION VII – Religious Coping

Complete the following statement with each of the responses below.
(circle one answer for each line)

Because my spouse has diabetes I have….

		Not At All	Very Little	Some-what	A Great Deal
Q21a.	Looked for a stronger connection with God	0	1	2	3
Q21b	Sought God's love and care	0	1	2	3
Q21c	Sought help from God in letting go of my anger	0	1	2	3
Q21d	Tried to put my plans into action together with God	0	1	2	3
Q21e	Tried to see how God might be trying to strengthen me in this situation	0	1	2	3
Q21f	Asked forgiveness for my sins	0	1	2	3
Q21g	Focused on religion to stop worrying about my problems	0	1	2	3
Q21h	Wondered whether God had abandoned me	0	1	2	3
Q21i	Felt punished by God for my lack of devotion	0	1	2	3
Q21j	Wondered what I did for God to punish me	0	1	2	3
Q21k	Questioned God's love for me		1	2	3
Q21l	Wondered whether my church had abandoned me	0	1	2	3
Q21m.	Decided the Devil made this happen	0	1	2	3
Q21n	Questioned the power of God	0	1	2	3

	This section contains statements about religious beliefs and practices. Please respond according to how each item describes you. (circle <u>one</u> answer for each line)					
Q22a	How often do you attend services at church?	Less than once a month	Once a month	Two to three times a month	At least once a week	More than once a week
		1	2	3	4	5
Q22b	How much time do you spend in meditation or prayer?	Less than once a week	Once a week	Two to three times a week	At least once a day	More than once a day
		1	2	3	4	5
Q22c	How much time do you spend in Bible study	Less than once a week	Once a week	Two to three times a week	At least once a day	More than once a day
		1	2	3	4	5
Q22d	Aside from attendance at religious services, do you consider yourself to be?	Deeply religious	Fairly religious	Only slightly religious	Not religious at all	
		1	2	3	4	
Q22e	How much is religion a source of strength and comfort for you?	None	A little	A great deal		
		1	2	3		

We Would Finally Like To Ask You A Few Questions About YOU.

Demographics Section I

Q23. Age: __ __ years old

Q24. Birth date: __ __ /__ __ /__ __
(Month / Day / Year)

Q25. How many years have you been married? : __ __

Q26. What is your race/ethnic origin? (check one box)

- ☐1 White
- ☐2 Black
- ☐3 Hispanic
- ☐4 Native American
- ☐5 Asian or Pacific Islander
- ☐6 Arabic
- ☐7 Other _____

Q27. How much schooling have you had? (Years of formal schooling completed) (check one box)

- ☐1 8 grades or less
- ☐2 Some high school
- ☐3 High school graduate or GED
- ☐4 Some college or technical school
- ☐5 College graduate (bachelor's degree)
- ☐6 Graduate degree

Q28. Which of the following best describes your current employment status? (check one box)

- ☐1 Working full-time, 35 hours or more a week
- ☐2 Working part-time, less than 35 hours a week
- ☐3 Unemployed or laid off and looking for work
- ☐4 Unemployed and not looking for work
- ☐5 Homemaker
- ☐6 In school

☐ 7 Retired

☐ 8 Disabled, not able to work

☐ 9 Something else? (Please specify): _____

Q29. Did you mark **working full or part time** in the previous question (Q28.) (check one box)

☐ 1 Yes ☐ 2 No → **SKIP TO QUESTION Q31**

Q30. Which of the categories below most closely represents the category of your occupation (check one box)

☐ 01 Arts, Design, Entertainment, Sports, and Media

☐ 02 Education, Training, and Library

☐ 03 Office and Administrative Support

☐ 04 Building and Grounds Cleaning and Maintenance

☐ 04 Financial

☐ 06 Sales and Related

☐ 07 Legal

☐ 08 Transportation and Material Moving

☐ 09 Mathematical and Computer Scientists

☐ 10 Production

☐ 11 Management

☐ 12 Farming, Fishing, and Forestry

☐ 13 Protective Service

☐ 14 Construction and Extraction

☐ 15 Installation, Maintenance, and Repair

☐ 16 Life, Physical, and Social Science

☐ 17 Engineering, Architecture, and Surveyors

Q31. Which of the categories best describes your total annual <u>combined</u> household income from <u>all</u> sources? (check one box)

- ☐ 01 $10,000 or less
- ☐ 02 $10,001 to $14,999
- ☐ 03 $15,000 to $19,999
- ☐ 04 $20,000 to $29,999
- ☐ 05 $30,000 to $39,999
- ☐ 06 $40,000 to $49,999
- ☐ 07 $50,000 to $59,999
- ☐ 08 $60,000 to $69,999
- ☐ 09 $70,000 to $79.999
- ☐ 10 $80,000 to $89,999
- ☐ 11 $90,000 and over

Thank You for Your Participation